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# Prostate Cancer and the Lives of Current Survivors: A Phenomenological Study.

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## Abstract

An interpretation of the experience of surviving prostate cancer as described by current survivors, this paper explores issues originating from diagnosis, treatment, and post-treatment stages with emphasis on the participant's current understanding. Participants (N=8) were interviewed individually and their accounts interpreted via hermeneutical phenomenological methods. Participants experienced a sense of progressing through 'pages' in the story of prostate cancer, reflecting past, present and future experiences. Within this process participants moved through several fluid phases of coping including shock, information and support seeking, frustration, acceptance and 'work', and progression. Phases were not discrete in their boundaries or necessarily experienced within a set sequence and could be revisited by participants. 'Work' included a process of 'crusading' whereby survivors sought out others to share their experiences and to encourage others to be tested. Conclusions from the study point toward further research in the area of prostate cancer and its impact on New Zealand men's lives, including possible Maori/Pakeha differences in interpretation, the input and role of caregivers/spouses, and the impact on carers' lives. Involvement from psychologists and other health professionals in planning tailored support services will also be discussed.

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## The Psychological Issues of Prostate Cancer

Prostate cancer is the most common form of cancer in New Zealand men, and ranks among the top three leading causes of cancer related death within this gender group (NZHIS, 1998). To compound matters, the rate of diagnosed cases of prostate cancer is increasing (Cancer Society of New Zealand Inc; Lavery & Clarke, 1999; Lepore & Helgeson, 1998; NZHIS, 1998; Ptacek et al, 1999). Registered cases of prostate cancer are almost three times higher than those recorded in 1990 (NZHIS, 1998). Registration rates for prostate cancer in 1998 reached <sup>1</sup>97 registrations per 100,000 population, marking prostate cancer as the most frequently registered cancer type in New Zealand across both gender groups (NZHIS, 1998). In 1999 this figure increased to <sup>2</sup>98.4 registrations per 100,000 population (Personal Correspondence, 2001). The growth pattern may be attributed primarily to an ageing population, the introduction of the Cancer Registry Act in 1994, and increased screening for the disease, including the use of the Prostate Specific Antigen (PSA) test (Cancer: New Registrations & Deaths, 1996; Cancer Society of New Zealand Inc; Lavery & Clarke, 1999; Lepore & Helgeson, 1998; Ptacek et al., 1999). Research examining the psychosocial issues of cancer has failed to match this growth curve (Carter, 1993; Helgeson & Lepore, 1997; Lavery & Clarke, 1999). Moreover, despite some research examining the psychosocial aspects of breast cancer, the psychological health of prostate cancer patients has been virtually ignored within the literature (Helgeson & Lepore, 1997; Lavery & Clarke, 1999; Ptacek et al., 1999; Whitrod, 1996). The vacuum is recognised by Lavery & Clarke, (1999) who comment; "*The limited literature on the psychological effects of prostate cancer is somewhat surprising given its increasing prevalence, the controversy over its appropriate management, and the seriousness of its treatment after effects...*"

There is a clear and pressing need for psychological services within the area of post-diagnosis and treatment of prostate cancer (Helgeson & Lepore, 1997; Janoff-Bulman, 1992; Lepore & Helgeson, 1998; Ptacek et al., 1999; Stone, Mezzacappa, Donatone, & Gonder, 1999; Whitrod, 1996). A diagnosis of prostate cancer, unsurprisingly, may lead to a great deal of upheaval, and emotional and interpersonal stress (Helgeson & Lepore, 1997; Janoff-Bulman, 1992; Lepore & Helgeson, 1998; Taylor, Placido, Redd, Faccenda, 1999). Aside from the actual physiological effects of cancer, patient's often experience individual specific strain such as changes to routine, identity and sexuality, activities, and finances (Gray, Fitch, Phillips, Labrecque, & Fergus [a], 2000; Helgeson & Lepore, 1997; Janoff-Bulman, 1992; Lepore & Helgeson, 1998; Ptacek et al., 1999; Whitrod, 1996). Much of this anxiety is exacerbated by scanty information regarding the process of diagnosis, treatment, and

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<sup>1</sup> These rates have been age standardised to Segi's world population. In keeping with Statistics New Zealand policy, the population is an estimated mean of usually resident population figures.

<sup>2</sup> At the time of writing, this is the most up to date statistical figure available, and is of a provisional nature only.

possible outcomes (Ptacek et al., 1999; Steele, Miller, & Maylahn, 2000; Whitrod, 1996). Open and comprehensive discussion of these processes between health professional and patient could be extremely valuable (Helgeson & Lepore, 1997; Fife, 1994; Ptacek et al., 1999; Rime, 1995; Steele et al, 2000; Stone et al, 1999; Whitrod, 1996). Johnson & Laver (1989) among others, argue for the efficacy of preparatory information interventions, in particular self-regulation theory (Johnson, Laver, & Nail, 1989; Johnson, 1996). The authors describe the core components of this successful intervention as informing patients about the objective experiences likely encountered during treatment, such as what can be seen, felt, smelled and tasted (Johnson & Laver, 1989). Obviously information from those who have actually experienced these procedures is essential for the interventions success (Lavery & Clarke, 1999).

Health professionals and researchers often misinterpret the cancer patient's experience of diagnosis, treatment, and coping (Ptacek et al., 1999). Ptacek et al., (1999) were surprised that the participants in their study made extensive use of support networks as a method of coping with prostate cancer. In accord with the thinking regarding gender differences in coping style, the authors expected that support seeking, viewed traditionally as a feminine style of coping, would be utilised infrequently by their participants. Likewise, the authors found that spouses of patients, presumably a principal source of support, differed significantly from their husbands in their perception of the cancer diagnosis and treatment process (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Ptacek et al., 1999). The degree of misperception between non-cancer and cancer patients seems to be pronounced. In a study by Peters-Gordon (1982), 72% of cancer patients reported being misunderstood, and 50% reported inadequate support (cited in Ptacek et al., 1999). To highlight the disparity in perception; 66% of the non-cancer group "reported that they would go out of their way to cheer up a cancer patient, a behaviour that patients reported disliking the most" (Ptacek et al., 1999). Certainly a greater emphasis should be placed on actually listening to and accurately interpreting the experiences of prostate cancer patients and survivors (Lavery & Clarke, 1999). As Ptacek et al., (1999) argue "*Cancer researchers have generally failed to attend sufficiently to the role played by individual-level variables in coping and support processes*". Of the modest volume of research in the area, most studies have attempted to fit prostate cancer patient's experiences to preconceived models, theories or values, with little success and unexpected results (Johnson & Laver 1989; Ptacek et al., 1999).

Contrary to most areas of study within the field of psychology, men are an underrepresented population in psychosocial cancer research (Lavery & Clarke, 1999; Ptacek et al., 1999). The literature examining the coping strategies, experiences, and support networks of cancer patients has focused almost exclusively on women (Lavery & Clarke, 1999; Ptacek et al., 1999; Whitrod, 1996). In particular, research has focussed on women with breast cancer, a group tending to experience onset of the disease at an earlier age than populations

encountering other types of cancer (Ptacek et al., 1999). Prostate cancer is most common in men over the age of 65, an age group that tends to receive less research (Lavery & Clarke, 1999; Sharp, Blum, & Aviv, 1993; cited in Ptacek et al., 1999; Whitrod, 1996). Also, as the majority of the literature has explored the psychological aspects of breast cancer, there is a danger of generalising these findings to all cancer patients, including those with prostate cancer (Gray, Fitch, Davis & Philips, 1996; Gray & Fitch et al., 2000; Ptacek et al., 1999). The experiences of prostate cancer patients may differ markedly from those suffering cancer of the breast. Certainly, it is likely that men over 65 have worldviews, experiences, and lifestyles differing significantly from those of younger women, and research suggests that coping-styles and perception of stress may vary across age and gender (Gray et al., 1996; Gray & Fitch et al., 2000; Lavery & Clarke, 1999; Ptacek et al., 1999; Whitrod, 1996). Whitrod (1996) clarifies this point when discussing a prostate cancer self-help group; *"Indeed, none of the 20 men expressed thoughts which could be classified as 'wishful thinking', nor referred to the well established response in breast cancer of, 'why me?'... the absence of the 'why me?' suggests there may be some basic differences in the underlying world-view assumptions of the two genders, or between the two generations involved"*.

Finally, while there are few studies examining the psychosocial aspects of cancer per se, an even smaller proportion address the impact of the 'cancer experience', or diagnosis/treatment process, on the lives of survivors (Carter, 1993; Woods & Earp, 1978). Many questions remain unanswered in the literature. For instance, What is life like after cancer treatment? Is there a sense of enrichment for patients after successful treatment, or do survivors of cancer go on to live a life of doubt, and fear of recurrence? Is there a need for continued psychosocial intervention? Due to the dearth of research in this area, it remains unclear as to whether the 'cancer experience' actually ends after successful treatment (Carter, 1993). Examining the accounts of survivors of cancer, rather than current patients, may hold the advantage of a more thorough account, including many dimensions of the experience rather than an intense cross-sectional stage or period. Also, as so little is known about the experiences of prostate cancer patients, it may be important to consult those who have undergone treatment, experiencing the benefits and drawbacks, rather than those who have yet to pass through the health system. Gray, Fitch, & Phillips et al. [a] (2000) found that the prostate cancer patients in their study actively searched for survivors, requesting information regarding the prostate cancer experience. Studies examining post treatment populations therefore, may provide leads for further research into the specific stages of that experience.

To briefly summarise, the population living with a diagnosis of prostate cancer is increasing steadily. Currently research examining psychosocial aspects of cancer has failed to match this growth rate. There is also a clear and growing need for psychological services within the area of cancer diagnosis, including the provision of comprehensive, clear information for the

patient regarding objective first-hand experiences of treatment. Misinterpretation of the cancer patient's experience is widespread and of significant magnitude to warrant attention. In addition, of the few studies that have been conducted in this area, research has focussed on the experiences of women with breast cancer, a population differing in both gender and age from prostate cancer patients. We currently know very little about the effects of prostate cancer on the lives of patients or survivors, and current models and theories of coping rarely fit the actual matrix of strategies employed. Psychological intervention and support for patients is needed, yet in order to provide effective services, exploratory research must be conducted. As yet, the need for continued psychosocial support after treatment is unknown. In the words of Whitrod (1996); " ... *what seems to be required to improve the quality of life for [prostate cancer] men is first, research, not so much to reform detrimental responses and substitute beneficial ones, but to identify which is which in the ambivalent world of [prostate cancer] disease*".

## Research Aims

The aim of the study was to explore the impact of prostate cancer on the lives of current survivors. Acknowledging the background of prostate cancer, I intended to explore how this context influences, and impacts on, the life of the survivor. Due to the explorative nature of the study, the research was not guided by a list of specific questions. However, areas of interest do exist, such as participants views of the medical profession after treatment, and the possibility of coping with the disease. The psychosocial functioning of prostate cancer survivors in research terms is currently uncharted or at most sketchy and is clearly a valuable area of study. By exploring the perceptions of survivors, - those who have a wealth of experience with prostate cancer, the study may be able to offer insight into issues salient for both 'veterans' of cancer, and patients.

## Theoretical Perspective

A qualitative phenomenological methodology was utilised to collect and analyse the verbal accounts of eight men. This choice was made because so little is known about the experiences of prostate cancer survivors, the aims of the study required an exploration of their perceptions in-depth, and a phenomenological approach has been used in previous studies exploring cancer patient's understanding. (Carter, 1993; Coward, 1994; Lavery & Clarke, 1999; Schwartzberg, 1993). A qualitative methodology also enables an exploration

of cancer patient's experience in far greater detail than is possible via quantitative methods (Lavery & Clarke, 1999).

## Hermeneutic Phenomenology

Hermeneutic Phenomenology differs from traditional empiricist views of the form and origin of knowledge, the idea of what constitutes 'the proper object of study', and the type of explanation sought by investigators (Bauman, 1978; Bleicher, 1982; Packer, 1985). These epistemological assumptions lead naturally to issues of methodology, which will be discussed briefly within the context of hermeneutics and empiricism.

The aim of hermeneutic phenomenology is the detailed study of human action, and in particular, the meanings attributed to that action (Bauman, 1978; Bleicher, 1982; Packer, 1985; Stewart & Mickunas, 1974). Hermeneutic inquiry is based on a practical understanding of behaviour, and distances itself from prior theoretical assumptions regarding the nature of a studied behaviour (Packer, 1985). Originally the discipline of hermeneutics was dedicated to the study of religious texts, for the purpose of uncovering and reconstructing the 'true' meaning of the script, as intended by God (Bauman, 1978; Bleicher, 1982; Packer, 1985). The term 'hermeneutics' comes from the name given to the Greek god of cunning and eloquence, *Hermes* (Bauman, 1978; Packer, 1985). The term phenomenology, unsurprisingly, also has Greek roots, *phainomenon* meaning an 'appearance' and *logos* meaning 'reason' or 'word' (Stewart & Mickunas, 1974). Hence phenomenology is the study of 'the meaning of an appearance' (Carr, 1985). In the context of the research therefore, transcripts of verbal interaction were examined for their meaning.

The principal source of knowledge according to hermeneutical epistemology, is practical activity, everyday experience with people, objects and situations (Bauman, 1978; Bleicher, 1982; Packer, 1985). This knowledge however is comprised of elements that are context specific, and bound by the interpretative standpoint of the researcher (Bauman, 1978; Packer, 1985). Of great importance within the epistemological framework of hermeneutics is the concept of 'Heidegger's modes of engagement' (Packer, 1985). Three distinct, although interrelated forms of interaction were proposed by Heidegger, an influential phenomenologist and theorist (Bauman, 1978; Carr, 1985). These modes of engagement describe the varying relationship an individual may hold with their environment (Packer, 1985). The first is the 'ready-to-hand' mode of engagement, which involves practical, first-hand experience in the world, such is driving a car, or talking to a person (Packer, 1985). Whilst engaged in these activities, our consciousness is aware of a dynamic situation in which the task at hand is enmeshed within our surroundings. Individual items and their

properties are not salient in such a sphere of awareness, the ethnic background of the acquaintance, or precise level of education do not stand out and enter our minds as we go about our conversation. However, feelings and past experiences may colour our awareness of the situation, guiding our actions and ruling out other possible courses of behaviour. Stereotypes or biases may limit topics of conversation for example. In turn, when a problem arises we may be cast into what Heidegger described as the 'unready-to-hand' mode (Packer, 1985). The cause of the upset becomes salient, although it is still perceived as an aspect of the environment and situation. For instance, in relation to the previous example, the participants' ill health during the conversation leads to a coughing fit temporarily interrupting the interview. The current health status and perhaps age of the participant become noticeable elements of the environment, but only in the context of our discussion, not in terms of the acquaintance's larger life experience. Finally, the 'present-at-hand' mode refers to the state entered when we detach ourselves from our environment and reflect upon the situation in an objective fashion. Elements of the environment may be considered as independent entities to be quantified, measured and separated from situational contexts. The age and health of the interviewee therefore, possess distinct dimensions, which only now become salient outside the context of the conversation. Date of birth, number of doctor's visits within the past six months, and other quantifiable information may be collected and compared to national statistics. Empiricism therefore is based ontologically within this 'present-at-hand' mode. Hermeneutic phenomenologists however, argue that from among these 'modes', it is the 'ready-at-hand' mode alone, which allows access to the true essence of behaviour and action (Packer, 1985).

The 'object of inquiry' via the hermeneutic approach, is the meaning of human action (Carr, 1985; Packer, 1985). Action or behaviour is seen as possessing a 'plot', a structure that is bound by context so that components of the behaviour become indistinct when separated from the whole (Bauman, 1978; Packer, 1985). Human action therefore takes on a Gestalt quality. Culture, context, and historical factors combine with physical actions to produce a 'performance' or set of actions that when combined, are far greater in complexity than any possible list of its 'constituent parts' (although these parts it is argued, cannot be meaningfully separated anyway). Hermeneutic phenomenology therefore, is used to describe, study, and understand human action in its entirety, it is 'hermeneutic' in nature because it is an interpretation of the phenomena (Bauman, 1978; Packer, 1985).

Because hermeneutic phenomenology is partly concerned with actual behaviour, it shares an interest with behaviourist empiricism and, in focusing upon human action, rather than purely theoretical systems of cognition, perceptions, and reflective thought (Stewart & Mickunas, 1974). Unlike empiricism however, hermeneutics doesn't remove behaviour from its context, or ignore the meaning and possible interpretations of the situation in which an act occurred (Packer, 1985). Where the empiricist strives to form causal and predictive laws of

effect by isolating and quantifying discrete behaviours, hermeneutics rejects the notion that such components of human action can be meaningfully separated (or even that such components exist), and aspires instead to gaining a greater appreciation and understanding of human behaviour within its situational context (Stewart & Mickunas, 1974). In fact, hermeneutic phenomenologists propose that practical human activity may only be understood within the boundaries of its context (Packer, 1985). This combination of act and context forms an intricate web, described by Heidegger as the 'referential totality' (Packer, 1985). Behaviour is seen to offer alternate interpretations to its intent and purpose. Meanings found within a particular action may be quite distinct for different observers of that action, positions being influenced by the unconscious motives and socio-historical perspective of the onlookers (Packer, 1985). Unlike empiricism, hermeneutic phenomenology rejects the possibility of a truly objective viewpoint. However, rather than become entangled within a totally subjective mire, actions are limited to a finite combination of possible interpretations governed by the context in which the act occurred (Packer, 1985). Empiricists also apply their perspectives to the behaviour under observation. However, due to the epistemology of empiricism, in which an objective stance is possible, this influence on the collected data is ignored or discredited, and a single interpretation may be taken as being 'truth'.

Human action is recorded by tape, transcription and first-hand observation, and then examined for themes, viewpoints, and participant interpretations (Packer, 1985). The interpretation of the researcher is acknowledged and becomes part of the data (Packer, 1985). Interpretations then, are not seen as either 'correct' or 'incorrect' as such, although their validity may be assessed by the degree to which they appear sensible in the light of the context of the action (Packer, 1985).

Finally, drawing conclusions from information gained directly from cancer survivors serves the research aims to a greater degree than possible via traditional methods. Packer (1985) gives an excellent analogy regarding the difference between traditional empiricist approaches and that of phenomenology; "The difference ... is a little like the difference between a map of a city and an account of that city by someone who lives in it and walks its streets".

## Cancer: a Definition

Cancer is a disease effecting the manner in which the body's cells divide (Cancer Society of New Zealand Inc; 2001). In healthy tissue cells divide in an ordered fashion. However this process may malfunction causing the multiplying cells to form a tumour or growth. Tumours are either benign or malignant. Malignant tumours are considered cancerous and may

spread to other areas of the body. If the cancer is not treated, the cells may spread to and destroy surrounding tissue. If some cancerous cells leave the primary cancer and spread to other parts of the body they may form another tumour known as a secondary cancer. This process is called **metastasis**. Secondary cancers effecting an organ are not the same as primary cancers effecting that body part. For example, if prostate cancer spreads to bone tissue it is known as a secondary cancer of the bone. It is not bone cancer, which is another disease altogether. Benign tumours do not spread from their point of origin to other parts of the body and do not invade surrounding tissue. They are therefore not considered cancerous.

## The Prostate

The prostate is a small walnut shaped gland situated just below the bladder and encircling the urethra (Cancer Society of New Zealand Inc; 2001). It relies on testosterone for growth and development, and produces semen. Prostate cancer therefore, is a malignant tumour of the prostate gland (Cancer Society of New Zealand Inc; 2001). If the cancer remains within the prostate it is referred to as a localised cancer. Localised cancers may not display symptoms, progress to more advanced stages, or even require treatment. If the cancer spreads beyond the prostate to surrounding tissues, it is known as a locally advanced cancer. There are also lymph glands near the prostate that provide access to the lymphatic system. Prostate cancer therefore may spread throughout the lymphatic system or blood stream infecting other sites throughout the body.

Benign prostatic hyperplasia (BPH) is a common condition in men over the age of 40 (Prostate Awareness and Support Society, 2001). BPH is the swelling or enlargement of the prostate and is not a form of cancer (Cancer Society of New Zealand Inc; 2001). The symptoms of BPH may be very similar to those exhibited in conditions of prostate cancer. If symptoms occur, it is usually once the swollen prostate begins to apply pressure to the urethra. Common symptoms include difficulty or pain in passing urine, reduced flow, increased need to urinate, or occasionally blood or pus in the urine (Cancer Society of New Zealand Inc; 2001). Suffers of prostate cancer however, often experience no symptoms until the disease has spread to other areas of the body. Treatment of prostate cancer is more successful when the cancer is diagnosed early in the development of the disease. However, a common lack of symptoms in early stages can make effective detection problematic (Cancer Society of New Zealand Inc; 2001).

There are several tests commonly used to diagnose prostate cancer. Some of the tests ascertain whether cancer is actually present, whilst others examine its dimensions, size and whether the disease has spread. The digital rectal examination (DRE) is a common test. A doctor checks the size, surface texture, and shape of the prostate by pressing a finger against the inside wall of the rectum. If irregularities are detected, a blood test may follow. The prostate-specific antigen (PSA) test involves taking a small sample of blood and examining the level of antigen excreted by the prostate. Levels above 4.0  $\mu\text{g/L}$  are considered high (Gilling, 2000). If PSA levels are elevated or the DRE detects anomalies, at some point a biopsy may be carried out (Gilling, 2000). A small tissue sample is removed from the prostate gland to be examined for cancerous cells. This process can be uncomfortable or painful, and a local anaesthetic may be administered.

Unfortunately the effectiveness of screening procedures in reducing death rates for the illness is uncertain (Cancer Society of New Zealand Inc; 2001). It is important to outline the possible drawback to widespread prostate cancer screening. Prostate cancer may spread quickly beyond the prostate, whilst in other individuals the disease may progress only gradually. Current screening methods are unable to predict how a patient's cancer will develop. If widespread screening is implemented men with a slowly developing cancer that will not spread beyond the prostate will be treated in an identical manner to men with more aggressive forms of the disease. The treatment will be of little use to men who have slowly developing cancer, and they will risk experiencing the common side effects of treatment, such as incontinence and impotence (Cancer Society of New Zealand Inc; 2001; Gilling, 2000). To compound matters, the PSA test is known to have limited accuracy (Cancer Society of New Zealand Inc; 2001; Gilling, 2000). Men with cancer of the prostate may go undiagnosed whilst others without the disease go through treatment unnecessarily. However, in support of screening measures, early detection of the disease can significantly improve prognosis whilst advanced stages of the disease can be much more resistant to treatment (Gilling, 2000).

There are several treatment options available for prostate cancer sufferers. Options include surgery, radiotherapy, and hormone treatment (Cancer Society of New Zealand Inc; 2001). The form of treatment may depend on several factors, including the size, growth rate and location of the cancer, the patient's general health and age, and personal preference. If the patient is of advanced age, and exhibits only the early stages of the disease, treatment may be avoided altogether, an option termed 'watchful waiting'. If prostate cancer has remained within the prostate gland itself, surgery can be performed to remove the cancerous prostate completely. This process is known as a radical prostatectomy. This form of treatment involves a hospital stay of usually several days, with the patient being able to resume normal activities after four to six weeks. The procedure relieves some of the symptoms associated with prostate cancer, such as difficulty in passing urine, and increased need to urinate.

However, some undesirable side effects are associated with total prostatectomy including possible impotence and urinary incontinence.

As the prostate gland including the cancerous cells requires testosterone to grow and develop, surgery aimed at reducing available levels of testosterone can be effective in retarding or halting the growth of the cancer. Without a supply of testosterone the prostate and any areas of cancer begin to shrink. Atrophy of the prostate results in a reduction in pressure on the urethra, relieving some of the symptoms of the illness. One form of treatment to reduce testosterone levels involves surgery to remove the primary source of the hormone, the testes. This procedure known as an orchidectomy may leave men impotent, and sometimes patients experience hot flushes due to hormone changes. Alternatively medication may be used to restrict the level or availability of testosterone. Anti-androgen drugs block testosterone from interacting with the prostate, thereby starving the cancer. Other drugs are available which reduce the amount of testosterone produced by the body. Treatment may involve a combination of these drug types. Unfortunately, like many of the other forms of care discussed, impotence may result from this treatment.

Radiotherapy may be used in conjunction with surgery, or as the primary method of treatment. The process involves bombarding the cancer cells with x-rays whilst taking care to avoid surrounding healthy tissue. Treatment is often given over four to six weeks, although varies from case to case. Again, impotence can be a side effect.

Treatment for prostate cancer is most effective when the disease is in the early stages and remains within the prostate gland itself (Cancer Society of New Zealand Inc; 2001). Often the cancer will not totally disappear after treatment, but reduces in size or stops growing. Remission of the cancer may allow patients to return to normal, or close to normal activities and health, spanning months or possibly years (Cancer Society of New Zealand Inc; 2001).

# Methods

## *Participants*

Eight New Zealand men located from two regional centres of the North Island were interviewed. <sup>1</sup>Seven of the participants identified as New Zealanders of European descent. All men were sixty years or older and lived in their own homes.

Two participants had been treated by radical prostatectomy. Five men had orchidectomies, whilst one man was treated solely by radiotherapy. Two men suffered from secondary bone cancers, and had received radiotherapy in addition to their orchidectomies. All but one man were impotent. One man suffered from chronic incontinence since his radical prostatectomy, whilst another participant had undergone a Trans-Urethral Resection of the Prostate (TURP), to ease symptoms. Four men continued to experience hot flushes.

Participants were contacted through the Rotorua branch of the New Zealand Cancer Society or through the Prostate Awareness and Support Society (PASS) in Tauranga. A Cancer Society worker contacted potential participants in Rotorua on behalf of the researcher and forwarded the phone numbers of men interested in participating. The co-ordinator of PASS was also contacted and invited the researcher to present at a local support group meeting. Interested men offered their contact details. Potential participants were later contacted and details of the study were discussed. The men were also asked if they would like to receive an information sheet that would be mailed to their home. Potential participants were contacted after the information sheets had been posted, and asked if they had questions pertaining to the study. Interviews were arranged with participants after receiving their signed consent forms.

During the process of recruitment the researcher was also invited to attend several support group meetings and spent some time chatting informally with survivors within social atmosphere. This contact undoubtedly influenced the researchers later interpretation of data.

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<sup>1</sup> One participant passed away before this information could be gathered.

## *Data Collection*

Data was collected from participants via semistructured interview. Seven of the eight interviews took place in the homes of participants. One interview was conducted at the researcher's home. The time taken during each interview varied from approximately forty-five minutes to ninety minutes. An interview sheet prepared by the researcher was used during interviews. Questions were devised by the researcher, and were based on expected issues of relevance. Table 1 in Appendix A provides an example of this information sheet. After a brief introductory period with each participant, the researcher encouraged interviewees to talk about their experience of prostate cancer and any issues they felt relevant. Participants also answered questions from the interview sheet. Interviews were conducted in an informal manner, and occasionally short anecdotes related to the topic were shared between the participant and interviewer.

## *Recording Data*

Interviews were audio taped. Some notes were taken during the interviews regarding observed behaviour and interpretations. Issues raised by the participant that were not represented on the interview sheet were also noted. These topics were included in the interviewing of other participants if appropriate. Immediately after each interview a verbal note was taken covering immediate interpretations of salient points, and the interview as a whole. Interviews were later transcribed and included references to observed behaviour if appropriate.

## *Data Analysis*

Analysis of the data loosely followed the seven steps suitable for use in analysing phenomenological transcripts outlined by Colaizzi (1978), and presented as Table 2 in Appendix B (cited in Coward, 1994; Schwartzberg, 1993). These steps have been quoted in several published pieces of research, and appear to present a clear, logical method of explicating participant interpretations (Coward, 1994; Schwartzberg, 1993).

Initially transcripts were read several times in order to immerse the researcher in the content of each account. Prominent **issues** for each transcript were extracted on a line by line or

paragraph basis and coded with transcript number (1-8), page number and line number for later reference. Issues were the initial interpretations of participant's statements. Where interpretations became larger **explanations**, direct quotes were included to 'anchor' explanations to the data. Data from post-interview notes and other material was also analysed.

Interview transcripts were examined on an individual basis for recurrent issues or **threads** within the account. Threads were then grouped under **sub-themes**. Sub-themes served as precursors to a particular **umbrella term** or title, some umbrella terms being composed of several sub-themes and their corresponding threads, others emerging directly from a particularly prominent sub-theme. Prominent sub-themes were typically generated from several of the larger explanations mentioned previously, as opposed to multiple smaller threads. Thus some umbrella terms were composed of a 'solid', rich interpretation of the data, rather than a coagulation of 'smaller' multiple interpretations.

Once all interpretations had been classified under umbrella terms, categorisation continued across interviews. Similar or identical terms were merged creating a larger data rich category that represented many threads or issues for several participants. These categories were termed **themes**. Umbrella terms that had no corresponding category remained unchanged as a representation of an individual's experience. Themes were grouped under **larger headings**, mirroring the organisation of sub-themes and umbrella terms for individual accounts. Therefore large headings covered issues relevant for several men rather than a single individual.

At this point participants were sent an update of the progress of the study including a list of the large headings and example interpretations. Participants were encouraged to supply feedback to the researcher regarding the appropriateness of headings and interpretations via an included self-addressed envelope. Participants were also contacted via telephone, enabling verbal feedback and a sense of closure for both participants and the researcher.

Finally headings were placed into one of three '**spheres**'. Interpretations were checked to ensure that the organisation of data fitted within the appropriate category and that material wasn't repeated unnecessarily across spheres. At this point some headings merged.

# Interpretation and Discussion

Throughout the following chapter the reader will notice issues or 'threads' recurring or merging to become larger descriptions. The separation of the participants' accounts into distinct themes, result in an artificial organisation of my interpretations of these experiences, yet was necessary to allow some sense to be made of the data. Repetition therefore has been avoided as much as possible, although may occur in places to preserve the integrity of themes composed of multiple threads. Data has also been grouped under loose headings, although these categories are intentionally fluid rather than discrete.

Ultimately the issues raised by the participants were divided into three overlapping spheres; The Medical, The Social, and The Personal.

## The Medical

### Diagnosis

*"I was feeling pretty good! So I went and saw my doctor and I said er, um, I said 'I want a full medical' I says, the lot. I says 'I'm feeling pretty good at the moment', you know. And so er, he gave me a full check and um, and I had a test for the old heart and blood pressure, diabetes, checked for prostate everything else. And er, anyway he got back to me. And he says 'I think there's something abnormal about the prostate'"*

For most men the diagnosis of prostate cancer came as a complete surprise. Several had no symptoms whatsoever, whilst others visited their doctor for what were initially considered general aches and pains. Other participants endured problematic symptoms. These manifestations could be frustrating and inconvenient for both sufferer and those close to him. The need to urinate frequently was described by a couple of participants, and for one man, the experience during social situations resulted in chronic embarrassment. For participants without prostate related symptoms cancer was identified during a general check-up or via the exploration of unrelated symptoms by their GP. On one occasion a participant visited his doctor with a sore back and was diagnosed with cancer after his spouse requested a PSA test. Another participant, to substantiate feelings of good health, requested a general check-up. In the men's accounts of diagnosis therefore, cancer was often detected via

serendipitous circumstances, rather than as a direct result of symptoms pertaining to prostate cancer. The insidious nature of the disease, and the lack of symptoms in many cases created a mystique, however macabre, around the development of cancer. Otherwise healthy men were astonished that they could have a disease associated with ill health, wasting of the body and death, or as one man termed it; "...the big C, ... the dreaded lurgy".

The shock of being diagnosed was described as one of the most poignant moments in the experience of cancer. It "*ruins your life*" was the comment made by several participants. At the moment of diagnosis, participants were introduced to a disease of which they knew very little and had seldom considered. Even the word 'cancer' held connotations for some patients that weren't intended by the doctor. The term summoned images of a lingering and painful death, and reminded patients of 'others'; those who may have been pitied in the past; "... *it's a big blow its more or less saying 'you, you've got cancer (Mr E)', and, and it's almost in the same sense you're saying 'you're gonna die', you know. Because getting cancer, all we know about cancer at the layman base most of the time it's somebody that you know has had cancer and they've, died in six months or, lingered on for, for three or four years you know. But they do die. So it's, you, you take it as a death sentence...*". The emotional impact of such news was described primarily in terms of shock. The worst case scenario for those with symptoms had become a reality. However, despite an initial sense of surprise, participants described an immediate desire for knowledge. Rather than describing a complex emotional response to receiving diagnosis, or expounding on the experience of shock, most men summarised by saying that at the time they wanted to know more about their situation. In the first instance therefore, information was crucial. The transition may have been speeded by the additional fear of an unknown illness, and a desire to 'fix' the problem as soon as possible. Answers relating to estimated life expectancy, availability and forms of treatment, and the course and nature of the disease were most sought after. For some men diagnosis evoked an intense desire for activity or sense of purpose that later drove the participant to gather information in greater detail, and to reach out to others.

Crucial to diagnosis was the result of a PSA test. Participants felt that the test itself was not a hard procedure to endure, and could provide some sense of security if the reading was below the threshold of 0.4µg/L. However, many patients also discussed the experience of having a DRI and biopsy after a high PSA reading. During this period the patient's body was exposed to pain, examination and probing. The pain and discomfort of the biopsy for example, was almost legendary, and needed no further explanation if one had already spoken to a prostate cancer survivor; "*So then we had to have biopsies, which is well, everyone will tell you the same thing about that procedure*"!

Although generally the DRI was seen as both repugnant and painful, the men suggested that ultimately the image of the procedure was more offensive than the actual experience. Aside

from the physical discomfort, participants described the embarrassment of the screening measure. Feeling tense or uncomfortable could lead to a tightening of the sphincter muscles resulting in even more pain. Therefore participants adopted a practical and down to earth approach, seeing the proceeding as just one of many necessary actions. Adaptation and progression appeared to be a common feature in the participants experience of prostate cancer, and the DRI was no exception. Coping centred on accepting the situation and viewing the measure within the larger context of prostate cancer; "... *once you get something like this you're used to people sticking their fingers up your bum!*"

For some participants diagnosis was experienced as a computer assisted process whereby doctors were no longer interested in individualised concerns, but in assigning tags of illness or health, and allocating particular treatment plans. However, as one man mentioned, the situation had the potential to backfire on the medical profession. As doctors continue to loose interest in individuals, so patients may head straight for the diagnostic tool themselves, a situation highlighted by the rise in self-diagnosis via medical Internet sites; "... *and it's so easy today because they've got, er, they've got a computer and all they've got to do is feed the stuff in and they've got, they've got it right at their fingertips haven't they? You know diagnose, yeah. Computer. Just the top line, the top in the country. Well look at that bloke last night on um, with the brain cancer. He went to Hawaii, and found it on the er, found it on the Internet. Found all the relevant details, went to, went to Hawaii, brain cancer. He was out of hospital in three days. Walking around. Yeah. And he's back, he's back here. Cured. Oh, he's right as rain.*"

#### Information & Communication

The period between diagnosis and treatment often involved a great deal of waiting. This period held the potential to be either a negative time of anxiety and concern for one's health, or as most participants saw it, a positive interval that could be used to collect information about the imminent treatment. Participants also felt a need to gather information about prostate cancer itself as they "*hardly knew about it*". One participant who appeared to have adjusted particularly well to the impact of prostate cancer felt that he needed to know "*all the ins and outs*" of his surgery and so actively made use of this time.

Although Information regarding prostate cancer may be found in most doctors' surgeries, participants remarked that pamphlets and posters hadn't attracted their attention. Also, pamphlets clarified the basic details of prostate cancer but weren't able to explain other aspects of the disease. These sources of information offered little in terms of dealing with the practicalities of the disease or what local resources were available to patients. Most had no

symptoms prior to diagnosis, and therefore didn't think prostate cancer information was relevant to them. The stereotyped remark; "*I didn't think it would happen to me*", voiced by one man, appeared to represent all participants. Cancer was associated with very ill, emaciated people. Most participants generally felt fit and healthy prior to their diagnosis. The news that they had cancer therefore often came as a surprise, and most men felt they faced an unknown opponent. Reactions to this sudden challenge varied, with some participants taking a proactive, almost enthusiastic interest in the experience of 'surviving prostate cancer'; "*I knew nothing about it, no one ever, I didn't know any bugger that had prostate cancer when I er, when I was diagnosed. And um, so I said to the wife I said well, I don't know any answer I said, but if it's got to be done it's got to be done and I want to experience it all and um, and er, and take it from there*".

For some men the process of gathering information was facilitated by their GP, who gave them a solid foundation on which to build their own understanding of prostate cancer. However, participants gave varied accounts regarding the way in which they were informed about the presence of cancer. Generally participants felt that their doctors were direct and spent little time in disclosing the results of PSA tests; "*So I went in and had this blood test ... and er, I was at home and it was a few days later and he said 'I'd like you to come in' he said 'I think you've got', well I think he just laid it on me, I had prostate cancer*". One participant felt gratitude toward his doctor for ensuring that the PSA test was positive before concerning him with mention of cancer. Unfortunately other men didn't feel they received the same degree of consideration. High workloads, low staffing levels and poor communication between medical professionals could leave covering doctors in awkward positions regarding informing a patient of their diagnosis. This situation could be appreciated by patients, but did nothing to relieve the anguish and shock of being told one had cancer in an unsympathetic manner; "*I do think that the doctors could be ... a little bit more sympathetic, although I realise that, that in their role they have to tell people this sort of thing all the time. Um, or frequently. Um, but some of them are a bit, bit hard nosed about it. It's a bloody great shock when you're told that you've got cancer*". The result for one participant was that he was informed in a cold, clinical manner without the opportunity to ask further questions and was provided with very little information. In an effort to find further details he studied books and pamphlets whilst gathering further information via word of mouth. Obviously the situation held the potential for future confusion and frustration as the participant may have been misinformed by out of date literature, or widespread myths. One participant's caregiver held the view that enlargement of the prostate was specifically related to sexual deviancy, STD's, or promiscuous sex. As the prostate has a role in sexual functioning, fables and misconceptions regarding prostate cancer and sexual activity may be commonplace. Unchecked, such beliefs can only help to stigmatise those with prostate cancer.

Being informed about the expected outcomes of treatment was seen as essential. One participant awoke from his prostatectomy to find his genitals had been mutilated. Removal of tissue around the prostate and a subsequent shortening of the urethra had resulted in the penis being drawn into the body. The result for the participant was particularly disturbing. Despite the physical change itself, having no warning of this possibility intensified feelings of confusion, shock, disgust and vulnerability; *"It was not contained in the prostate, so they took out additional tissue. They took out part of my bladder. Er, so quite a section of urethra had to be removed so to reattach it to the bladder they had to pull (gestures) everything up. And er, (pause) that's disgusting. I'll tell you what that, that, that psychologically, that was a hell of a shock. Because I didn't anticipate it"*. The description reads like the script of a horror film. Lack of psychological preparation, via information and discussion, added to the trauma of disfigurement. In contrast incontinence, while perhaps a condition more threatening to everyday quality of life was described in lighter terms. This was an expected outcome, the participant being forewarned of its possibility; *"Um, .. of course incontinence is, is part of parcel of the deal, I expected that"*. Information about how to improve bladder control was provided and had a positive effect on the participant's life. However a large problem during this time was the unavailability of male incontinence pads. Although the participant later found that incontinence aids could be obtained, the abundance of material regarding bladder control was in contrast to that advertising a supplier of pads.

Although information was highly valued by participants, without clear communication between supplier and receiver, it was rendered useless. Communication was perhaps most important between doctor and patient. Physicians were respected for their skills and knowledge, and generally participants felt a great deal of gratitude toward their doctors. Several participants felt that their physicians had spent time to discuss treatment options and the nature of prostate cancer with them in detail. However, all the men described difficulty in understanding these explanations. Doctors were described as using a *"foreign"* language, making communication very difficult. Even those men whose doctors had spent time explaining issues to them, found the exchange of information difficult to interpret. At best explanations were described as *"more or less"* in layman's terms, at worst indecipherable.

Clear verbal interaction is important, as arguably the patient's need for information is higher at the moment of receiving a diagnosis than at any other. Shock may reduce the amount of information that can be absorbed by the participant and combined with a language barrier, many participants may have missed crucial information. Generally participants felt that the medical profession didn't place enough emphasis on communication skills. One man actually had to wait until he returned home from a doctor's appointment to have the discussion translated by his wife; *"When the doctor talks to you he talks, he uses, big, big words, you know. He says 'orchidectomy', now I don't have a clue what an orchidectomy was. And um, and they tell you 'well, I'm afraid we're going to have to have an orchidectomy"*

*mister E'. You can't wait to get home to see your wife and find out what the hell an orchidectomy is! So they talk to you in such a way that it makes it very hard to understand for the layman, you know. If they'd only learnt to talk in layman's language. But talking doesn't seem to be part of their scheme they don't seem to put any emphasis on the fact that you need somebody to talk to and you need the whole thing explained, in a down to earth man to man way of thinking. They tell you a certain amount. But you have to have it all explained again afterwards".* The inefficiency of this style of communication combined with the high probability of misunderstanding is pronounced. It is also important that medical professionals are aware that patients do not necessarily understand the meanings behind terms. The communication skills of GPs therefore are particularly important as treatment decisions may be made soon after diagnosis.

Patients who felt prostate cancer had a more devastating effect on their lives, tended to be the men who described the greatest communication difficulties with their doctor. Conversely those participants who felt the most content with their treatment decisions, reported discussion of their alternatives with a doctor. Aside from making more suitable treatment choices after being well informed, It may be that participants found it easier to deal with prostate cancer after being given a choice, and having a feeling of control over their treatment decisions. The increased sense of wellbeing may occur even if all options are unattractive. Feeling well informed, and that one has control over one's life and treatment decisions, therefore promotes an active coping response. Even a procedure as potentially stressful as an orchidectomy may be made easier by the knowledge that one has chosen surgery from a list of options, and that the choice medically speaking, is the best one possible. Information regarding successful coping strategies or attitudes to 'dealing with' cancer may be useful, provided care is taken that attitudes are not directly linked to particular treatments, an issue described presently. One participant appeared to have adapted fairly easily to changes resulting from prostate cancer, and approached the experience with a focused attitude of self initiated action and positive outlook. Armed with comprehensive information from his doctor, he made contact with a specialist about possible treatment right away. Information then was considered a powerful tool, and those who reported having enough information generally responded that they had made the right treatment decisions.

Generally the men felt that after their own experiences, patients should always take the initiative and monitor their own health. The shock and fear aroused at the time of diagnosis often brought out a warrior spirit in participants that drove them to fight against not only cancer, but also the bureaucracy of the health system. Therefore several participants felt details of treatments and their effectiveness had to be sought out independently rather than relying on doctors. One man for example, suggested that statistical information regarding the outcomes of treatment be provided when choosing between options. Ultimately the main sources for information were magazines, books, word of mouth, and occasionally the

Internet, which generally provided sought after explanations. Even after treatment, participants continued this campaign with their own work to arm and prepare others in a way that they felt had been missing from their own experience.

### The Medical Profession

Participant's conceptions of doctors typically followed two strands; doctors as busy professionals, and doctors as self-important experts. 'Busy professionals' were seen as hard working with little time to inform patients of their diagnosis in detail, often having to resort to an efficient direct approach. Professionals considered the patient's interests, and when time allowed would spend a moment to 'chat' and make conversation. Professionals were good at their job and put participants at ease, explaining information as best they could. 'Self-important experts' however were portrayed as rude and ignorant of patient's psychological needs. Experts appeared to disregard participants, although may have been deemed capable of their job. Some experts were even seen as possessing excellent technical skills but poor attitudes. It was not uncommon for participants to be torn between these conceptualisations. Feelings of indignation for poor behaviour contrasted with gratitude for treatment, pulling the men from one view to another.

There was also a tendency for some participants to polarise their view of doctors beyond the classification of 'busy professional' or 'self-important expert'. These classifications were permanent rather than temporary allocations. Some doctors could be idolised or alternatively cast as a villain, a concept that I have tentatively termed the 'pedestal phenomenon'. This degree of classification therefore was an extreme extension of the 'busy', 'self-important' dichotomy. The distinction is perhaps clarified by explaining that 'busy professionals' and 'self-important experts' were regarded as approaching their work with different methods or attitudes. 'Heroes' or 'villains' however, were distinguished not only by their medical practice, but their personalities. 'Heroes' were kind people, whilst 'villains' were indisputably offensive individuals. Amongst this ensemble of characters, a few unfortunate physicians were relegated to the doldrums of mediocrity, their personalities presumably not possessing enough flare to influence their professional conduct in either direction; *"... so we've lost him doctor (x) and he was the top urologist over there you know, and um, radiation expert. But then you've got some of his, some of the blokes he's trained, well they're not too bad I suppose but, they're not the same you know"*. In contrast one participant described a 'hero'; *"... and they had an oncologist there er, ... he was a wonderful man and he really put life back into you. You know he spoke to you as though um, he's part, part, you know part of me"*. The 'hero' in this case takes on almost messianic qualities being "part of" the participant and returning life and vigour to the patients or 'disciples around him.

The phenomenon of stereotyping may explain to a degree the pronounced effect physician's communication style had on patients coping, as reported by participants and discussed presently. However, the image of physicians as local deities or 'star' personalities, perhaps more prevalent in rural communities, can only lead to disappointment and resentment. Ultimately unrealistic expectations result in frustration for both parties. Moreover the pattern may perpetuate via continued societal values and stereotypes, media representations, and the potential for select practitioners to enjoy and encourage such adoration. Increased communication between patients and doctors therefore, may help to match expectations with outcomes.

Despite participants mixed views toward their doctors, all agreed on the excellent skills and manner of related health professionals, such as radiographers and nurses. These workers were always described by participants in positive terms, as "*(not being able) to do enough for you*", and as "*wonderful people*". The uniformity of these glowing comments therefore, adds weight to the possibility of the 'pedestal phenomenon' described earlier. Whilst essential medical workers, nurses and radiographers do not command the same level of eminence accredited doctors. Therefore an amiable mode of conduct and professionalism are appreciated rather than necessarily expected.

Doctors had power via their social standing, role, and patient's expectations. This influence could be used in a positive way, providing the patient with a sense of control over their treatment choices, and equipping the patient with confidence and a 'fighting spirit' to overcome the cancer. However, a doctor could also use this influence, however inadvertently, to demoralise, belittle and further reduce patients who were already struggling to come to terms with their illness. 'Self-important experts' or arrogant doctors kept communication at minimal levels. This lack of information sharing protected the physician, whilst exposing patients. Restricted communication was also used as a tool to gain purchase with patient's treatment decisions. One participant gave an example of this attitude relating his own experience with a doctor at diagnosis; "... *'I'll ask the questions!' - I was going to tell him the symptoms, you know; 'I'll ask the questions if you don't mind!' 'I'm the specialist'!*" This level of arrogance appears startling, yet the participants described numerous instances of such behaviour in their interactions with medical professionals. The example above highlights not only an attempt by the doctor to dominate the level of communication, but also an assertion of 'rank' or position of power. The physician declares his status as the 'possessor' of knowledge, "*'I'm the specialist'*", indicating that the participant lacks knowledge. However rather than share this information with his patient, the physician controls communication by keeping the flow of information in a single direction. Therefore, by minimising the amount of information provided to patients, and communicating in an elaborate style via the use of technical medical terms, doctors create an empowered position

for themselves whilst reducing the authority of the patient. 'Ownership' of medical knowledge remains with physicians, and through prescribed modes of communication, societal expectations, and an enforced hierarchy, doctors are able to lay claim to the bodies of their patients.

Some participants felt that physicians had seized all control over their bodies, and that they had been denied treatment choices completely. One participant was shocked after treatment to find that other options actually existed. The decision for treatment was made entirely by his urologist, who decided the participant should have an orchidectomy, a procedure involving removal of the testicles. The participant was only made aware that other options were available via a chance conversation with a doctor in a completely different area of medicine; "... Well it was a bit of shock to find out after that I had other options ... But um, I wasn't given a chance, my urologist said 'oh well', he said er, 'we'll put you into hospital and remove the testicles', and er, I didn't find out that I did have other options until I saw my eye specialist!". In response to attempted control by some medical professionals, participants designed strategies to ensure their needs were met. One man suggested questions be prepared before visiting one's doctor. By having an organised list they could be 'injected' into the conversation before the doctor could bring communication to a close; "... when you go to the doctor, you want a list really of, of what you're going to ask them you know, and then if they say 'well I'll ask the questions' well then go to another doctor! But if you can tell somebody your symptoms you see, if they don't ask you your symptoms how are they going to find out what's wrong with you"? Even if physicians are able to diagnose patients without listening to their complaints, having a doctor listen to the explanation of illness, and accepting experiences as legitimate, in turn provides the patient with the feeling that they have been recognised as a cognisant individual. This recognition was extremely important for all participants, and in instances where it was not received, participants described their despondency and anguish. Research in the area of doctor-patient communication has highlighted the positive outcomes for patients who received an unhurried and empathic diagnosis, yet further work is needed to explicate this relationship (du Pre, 2002; Ellis & Tattersall, 1999; Gray, Fitch, & Phillips et al. [a], 2000; Ratter, Iconomou & Quine, 1996; St Claire, 2000; St Claire, Watkins & Billingham, 1996; White, Rosson, Christensen, Hart et al., 1997; Young & Flower, 2002).

Information about the cancer's development was also sometimes limited, or concealed altogether. Restricted communication regarding the patients' bodies therefore, left most men feeling as though they no longer held ownership over their bodies. One participant was informed that a tumour developing outside the prostate was effecting surrounding tissue. However, the potential impact of this growth was not explained, leaving the participant anxious that the cancer had metastasised, or spread into the bone; "... he said 'I'm sad to say we found a tumour outside the er, prostate', and um, it's um, which was affecting the

*pubic ramus muscle I think, I'm not sure, or bone. But er, they don't tell you anything when they say 'it's affected', it doesn't say what, what it means I don't know whether, does it mean it's in the bone? Or is it outside the bone?"* Another participant experienced substantial fears regarding his scheduled orchidectomy. Primarily these concerns stemmed from "old wives tales" that had been ingrained during his early life. These beliefs caused considerable unease and positioned the orchidectomy as a serious threat to both his masculinity and self-image. It was only through personal experience, rather than supplied information and communication with his doctor, that the participant was able to discredit these fears.

Most men sensed some reluctance from their GP in offering or suggesting a PSA test, although the existence of a reasoned argument behind such obstinacy was unknown to participants. Without being informed of the debate regarding the use of the PSA, participants attributed reservation to incompetence or neglect. Therefore all participants felt that the initiative in screening for prostate cancer currently rested with patients, rather than doctors. To the sensibilities of the participants, a shift in traditional roles of responsibility demonstrated a failing in the medical profession to recognise the severity of prostate cancer, and its impact on New Zealand men. Several participants described a general disinterest by the medical profession toward prostate cancer, and a blasé approach to early detection. There seemed to be a dearth of information and support for those recently diagnosed, and participants felt lost within a system which cared little for the individual.

Despite reports of attempted control and domination by medical professionals through limited and complex communication, some participants found their doctors to be extremely helpful. One participant was pleasantly surprised when his GP referred him to another practitioner specialising in herbal remedies. Alternative treatments provided pain relief without unpleasant side effects. Therefore although the participant's doctor did not practice alternative medicine themselves, open communication and a sharing of knowledge regarding those physicians that did was extremely beneficial for the participant. Another man found he was able to talk to his doctor candidly about masturbation and the effect his orchidectomy might have on sexual functioning. Communication therefore could be used as a means of confusing patients, constricting their options and exerting control through fear, or as a means of finding the best alternatives for each individual.

Participants felt that there was a need for greater honesty regarding the roles and responsibilities of both doctors, and their patients. Participants felt frustrated at the costs of treatment, the perceived need to self-initiate prostate cancer screening, and the high salaries of specialists. Some participants felt their suffering was exploited; *"... and he gets, he gets er, oh well they're doing, you know, they're putting hundreds through because there's a lot of it about. And he must be making, you know, well over, well I dunno how many millions he'd be making but, it's terrific, and it all comes out of the government see? Well this is where all*

*the money is going you see, no wonder there's no money for anything else, they're specialists you know! Those specialists are on millions!"*

Comments made by doctors could also have significant consequences for patients. Some men found that particular statements dwelt with them, accelerating their sense of depression or hopelessness. One participant had a particularly unpleasant experience with his urologist who after a scheduled appointment made a brusque comment that he would see his patient in two months, provided he survive that long. Naturally the participant felt very angry and hurt about this comment; " ... Then er, I didn't take too kindly to that and um, ... But, (pause) his bed manner has something to be desired, and I sort of er, just sort of took it at the time and when you get home and think about things you think 'by crikey that was a bit rude!'. The trauma led to the participant 'mentally blocking' the specialist, in a manner similar to victims of violent crime wishing to block out the details of their attacker. Treatment options were also denied, further reducing the participant's sense of control; "But he's the one that didn't give me any options at all, just told me that er, you know, it had to come out and that was it! ...Um, but he, he er, he was, two or three things, he was quite a, quite a naughty man what he said me, and, but I wouldn't go back to see him, I'd rather go somewhere else, if I have to. Yeah ...I, I blanked him out of my mind". Inappropriate remarks made by physicians therefore may go unchallenged by participants weighed down with concern for their own survival. The social status and professional standing of physicians may suppress overt complaints. However, despite a lack of confrontation, inappropriate behaviour may linger in the minds of patients, colouring future interactions with the medical profession as a whole.

In reaction to poor behaviour, some patients found conflict with their doctor added fuel to the fighting spirit, or provided another reason for continuing the battle against cancer. One participant who felt his urologist had been particularly rude was overjoyed that he survived the two months estimated. The urologist had made the comment that he'd see the participant in two months if he could make it that long. The negative experience with this 'villain' contrasted with the 'hero's' and professionals at a nearby hospital; "I think I counted every minute of the day! But that's the only regret I've got about the medical profession, is that happened. But the rest of them are good as gold, excellent. Can't do enough for you really, and considering um, the way they've got to operate and they haven't got enough money to run these hospitals, you know, they're doing a good job, and they can get bigger money, you know, overseas. Yeah, it's good of them, they're excellent".

Deception regarding the amount of pain likely experienced during a procedure was another complaint. For one participant, honesty about what to expect during the removal of his catheter would have eased the experience. Instead the resulting pain was an unpleasant surprise; " ... oh saying there is no pain you know, like when the catheter, when the catheter has got to be removed you know, there'd be no pain, well there was pain. I feel it would be better to be honest with someone and say 'yeah it might hurt a little bit it's only for while'".

There were two connotations to this form of deception apparent to participants. The first was the impression of being patronised by the medical professional, leaving the patient feeling disrespected and further belittled. The second was that pain associated with the procedure was unexpected and perhaps more pronounced. The implication is that men believed they were having a worse experience than others, or were just not 'man enough' to cope with the pain. Ultimately the situation has the potential to condense to the patient feeling belittled, weak, vulnerable and in physical discomfort. The experience only adds to a growing discontent and mistrust patients may feel toward medical professionals.

The men's views of the medical profession influenced their attitudes toward treatment and health related behaviours. Some participants with secondary bone cancers were prepared to experience the physical pain and discomfort of travel in order to avoid 'bad' doctors in favour of 'good' ones. Sympathy for overworked medical staff also tended to increase as participants discussed 'professionals'; *"But mind you now, I think they are stretched a bit"*. For some men, secondary cancers and treatment could lead to a reliance on pain medication. 'Gate keepers' therefore were able to provide and deny at whim, further enhancing their position of power whilst reducing that of patients, *"I'm frightened to stop using it"*, and *"one tablet they took off me"*. The fear of being manipulated by physicians and other powerful agencies contributed to some men circumventing the source of influence entirely, turning instead to alternative therapies.

Most participants preferred not to have to visit their doctor if possible. Appointments not only cost money, but also signalled that the participant was unwell, or unsure about his health. Several men however reported that written feedback from their GP was valuable, and preferable to having an appointment. One man was very impressed when his doctor *"wrote (him) a letter"*, and said *"thank you for going along"*. After a regular PSA test he also *"said he was pleased with the result"*. Feelings of independence, self-reliance and good health therefore remained intact, whilst security that the cancer was being monitored aided coping.

Some physicians were simply insensitive or careless; *"... when I had to have that part of it, down in the doctors room there and I, and course the nurse came along, she said 'lie on the, stomach' and all this sort of thing you see, so she started to prepare me. Then he arrived, and er, and then he said 'oh by the way (Mr B)' he says 'this is my wife so and so' and I says 'well, what a great bloody time to introduce me to your misses'. I says 'she'll remember me backside man she won't remember me face'!"*

Dependence on the skills of medical professionals varied. Some men took an independent stance to their battle with cancer, utilising doctors as consultants, or 'contracting' their technical skills. Other participants however, invested much more heavily in the expertise of their doctors; *"um, let me think er, no, no I sort of er, I sort of gave, implicitly trusted them, er,*

*in what they were doing. But er, I think I was rather tired at the time, ... but er, um, they always left me with the choice".*

Participants could appreciate the difficult situations sometimes faced by medical professionals. One man acknowledged that the pain involved with some procedures could also be challenging for the medical staff to witness; *"Um, and I came out of there with the catheter still in and I had to keep that in for another three or four weeks, and when I had to go back and get the catheter removed they said "would you do it!"*

Participants saw the medical profession as improving their techniques constantly, and making frequent and exciting advances in treatment procedures and options. However it was felt that this commitment to progress should expand to include the monitoring of physicians interpersonal skills, and possibly the development of social skill training if necessary. Also, some men felt that they may not have had surgery if they had known the troubles ahead of them. Participants felt that the voices of survivors should be heard by the newly diagnosed so that informed decisions could be made. Therefore prostate cancer treatment was regarded as having a very nasty 'side to it' which was not often discussed by physicians.

Some participants enjoyed 'contact' or an interaction with medical professionals at a less impersonal level. One participant was greatly encouraged with the feedback he received from his doctor. The physician not only provided information on his patient's health but also included some personal contact. This enhanced the participant's feelings of wellbeing, and identity; *"(The doctor) wrote me a letter ... and er, thanked me for going along to have the test ... and saying he was very pleased with the result "*. Another man particularly enjoyed chatting with the hospice nurse. The importance of feeling 'human' after the probing of diagnosis and treatment was emphasised by participants. Easy going, down-to-earth communication between patient and doctor strengthened feelings of 'normality'. Taking time to chat with patients, even about mundane everyday matters, boosted the psychological well being of participants. One man found his ability to cope dramatically increased with positive feedback from his doctor; *"I've been to (another hospital) and they're wonderful people, no, they couldn't do enough for you! Er, they were, they were just really lovely, and they had an oncologist there er, ... he was a wonderful man and he really put life back into you. You know he spoke to you as though um, he's part, part, you know part of me and er, it was, really good, and er, from then on I thought 'blow, I'm going to', you know, 'beat this'. No, no problems with any of the medical er, people. I think they were first-class ... Because this guy ... was a brilliant man. I heard that he'd gone to Australia, but then someone else told me he's back! So I hope he is because he is er, a wonderful, you know, a guy to have amongst people with cancer. He just um, you know, revives them".*

## Health

After treatment the functioning of the participants bodies had often altered significantly. Props and aids were used by some men to regain pre-treatment, although not necessarily pre-morbid levels of functioning. Pills and other aids however could be inconvenient to use. One participant had to prepare eight different types of medication for his daily use, and ensure that he had ample supply for any trips he might make away from home. Having to carefully plan trips significantly impeded his ability to be spontaneous, a previous idiosyncrasy. Another man found the paraphernalia associated with impotence aids unappealing, and decided celibacy a more convenient option.

Medications could have undesirable side effects including dysentery, light-headedness and even visual hallucinations. Some men found they had to try many different types and doses, until a suitable compromise could be reached, whilst others had to take additional drugs to counteract the side effects of their medications. Hot flushes could also cause a great deal of inconvenience to participants, especially as their onset could be sudden and result in pronounced sweating. Flushes could seriously interfere with practical activities, such as gardening or performing chores; *"I had to change my tire the other day and I, I couldn't line the wheel up, you know, because I, and I was sweating and sweating, the water was pouring down my back and everything"*. One man reported experiencing 25 to 26 hot flushes a day, which prevented him from eating certain kinds of foods, performing physical activities or socialising. Eventually medications were made available that alleviated the problem, but not before doses of the drug had been adjusted to reduce unpleasant side effects. The impact of excessive sweating may be hard to comprehend for those not experiencing them, therefore most participants indicated that they had a greater appreciation of women's experience during menopause. In fact several men approached older women for advice on how to monitor the condition.

A significant problem for several men was the unavailability of male incontinence pads. One man found he had to adapt female pads which could not only be embarrassing, but also inconvenient and expensive; *"But, one of the problems that men who have this sort of operation face is that they are all incontinent for a while once they have a radical prostatectomy. And um, we needed padding, we needed incontinence pads, - no male incontinence pad that I know of. So what you had to do was adapt female incontinence pads, which is a difficult, a difficult thing. And it's costly, it's an expensive exercise, it's, it's quite dear. Um, I found a very large pad that I was cutting in half and chopping it around to fit, modifying it, which worked okay. But, but as I say all those sort things were er, ... I think it made you, concentrate on the exercises and try and get over the problem"*. For some men,

despite training, bladder control varied daily. Leaking was another issue that caused considerable embarrassment, as participants could be unaware of the predicament until noticed by others. Hot weather and bulky padding could cause considerable discomfort and increased participants feelings of discontent, frustration and depression.

Messages promoting the 'correct' attitude to take in regard to treatment were presented in the media via newspapers and television. To an extent participants discussed this influence. The experiences, attitudes and treatment decisions of personalities, such as Paul Holmes, were promoted in the public domain as models to be aspired to. Attitudes deemed as 'correct' however, stem from the treatments currently available. Campaigns promoting a 'life is better than sex' approach for example, are based on present treatment options rather than necessarily representing the most effective approach for coping with cancer. If current surgery in New Zealand does not spare nerve tissue, it is possible that a 'grin and bear it' attitude to loosing sexual function and bladder control is promoted, despite the potential fallout of such an approach. Promoting attitudes based on current treatment procedures may trivialise sexual functioning, stagnate the development of alternative treatments, and silence the voices of men who feel that life has been wrecked by incontinence. Therefore further treatment options, such as nerve sparing techniques, and statistical data regarding treatment outcomes, may be more useful to prostate cancer men than media campaigns.

Several participants turned to alternative therapies after initial treatment. This shift in paradigm was due to the harsh side effects of medications and treatments. Traditional treatments involved cutting, removing, radiating, injecting or flooding the body with toxins. The effects of this process, whilst limiting or removing cancer, damaged healthy tissue and crippled some functions. The body emerged wrecked, yet alive. Whilst participants were thankful for their lives, all suffered to some extent from the necessary severity of this treatment. The "*nicesst*" way of dealing with the disease therefore, was to 'watch and wait' if one was old enough. Alternative therapy was used as an addition rather than as primary treatment. Alternative therapies could also be expensive via their own class of drugs, 'supplements'. However the client centred manner of specialist differed vastly from the acerbic response some patients received from the mainstream medical profession. Having personal attention, courtesy and information explained clearly in a compassionate manner gave participants a psychological boost. Alternative treatments were also described as gentle and effective, or as one man explained; "*you know it's just like oil running down you*". A sharp contrast to the men's previous experiences with therapy.

Treatment was a very individual experience. Whilst some men found surgery frightening and crippling, others found it "*... a piece of cake really*". One man hated his catheter and was greatly relieved when it could finally be removed, whilst another participant found his "*marvellous*" as it meant he was able to stay in bed and recover. Ultimately survival was

prime concern for the participants however. Retaining sexual function although considered important by all men, was not the top priority. If their doctor gave them an option, each participant considered the implications of treatment carefully. Some men did not want to pollute their bodies with drugs, whilst others wished the cancer completely removed from their bodies altogether. Radiation treatment, while a procedure possibly sparing sexual potency, was seen as inferior to a radical prostatectomy; *"He opted for um, radiation treatment that was first option. Now, I didn't, I, I deliberately wished to have, have a radical because I just didn't want to die, I didn't want to die of cancer. So um, that was the main reason why I opted for a er, a radical"*. One man however was deemed too old for an anaesthetic by his specialist, and so had no choice but radiation. His intact potency however was regarded as a very welcome bonus of the procedure.

Even with successful treatment, relapses were common, and so the fear of prostate cancer remained lodged in some men's consciousness. Despite a radical prostatectomy, the potential for recurrence remained. As a consequence some patients considered radiation treatment in a last ditch attempt to survive the disease. Participants therefore emphasised the need to consider long-term treatment options rather than just focusing on initial treatment. As one participant explained; *"... most of them have had a relapse of some time, at some time. Very few of them are there who have been completely cured by whatever treatment they had initially. Um, radicals, um, very often, yeah it's very often that guys have to go on, later on to radiation treatment. Um, that's another good reason, to my mind why a radical should come first. There should be a natural progression, and a radical should be first and then radiation. Because if you have radiation first you cannot have a radical. Because the, the radiation can damage the tissue so that it won't heal up afterwards. So the progression as I understand it is radical, er, radiation, castration. Is, is, is the way it should go. Um, hopefully it doesn't come down to that"*.

Participants were generally dissatisfied with the New Zealand health system. Most felt that 'the system' failed patients whilst privileging it's agents, the medical profession. Waiting lists were so long that without health insurance participants felt they would *"... wait two or three years and get nowhere"*. The costs of treatment also left some men feeling short-changed. Physicians, those without cancer, were perceived as receiving generous wages whilst patients struggled to meet the costs of treatment. Therefore despite offering 'care', the health system allied with cancer in draining the financial, emotional and physical resources of patients. Private health care offered improved facilities and even higher salaries for physicians, thus attracting specialists away from the public system and causing it to degrade further. Consequently the commodity of health was offered to the highest bidder. Advanced treatments with reduced side effects were available for some men, depending to a degree on the cancer's progression. Reduced side effects led to increased quality of life and enhanced well being. Health therefore became a luxury available for some, but denied others

depending on a host of factors not excluding the financial resources of the patient; “ ... you've got to get there in the first place, if you can get there, it's not so bad, you know, ... But you've got to get there in the first place see, because all this waiting list, and by that time people are dying, you know, ... But I've just, I've just, er, went to the meeting this morning, and, there's a woman there with the brain cancer and ... she gets three days, and she's in hospital, for an operation, then she's back out, right as rain, same thing ... I don't know whether she paid for it. But, it's not the thing is it really? It shouldn't just be for the rich people eh?”.

Communication within the system was also seen as poor. Physicians abruptly passed responsibility of patients to colleagues leading to awkward situations at diagnosis, forgot to make appointments with radiographers, and were surprised at one another's actions when recounted by participants. The men described an 'organised chaos' of grand proportions. The culture of the health system had no place for individual needs or personalised support. Patients were consumers of the system's funds and resources. A continual juggling took place between treatment costs and effectiveness, thereby the health of the patient was tweaked, tinkered, and ultimately manipulated until the most cost effective solution for the 'system' was found; “You see ... um, I had my blood pressure pills, okay they suited me fine they kept my blood pressure right down you see, where it wanted to be, you know, 120/70 and they were ideal, so Pharmac come along and they said those pills are too dear. And any rate, they gave us some substitute. And of course they gave one lot of substitute which didn't agree with me at all, you know, I was crook, you know. I had diarrhoea I had everything. And I couldn't take it home, made me jittery and goodness knows what all ... So I went back and then they gave me two lots more. One lot didn't agree with me again, then they, then they said that was too dear, took that off me and by this time my blood pressure was jumping up and down, you know, it was going right up right up, right up! And then right down, and they couldn't adjust it. And you know, I was faint, half-pie fainting”.

The health systems of other countries were seen as superior to the New Zealand model. Improvements were seen in three areas; financial demands on patients were less, the attitude of medical professionals more positive, and finally a greater number of treatment options were available. One participant was particularly impressed with the health system in Australia, which he felt provided better working conditions for doctors and specialists, in addition to improved services. The utopian health system was within the realms of possibility; “But you can go over to Australia and do it, a friend of mine went over there, and he got a, he got a heart transplant from Australia actually he was on holiday! Yeah, went over there to visit his son for three months, got a heart transplant. Inside three months. So it's possible isn't it”? The New Zealand system in contrast, was an archaic and slowly decaying institution; “But the system, the system here is absolutely terrible”.

## Metastasis

Most participants mentioned that at diagnosis their primary fear was that the cancer had spread outside the prostate, or metastasised, to other parts of the body. Cancer contained within the prostate was often treatable and most men were able to continue with their lives. However if metastasis had occurred, patients were assured of a never-ending battle with the disease. Participants described men with secondary bone cancers as “*real battlers*”, a mark of both respect and condolence. Men who suffered with “*secondaries*” were often the people others compared their situation with when feeling depressed. For those participants surviving with secondary bone cancer, life continued and was dealt with on a day to day basis; “*I just, I just wake up in the morning and I think ‘well okay here’s another day’ and I just except, take that day as it comes, and I, and I just get on with life and um, make, make, do, do the best I can, make the most of things*”. However, the struggle with cancer was often a physically painful experience, in addition to the inconveniences of impotence, incontinence or the other side effects of treatment.

For men with secondary cancer of the bone, the ability to remain active without pain was essential. Not being able to carry out certain functions, especially those relating to practical everyday activity, could cause a great deal of frustration and depression. One man was particularly relieved that he was able to drive his car, despite having to give up some other pleasurable activities; “*Um, I found that with, with my prostate cancer, certainly since it went into, into secondaries, it, it went into the bones, into the bones of my right leg that it’s affected me in so far that um, I’m not able to do the things I, I want to, I can’t bend my leg but fortunately with a bit of, I’m able to drive my car. Although it’s a bit, a bit difficult getting into the car with my right leg, it’s a bit stiff, but I’m able to drive the car for which I’m very thankful*”.

The fear of metastasis spurred several participants into having radical prostatectomies. Most men did not want cancer within their bodies for fear that it could spread to other tissue and cause further complications; “*... well anyway it come to me pretty quickly that if I had cancer of the prostate I didn’t want, I didn’t want it in my body and I didn’t want it spreading anywhere else which is, which it does in a lot of cases, as he explained well ... So we decided straight away oh, well I’d have it removed*”. Apprehension regarding the possibility of metastasis also compelled participants to become firm advocates of the PSA test and global screening. The first hand account of one man who experienced considerable difficulty due to secondary bone cancer, presented a compelling argument for early detection. However, just as compelling were the descriptions from participants struggling with incontinence and impotence. The risk of subjecting men without prostate cancer to such side

effects, through over-diagnosis of the disease, supported continued controversy and discussion.

The life threatening status of secondary bone cancer caused considerable concern. Affected men were especially aware of the need to enjoy life and make the most of their remaining abilities. However despite focusing on the positive aspects of their condition, several men felt that metastasis had wasted their lives. Having cancer in the bones could have been prevented by an early PSA test, a measure held up as a beacon for others. Hope then rested in the future of others rather than one's self, and the use of the PSA to prevent further cases of metastasis. As one participant described it; *"Without being er, without being er, any way embittered um, towards anyone for the fact that ah, perhaps the doctors should have told me to, to have a test taken years ago in which case it could have been, it, it could, it could have been prevented, it would have been prevented! But however it wasn't done in those days, there was no such thing as PSA tests taken and er, so as a result of, I've just been caught so those people that are coming along now, er, er, in the middle aged category can have these PSA blood tests taken and er, if there is any, any problems there it can be stopped in time and they, they won't have to go through what some, some others of us have had to go through"*.

Once prostate cancer reached bone tissue, in practical terms it became almost another illness altogether, requiring frequent radiation therapy to ease the pain. Patients were regarded as having past a certain point along the road of prostate cancer, after which challenges increased. Participants with metastasised cancer never 'recovered'; *"When you've got pain, and it's starting to hurt, you are too well advanced, you, you, you are passed the point of redemption basically ... Um, I was lucky, I was very lucky because I didn't have it in the bones or my lymph system"*.

Secondary cancers could cause physical limitations to participants by making movement painful, or joints stiff. One man found he often became depressed as he could no longer participate in activities he had previously enjoyed, such as dancing with his wife. Travel to meetings and appointments could also be difficult.

News that one had secondary bone cancer could come as an unpleasant surprise. One participant felt *"as good as gold"*, until a scan revealed the cancer had reached his bone. Radiotherapy to the groin was successful, yet the same treatment to the shoulder created a large amount of pain to the extent that treatment was halted. Also radiotherapy could leave participants exhausted. As an alternative, or when radiotherapy was no longer possible, drugs were effective painkillers.

The PSA test was considered a measure of the cancer's progress, a high reading meaning that *"you're cancer is well, alive an, and kicking"*. Whilst a lower PSA; *"You're winning, that the cancer has been, compressed"*. With the passing away of friends and acquaintances, and further men being diagnosed with prostate cancer, the thought of having a medical test confirming that one was 'safe' provided much needed reassurance. Information was vital for participants, the highest commodity, and for those starved of this resource the PSA was the 'golden boy', an indicator that gave comfort or provided the initiative for further action; *" ... so, I used to believe that for a man with prostrate cancer (sic) every six months get your doctor to have your PSA done so you know if, if the PSA stayed low then you're okay. If the PSA started climbing that means your cancer was coming back. And so, I, I put a lot of faith in the PSA"*. However, despite their faith in the measure, participants did not necessarily comprehend the meaning behind the term 'PSA', or the implications of the test's results. Some participants acknowledged that they found the readings vague and confusing, as men in support groups had vastly different levels of the antigen.

The prestige of the medical profession and perceived supremacy of the medical model lent credibility to the results and reliability of the PSA. Therefore the devotion displayed by participants to the cause of global screening, is unsurprising. In fact one support group co-ordinator had a fairly up-to-date awareness regarding controversy surrounding the test, and opposed the stand taken by the New Zealand Cancer Society against global screening. However, reliance on the test was a double-edged sword. Rising PSA results after treatment could cause further panic and distress, despite never passing the threshold of 0.4µg/L; *"Um, my PSA reading when I first came out was down to 0., 0.01 um, stayed like that for a year, around about a year, then it started to climb. It went up to four. It went up one, two, three, four, and I started to get worried, I thought 'oh, I'm due to go on the right drugs' because that was the next logical step. And er, then it went down. So er, it, it sort of makes you a little bit nervy too, because you don't know how it's going to turn out"*. In turn raised levels of anxiety could effects the men's behaviour toward others, especially their wives. One man found that as the date of his PSA test approached, he became increasingly irritable.

A lack of information by health professionals regarding risk factors and screening measures was seen as a dangerous neglect of men's health. The results of a PSA test could be well above threshold levels before the participant experienced pain, therefore cancer would be able to destroy the body before the patient had time to be treated. One participant explains; *"... and er, early detection of course is, is the goal to be aiming at. As with all cancers er, early detection can save lives. When you've got pain, and it's starting to hurt, you are too well advanced, you, you, you are passed the point of redemption basically (pause) Um, I was lucky, I was very lucky because I didn't have it in the bones or my lymph system. ... I was .3, or three notches up above what was regarded as dangerous. And I had no pain. But um, I found them, ... Er, our main man down here, (Dr A), is, is, a very, very difficult man to speak*

to. *Um, he does not have a good patient to Doctor manner at all, um, ... he didn't tell me very much, he left it to me to find out (pause) but, (sighs) yeah I, I think that, that er, doctors, (pause) they've got to take a more proactive line with, with, with males over a specific age, er late forties, early fifties they should, they should be pushing guys to have a, er, have a PSA test".* Early detection therefore was seen as essential, and doctors in their silence, condemn their patients to a slow and painful death. Arguments against global screening, or the role of early detection were either not made available to patients, or were disregarded. Discussion of men's risk for developing prostate cancer therefore is barely audible, whilst the debate regarding use of the PSA test remains within the scientific community, rather than being broadcast to those in the public arena whom it chiefly concerns. Further research examining survivor's perceptions of the PSA test therefore is essential (Clarke, Lovegrove, Williams, & Machperson, 2000; O'Dell, Volk, Cass, & Spann, 1999).

## The Social

### Support Groups & Sharing Information

Information was considered a crucial commodity for participants throughout their experience with cancer. Information could be used to dispel fear, provide direction for further actions, or provide tools for coping with the aftermath of treatment.

Married participants discussed treatment options with their wives, and some believed that having their wives present at diagnosis would have been an advantage, as the process of absorbing information could have been shared. The time immediately after diagnosis was also an important period in which to filter and regulate information. Participants controlled this process in different ways. For example some men 'told everybody' and welcomed outside opinion, whilst others only allowed friends and relatives knowledge of their condition after successful treatment. One participant dealt with his prostate cancer by restricting knowledge of its existence within a marital relationship rather than sharing with extended family. Gathering of information and discussion of treatment was therefore kept between husband and wife, and so removed the added pressure and 'noise' of others opinions and emotional responses. For all participants, the process of gathering information didn't conclude after treatment. Participants found that the after effects of treatment required their own adjustments, and often information was sought to equip one for these trials.

Information covering the aftermath of treatment, such as acquiring male incontinence pads, was generally non-existent except by word of mouth via a network of experienced survivors whom I have termed 'informants'. Talking to others about personal experiences could be beneficial for both parties, as receivers gained information and informers developed an increased sense of worth and purpose. Generally it was necessary to join a local support group or know others with the disease to 'hook' into the chain and receive this kind of valuable information. As most participants didn't know other men with prostate cancer at the time of diagnosis, support groups were often the sole means of meeting other people with prostate cancer. Obviously becoming part of the chain or network could be difficult without first being informed of the existence of such a group. One participant in frustration created his own group, whilst another man met an informant by chance at a social gathering. Generally participants 'stumbled' upon support services in their area. However, even when a patient had found others to share information, instruction was largely passed by word of mouth. The potential for misinterpretation and confusion therefore, was pronounced.

The source of perhaps the most valuable information were a group of individuals I have termed 'veterans'. Generally veterans had survived with prostate cancer for over a decade, and were regarded as having 'made it' by patients and other <sup>1</sup>'survivors'. Veterans therefore comprised the bulk of 'informers'. Participants found the presence of veterans at group meetings encouraging and it was often veterans who advised newly diagnosed patients, or led the way in campaigning for particular issues. Veterans then were seen as the holders of knowledge, and through their personal experience, as experts in their own right. In turn survivors passed on their knowledge to others and campaigned or worked to inform friends and peers about the PSA and related issues.

The participants respected the expertise of doctors, alongside the practical advice given by informers. However, a gulf exists between the two. Medical professionals possess valuable knowledge yet are generally too busy to impart it to others, whilst veterans have considerable first hand experience, yet lack the breadth of knowledge relevant to treatment beyond their own history of morbidity. This situation left some men in a state of confusion, and reliant to some extent on anecdotal reports to guide treatment choices. It appeared that the prostate cancer community was aware of the limits of 'advice giving' and respected the professional standing of doctors. However, entwined within this acceptance was an intense frustration that access to knowledge is limited.

Printed information was often American based and some statements regarding recovery based on American procedures were misleading for New Zealand patients. Surgery in

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<sup>1</sup> I have made a distinction between 'patients' or those individuals being treated for cancer, and 'survivors'; individuals having already been through the process of treatment. A primary distinction between these groups therefore, is the volume and quality of knowledge each possesses regarding the process of surviving prostate cancer on a practical day to day level.

America tends to leave nerve tissue intact, whilst practice in New Zealand appeared to favour the removal of all surrounding tissue, including nerves, to ensure cancer doesn't metastasise.

Despite this confusion, the value of information, even that which didn't directly apply to New Zealand, was evident in participant's accounts. One man expressed the importance of pamphlets and booklets that had been imported from America. These were described as one might describe insightful literature, as treasured acquisitions, passed on to the individual through the local support group. New information therefore was a rare commodity passed from one individual to another along an extensive grapevine, or shared *en masse* at monthly meetings.

Several men found that after treatment their sexual functioning had altered in unexpected ways. One man found that sexual intercourse was still possible, although ejaculation had become more intense. Another participant found that an orgasm was possible although a full erection was not. Although some participants had relinquished their sexual identities to a greater extent, most continued to see themselves as sexual beings. Therefore comprehensive information regarding capabilities of sexual functioning post treatment would have been helpful for most participants.

The search for information often evolved and extended to the provision of knowledge for others. 'Students' of prostate cancer thus became informers and 'missionaries', some actively approaching men in bars and clubs to inform them about early detection and available support services. The motives of such 'work' may not have been completely altruistic, although participants generally were prepared for a high level of personal disclosure. One participant gave the explanation that he felt he was being useful as he had wanted additional information when he was first diagnosed. Another explanation was that the personal nature of prostate cancer demanded communication at an intimate level, rather than recycling the same general statements presented in traditional media. Information was perceived as having a value that could be raised by the manner in which it was communicated. Poor communication therefore, could render information useless.

Several participants mentioned that cancer used to be seen as an unmentionable condition, "*the dreaded lurgy*", and was rarely talked about openly. However generally the men believed the situation to be changing in a positive direction, with more people being open to discussion of cancer. One participant wanted all the information available, having a disease that to his knowledge, was unique among family and friends. Finding out about prostate cancer was a challenge, an adventure, and he immersed himself in this new pursuit of knowledge. Generally the participants saw a positive atmosphere and open discussion as helpful in reducing the stigma attached to cancer, and increasing the number of men seeking screening tests. Despite the language barrier that existed between doctors and patients,

medical professionals were regarded as valuable resources of relevant information, and the inclusion of such professionals in support group sessions could enrich the knowledge of both parties. "... *Prostate cancer is a bit like er, a woman in a nylon dress (chuckles). It's what you can only partially see, you know. It's um, you can never really fully understand the, the whole thing it's only, you only get a glimpse of it, and er, it's when you get a group together and start talking about it, and you invite the doctor along and get him to talk about it, that you all start to learn more about it and the whole thing is nowhere near as frightening as you first thought*".

All participants felt a need to talk to somebody about their cancer, and whilst some were pleased to have a communicative doctor, others were less fortunate. Being able to talk to other patients, especially when facing traumatic treatment options, was regarded as a necessity. The desire for discussion, communication and information led one participant to search out others with whom he could share his experience, and learn about prostate cancer. As there was not a support group available, the participant worked towards creating his own group. Communication was also particularly important for married participants. One man felt that open conversation within his marriage was imperative to his ability to cope with prostate cancer. Central to the relationship was a commitment to honesty about one another's expectations and desires. This level of communication was particularly important during the time the participant was choosing treatment options. Expectations regarding sexual function for instance, are important topics to discuss. In addition, the feelings of other family members can add extra pressure for the patient. Some participants therefore delayed informing other family members until after treatment. Thus communication was directed at those who could provide the most direct support, whilst avoiding potential areas of difficulty.

The manner in which information was shared regarding prostate cancer, was also considered significant. Some married participants received their diagnosis with their wives, and so avoided the difficulty of relaying the information to their partner at a later time. In these cases, their wives reactions to the diagnosis and views of available treatment options were of prominent concern. Spousal opinions regarding treatment options played an essential role in the decision-making process. Several men felt that information had to be explained in a "*down to earth*" way of thinking. Some sensitive topics were best clarified by those who had lived through the experience themselves, rather than by a doctor explaining physiological changes in technical terms. Suggestions for this approach included compiling the accounts of survivors for others to read through at the time of diagnosis, thus explaining the day to day lived experience of various treatment options, and their side effects.

Most participants believed that doctors have a very difficult job, and that some miscommunication was inevitable. Physicians had to be very careful how they phased certain concepts, as the emotional content of the topic of cancer could increase distortions

and misunderstanding. One patient actually mentioned that his doctor had suggested two friends accompany him when informed of his diagnosis, so that miscommunication could be reduced. Actions by the medical profession to increase the efficacy of communication therefore were generally recognised and appreciated by participants. Communication between doctors and prostate cancer patients may also be complicated by gender issues. Men may tend not to disclose details, or ask as many questions as female patients. For instance, one participant was accompanied by his wife whenever he visited his GP as "... *she thinks I don't tell the doctor anything*". In fact it was only via the participant's wife reminding the doctor that her husband was due for a PSA test, that cancer was diagnosed early, before the onset of symptoms. Another man suggested that men may not want to face the thought of prostate cancer because it can mean the end of their sex lives, and generally threatens masculinity.

#### Reactions of Others: Considering Family & Friends

Generally the participants were hesitant to inform others of their diagnosis. The reactions of friends and acquaintances were an unknown variable that some participants avoided by keeping communication limited. One participant feared that people might give up on him had they known of his condition; "*oh, he's dead, got cancer*" writing him off as a friend and being "*a bit funny about it*". Other men felt they were able to inform friends and colleagues after successful treatment, when the drama of the situation had calmed down. Humour was often used to broach the often awkward topic of prostate cancer; "*... later on I told quite a few people, I was in different organisations, and I told them what had happened and that and er, and I just sort of made light of it, and er, talking about anything it's er more in a joking sort of a manner or, this sort of thing*"

The participants noted that family support, especially from spouses was particularly helpful in terms of practical aid after cancer treatment. However, due to the expense of medications and treatment, some men had to rely on family for luxuries, such as unusual foods, drinks, or trips outside the home. Even buying a beer for one participant necessitated using money given to him by his daughter. This reliance could be limiting, as feelings of guilt about how the money should be spent caused reluctance to filter money into pleasurable commodities. Also some participants felt an obligation to go through the motions of being 'looked after' by family and friends. Financial aid that would have been useful for the participants in other areas was spent on services that were regarded as unimportant, but satisfied family that they were caring for their ill relative; "*... you get cobwebs and you get, you know the blinds get all dirty and the windows get dirty and you know I don't feel like doing it really. But I have to because my daughter comes up and checks on me, and I can't have a cobweb in the house*"

*or a dirty window when she comes up because she, she goes out and hires a whole bloody team of people to clean the house. And it costs 140 bucks a day for three people to clean the house. Well I could do with 140 bucks myself!*

The domestic environment of participants could have a significant impact on their ability to cope, and their decisions for treatment. To a degree some participants felt reluctant in seeking help and support from busy family members. Others however, also actively avoided informing family, as the excess concern could add additional pressure and anxiety; *"Had, had the son and family and his wife, they came down here ... and, so anyhow I said to them you're going to be pretty busy I says down here pulling all that paper down, and re-papering and all that, I says, I says don't worry come and see us a bit later on you know because I was booked to go and have this bloody operation. And so I did that and I came out, and then er, I think they came and paid us another visit the day after I came out of the hospital. But they still didn't know a thing about it not until later and I, I let them know you know. But I'd experienced everything by that time and er, I didn't mind."*

## Work

After treatment participants felt that sharing their experiences and views on the PSA test with others was important and personally rewarding. Giving advice re-established a sense of 'wellness', a feeling of completeness as a useful and potent member of society. Participants tended to spend a great deal of energy and time in this process, just as they had spent resources seeking information for themselves. This process was followed with such vigour that it was described by participants in terms of a "crusade" or "missionary work". I have termed it simply 'work' and made a distinction between two stages.

The urge to 'work' could manifest in two general areas. Work for oneself in seeking information and support, and work towards offering that desired support and information to others. The substance of this phenomenon should not be underestimated. For instance, work to find information often involved considerable effort on the part of the participant, searching through regional directories, phoning strangers or distant acquaintances, and generally taking an active approach to information gathering. Likewise informing others often involved organised trips to public places for the purposes of approaching men, or setting up 'stations'. Some men approached strangers in social situations and actively directed conversation to particular topics. Others contacted friends, family and work mates specifically to discuss the disease. Organising campaigns or going to meetings at night could be tiring, and often motivation was low when more pleasant activities were available. Certain skills were needed to run support services and organisations, and a considerable

amount of time was sacrificed. Therefore, the concept of 'work' did not include casual or social conversations about the experiences of participants, but rather a focused and prolonged effort to express a particular message regarding prostate cancer.

The men's personal identity could sometimes be threatened by the physical changes experienced after treatment. Even the suggestion of cancer at diagnosis, shook foundations of belief regarding life and one's place in the world. Therefore through 'work', participants took on the role of adviser and gained a sense of purpose. Participants had become experts in their field, possessing valuable knowledge about life with prostate cancer. The nature of 'expertise' in this sense was restricted to individual experience. Participants emphasised that the value of their knowledge rested with their having encountered a procedure first hand, therefore an 'informer' could educate others only on matters related to their own treatment decisions; *"I, I sort of, you know, went on a bit of a crusade for awhile and every, bloke I knew would, be sure that I'd give them the message. But a lot of them, oh, ah I don't, you know, I haven't got a lot of the problems so some things you don't know"*. In the area of which they were knowledgeable therefore, participants found personal experience and the role of advisor provided power and authority. Also a sense of personal control was an essential component in the coping process for participants. Therefore having power and authority increased this perception of control, thus raising coping levels, and reaffirmed the men's sense of identity after cancer.

Often work aimed at gaining information for self, developed into work for others. For instance due to a dearth of local support services, and seeking others to share concerns, one participant decided to create his own support group and invested a great deal of time approaching local businesses for donations, and broadcasting on a local radio station. Eventually through a great deal of work, the participant formed and led a support group for prostate cancer patients. Even after this mammoth task, he continued to approach others to suggest PSA testing and through anecdotes recounted examples of 'work' carried out by members of his group. Another participant, who had struggled to find support himself, added the details of a local support group to an information sheet available for Samaritan telephone operators. To some degree then, participants 'paid back' or contributed to the community information and support they had desired or received, and continued the chain of assistance for newly diagnosed men.

Participants found work particularly rewarding, as many had wanted additional information themselves when first diagnosed. Actively approaching others therefore allowed participants to feel that they were improving this situation. Generally men felt that it was more important to get information about day to day life with prostate cancer from an individual rather than from a pamphlet, therefore most participants also considered they had a legitimate role to play in educating the men of their area; *"I think the biggest positive is the message you get."*

*You have to acknowledge through your own experience ... to relay to other people um, who possibly haven't got it but are in the, the danger age group. To, to do a little bit of missionary work basically and er, I think that's the biggest positive".* One participant had been involved in many organisations around the community before treatment and so found 'work' fitted an established schema, providing a sense of returning to normality. Other men also gained a sense of personal satisfaction and usefulness from sharing with their peers. Sometimes 'work' could become a joint venture, with a group of experienced survivors visiting public places together. Panels of experts were able to give advice on a wide range of issues concerned with prostate cancer. Also, sharing experiences provided participants with an outlet for expressing their feelings about cancer. By giving advice to others the men diffused some of their stronger emotions and gained a sense of control. Just as physicians had been the holders of knowledge at diagnosis, so participants were able to reclaim some of this power for themselves by sharing their information with others.

Some men received phone calls from acquaintances asking for information. Participants generally were happy to offer advice, and could spend considerable time talking on the phone. Other work included visiting pubs and clubs. One man with several other survivors made 'a little sign', so that men who were interested could approach and talk about their own fears of prostate cancer. Generally the participants felt that most men were afraid to discuss such matters, especially with strangers in a public place. The reactions of men without cancer to the "missionary work" of participants varied between indifference, amazement, interest and disgust. Most participants mentioned that they found it easy to approach others and discuss the sometimes very personal details of their experience with prostate cancer. Despite occasionally meeting with negative reactions, all participants felt that the potential to change even one life was worth the hard work and effort. As one participant mentioned; "*... I think there might have been a lot that are, you know, they're, they're scared to, come and er. There was one, one, a Maori, a Maori fella, he came up. And he, we had a good yarn with him and, and he appreciated it too you know, because he was saying all sorts of, sorts of things about him and, and the misses and all this sort of thing. And so we had a yarn with him, but that's, that's the only one we saw but, at the end of the day we thought well, we've spoken to one person, and that's encouraging".*

Work continued within the support group environment when new members attended for the first time. Participants described offering themselves as experienced 'informants', and at times going out of their way to encourage patients to ask them questions; "*... we do have um, at, at, at these meetings some of the, odd times someone, someone new comes along and um, and, and they've got a lot of, a lot of concern or they've heard this they've heard that and um, and so we've, we've just turned round, sat around and er, said well ... 'well we'll just sit around here, around the table tell you what, tell you what, what we experienced, what happened to us'. And I said, and we said er, 'if you've got any worries, concerns, or might be*

*something else' I said, 'well you just fire questions at us and, someone will know an answer, or will be able to give you an answer' and that's what we did".*

Although all participants were willing to share with others, the way in which the men approached others differed. Some men enjoyed working in the community and approaching strangers in public places, whilst others preferred only to discuss their cancer within informal social situations, or with friends. One man found he was able to discuss his experiences in detail with others on a one-to-one basis, with a level of disclosure he felt rare among his peers. However, group speaking at focus group meetings or in public was uncomfortable; *"... I've always been able to talk about it. A lot of guys can't. I, I've never had that problem. I'm prepared to speak one-on-one, but I'm not good at group speaking. Excuse the excuse! But er, er, as I said, standing up in front of a group, it's not me at all".*

Whichever method suited the individual however, sharing about prostate cancer was an action, rather than just a topic of conversation. Participants worked at informing others and expressing their points of view. One man explained how he informed others about secondary cancers and the importance of early detection via the PSA test; *"... I find that I'm um, able to er, I'm able to help other people or if I, if I get talking with other people of, of a similar age category and er, usually I try to bring the conversation round er, perhaps people will say 'hello um, have you got a stiff leg? What's that? Why have you got a stiff leg'? And um, 'oh you've had an operation'? 'Oh no, it's, it's prostate cancer, it's from prostate cancer', and then I'm able to still say to people how it effected me and my advice to them, ... If I'd had a PSA blood test done several years before er, I, I started to feel I had problems with the old prostate er, it, it could have been stopped in time, it, it wouldn't have got into, into er, prostate cancer and er, nor into secondaries so um, that's er, that's a big, that's a big, that's been a big issue".*

Some participants therefore had their own messages they wished to express. Usually these arguments concerned the PSA test and the lack of global screening for older men. Several men worked to encourage friends to be tested for prostate cancer. The fervour of this effort was likened to a religious crusade; *"... I, I'm on current issues. I've turned religious; I'm constantly telling people to have a check up. My friends, my own friends have all been told and they've all gone and done it! So you know, it's a missionary thing basically um, and er, you know it, it, you do try telling people to er, to get themselves checked out, because early detection is, is half the battle".* Another participant felt that delayed diagnosis had resulted in metastasis of the cancer to bone tissue. Rather than offering general information to men about prostate cancer, the participant emphasised his views on the need for global screening and the value of the PSA. He felt there was a need to spread the message so that others wouldn't have to *"... go through what some, some others of us have had to go through".* For

this participant then, work provided an outlet to express his frustrations and attempt to change the policy of screening.

Although the participants felt happy to inform newly diagnosed patients about their own treatment outcomes and experiences, there was a degree of frustration regarding this extra responsibility. Some men saw the position of 'informer' as an obligation, resulting from the health profession relinquishing their accountability. Perceived abdication therefore pushed experienced survivors to take up the burden themselves, causing further strain to a population already under high levels of stress. Although the men also experienced positive feelings and a sense of accomplishment from advising others, the sheer effort and energy involved, developed the defining character distinguishing 'work' from informal discussions or conversation. Studies exploring the effectiveness of self-disclosure and active coping strategies amongst men with prostate cancer have had mixed results. Further research examining the role and efficacy of these methods would be beneficial. Moreover, the possibility of 'work' amongst other cancer populations may provide enhanced insight into the coping response of men with prostate cancer (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Lavery & Clarke, 1999; Poole, Poon, Achille, White, & Franz, et al., 2001).

Whilst participants found doctors could be very restrictive with information, most participants acknowledged that generally men are reluctant to approach doctors for details and testing. Therefore participants recognised a niche for informants who had personal experience with the disease, and could approach men 'informally'. Despite an energy and enthusiasm to work however, the men were cautious and sensitive in their approach, often respecting the professionalism and medical knowledge of their physicians. In effect then, participants were torn between feelings of obligation, enjoyment of work, and a desire not to step over boundaries, or encroach on the 'territory' of medically trained professionals.

#### Support Services & Future Directions

All the participants involved in the study found support groups useful to varying degrees. Whilst one man had gone to great lengths to create his own group, another participant found them of only marginal use. However, every participant had suggestions for improved support services, and felt that with changes these services could substantially improve the quality of life for future patients.

Most of the participants felt that support groups provided services that weren't or couldn't be provided by physicians. Whilst specialists tended to keep the flow of information to a minimum and regulate it's form, focus groups allowed a marketplace approach where

information was abundant and members could talk openly about their experience. The danger of the situation however was the potential for misinformation to spread quickly and become entrenched within the prostate cancer patient community. Without some measure of policing by medical professionals, unfounded beliefs may become firmly established. There also appeared to be little debate among participants regarding the role of the PSA test, suggesting perhaps a stagnation of information despite an initial sense that material is fresh and abundant.

Support groups provided essential information for the men. As mentioned in previously, 'veterans' or long standing survivors often provided the bulk of this information. Details such as locating suppliers of incontinence padding and dressings could be traded by survivors, and given to newly diagnosed patients. Talking to others about the experience was described as being beneficial both in terms of helping others and discussing one's own problems and feelings; *"I've also said to any, any, anyone I know, I says if you, but if you are concerned about yourself whether you may or may not have it due to the old waterworks playing up or not playing up and all this sort of thing, I said feel free to have a yarn to me"*. Although participants found the interaction very rewarding, belonging to a group whose members could pass away unexpectedly raised participants awareness of their own mortality, and saddened those who lost friends. Ongoing support services for prostate cancer survivors, even those involved in support work themselves, could be particularly helpful.

Support groups facilitate the exchange of personal first hand experiences. As participants tended to have very different experiences, personal stories covered a wide range of topics relating to the disease, and enabled participants to express their own fears and receive encouragement and support. Support groups could be useful for men before, as well as after, treatment. One participant described the comfort he received from sharing his fears of surgery with other group members and the usefulness of their responses. All participants felt that talking about cancer was beneficial and individuals were interested in how the disease effected others as well as themselves; *"... the group, the support group, gives you a greater knowledge of, an understanding of life. Um, it's amazing just how strong some people can be when they, when they find out, and how supportive it is ... when they're talking about it in the group, for the first time in their lives they talk about their own body and what's wrong with their, what's wrong with them, and they, and they're pleased to be able to be talking about it"*. Participants therefore found strength in themselves and others that they had previously been unaware of. Support groups encouraged a sense of community and allowed the men to draw energy from those around them. Participants were no longer alone with the disease. Support services provided a morale boost that facilitated continuity and acceptance in the life of the survivor.

A commonly mentioned advantage of support groups was the opportunity to compare one's self favourably with others in worse situations. Participants described having their eyes opened, and returning "to reality" when listening to the experiences of others. Those survivors who appeared to be in better situations were never mentioned. Recognising that others were in a worse predicament sometimes enabled grieving participants to see their situation in a wider context. Although perhaps seen by those without cancer as an undesirable method of dealing with the disease, human nature in this case provided participants with a clearer view of the positive aspects of their experience, what remained unscathed from the ravages of cancer. A general appreciation of life therefore became a priority, along with a view to being thankful for positive experiences, and avoiding negative thoughts; "So over, all in all, when I look back at it I, I think I made the right decision because I go to those cancer meetings over there and there are some poor guys who are in not a good state um, I've known guys who have died with it, well, since I've been going to meetings over there. There is the odd one or two who've passed away you know, and it makes you feel quite sad. Whereas I've, four years? I think it was four years last March, and all my blood tests seem to be spot-on, no problem. ... Odd time or two you get a bit depressed and I think when you go along to those meetings, once a month or whenever it is, and you comeback to reality a bit I think". Participants therefore focussed on the positive aspects of their experiences, highlighting retained abilities and control against a backdrop of negative possibilities.

Organising campaigns or going to meetings at night could be tiring, and often motivation was low. Certain skills were needed to run support services and organisations, and a considerable amount of time was sacrificed. Participants suggested that although survivors may have the enthusiasm to drive such enterprises through the process of 'work', younger and healthier individuals could provide substantial support before the men became too tired or ill. However most men believed there would be very little public interest or support from government agencies. One participant suggested doctors could play a pivotal role in local support groups, perhaps providing talks and updates, and generally representing the medical profession at meetings. This presence would also provide some measure of guidance in regard to circulating material, minimising the occurrence of inaccurate or harmful beliefs. However, participants felt physicians would be too busy or resent the additional responsibility of contributing to support groups.

As doctors possessed professional knowledge and expertise, cancer survivors set up local support branches then invited specialist guest speakers. In these cases publicity was essential to ensure a good turnout, yet also required considerable resources. Planning and organising took time and energy, something that some participants didn't feel they could spare. The value of guest speakers within support groups was also questioned by a participant. He noted that speakers were not particularly successful, and that the survivors

often lost interest; *“Er, I also found that when they stopped talking amongst each other about their cancer, we, it was because we were having guest speakers. People in their 60s and 70s which is the main group which you’re, you’re talking about are not that interested in guest speakers but they are very interested in how their own body, and how long their own body is going to hang together. So having a er, a group that you can lean on is very important and it worked very well”*. Doctors may feel therefore that their efforts to inform patients go unappreciated. As survivors tended to be willing to pass on information to others through other avenues of ‘work’ however, collaboration with health professionals could be beneficial for both parties.

Participants felt that medical science is continuing to improve treatment procedures and is beginning to explore methods at retaining nerve function vital for maintained potency and bladder control. This acknowledgement of the physiological concerns of patients was appreciated. However psychological needs haven’t received the same degree of attention, especially in regard to the process of informing the patient of their diagnosis. Generally participants felt that it was left to other survivors, rather than the medical profession, to make support and information available. As one participant viewed the situation; *“You get far more information, far more support from people who have been down the truth, down the track, ... I mean at times you get the opinion that the medical profession are only interested in their exuberant fee”*. Therefore, although the participants acknowledged the expertise of physicians, ultimately appreciation was focused toward other survivors.

Participants felt that after-treatment follow-up, and support services were vital for many survivors. One man also indicated that the cancer patient’s domestic situation should be considered when planning and implementing support services, both before and after treatment. The wives and caregivers of patients were made very welcome at group meetings, yet were rarely considered by doctors as needing this kind of assistance. Several men suggested that the meetings were beneficial for their **wives**, and that support groups specifically for caregivers and spouses could be beneficial. The experience of having a spouse diagnosed with cancer could be traumatic, and the lives of those close to patients could be disrupted; *“It’s very important that um, we remember the carer in, inasmuch as they are just as important as the person whose got cancer. In two ways; one, it’s because they are going to be the one that helps, helps you through, helps you over the hurdle. They, they have an understanding of what you’re going through, and they’re going to be going through an awful hard time themselves. You, you’ve just told, the doctors just told them that their husband’s gonna die. Well that’s what they feel anyway. They’re not going to have their partner much longer, not going to, have his grand children grow up and know him. And er, they’ve got to learn how to cope with you, the way you react to your knowing you’ve got cancer. And they need every bit and as much consideration as the person whose got cancer”*. Toward the conclusion of the interviews, it became apparent that research

incorporating the views of prostate cancer patient's spouses or caregivers, would provide vital insights into the mutual coping response. Remarks regarding the process of shared coping supported the notion that the research focused on a single facet of some men's experience, the boundaries of which were imposed by the researcher. For some participants surviving prostate cancer was not an individual or solo experience, but rather a process shared with their spouse.

One participant believed that interviewing both himself and his wife would have been a more accurate approach. However the aims of the research were to examine the impact of prostate cancer on the lives of individual survivors, not a co-constructed account of this experience. While it may be argued that the experience of prostate cancer was shared and 'survived' by both patient and spouse, some aspects of the experience of prostate cancer are clearly not. Therefore the combination of both interpretations would add 'noise' to the account of each individual. Certainly research exploring the experience of spouses or caregivers is needed (Friedrichsen, Strang, & Carlsson, 2001; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Lavery & Clarke, 1999; Ptacek, et al., 1999). However due to the relatively unexplored topic of prostate cancer patient's experiences, combining accounts may not be beneficial at this time.

Often support groups offered participants their first introduction to others with the disease, and provided the men with the feeling that they weren't alone. A sense of community was often described that became so rich, caregivers and family of the patients became involved. Relatives and loved ones of cancer patients could be generous with their time and resources and played a significant role in contributing to the community spirit of the meetings. Partners were not excluded from the cancer 'community', but could actually play important roles in administration, thus filling essential roles that would otherwise remain empty or be occupied by survivors.

Mixing with patients suffering different forms of cancer was described as helpful. Other than prostate cancer patients, women with breast cancer comprised the greatest number of cancer patients participants had contact with. Most men described having the view points of women regarding breast cancer as helpful for their own coping response, as women tended to see and cope with cancer in alternative ways, and had their own set of issues to deal with that could provide the men with a wider perspective. Women with breast cancer also tended to be of a younger age group, and the men enjoyed the less 'institutional' setting of mixed company.

Some participants were surprised by the sources of some support. For instances several participants found that older women had also experienced hot flushes during menopause, and offered valuable support and advice.

Some men stressed the importance of social contact as well as formal discussion of prostate cancer related issues at group meetings. A couple of participants described the social gatherings at their local hospice, where cancer was never mentioned. Not discussing the illness could allow the men to escape their concerns for a while and enjoy the activities. Participants described feeling 'normal', and being able to relax. The negative connotations of attending meetings at a hospice or cancer society building could deter people however; *"I go along to the hospice, in (Town), once a week and that's most enjoyable, we have a lot of fun, people don't talk about their illness, ... But it's good to see people you know there are well that have got cancer, and we just sort of have a good old yarn and what have you, yeah, never talk about illness. ...no, no it's a wonderful er, group and I would say that um, we'd like to see more people there but they, they think they're going to die when they go to a hospice. But it's not that at all, no it more or less keeps you alive!"*.

At the time of interviewing the participants, support services were an amalgamation of social activity and practical information sharing. For some participants the leaning toward social activity was frustrating, whilst other men wanted to keep the social activity, but separate it from the business of offering support and advice regarding prostate cancer. Participants therefore envisioned future support as offering two completely separate services. The first group would be dedicated to social interaction. Prostate cancer, and discussion of illness would be effectively banned, instead focus being centred on enjoying time with others and 'getting away from it all'. The second group would be dedicated to discussion of prostate cancer related issues, aspects of the disease, including practical support, and individuals case should they wish to share them. One participant continued this concept by suggesting the group be broken into smaller units, each unit comprising of members who shared the same treatment options or side effects, such as incontinence, impotence, or secondary cancers. As not all survivors experienced the same side effects of treatment, or advanced cancer, some men felt that they had to endure meetings which could contain very little information relevant to their own condition. Several participants therefore had spent some time in considering support services and how they could be improved.

Participants had strong views on the importance of global screening and early detection of prostate cancer. Areas perceived as needing further attention included the need to help younger men overcome the fear of having a DRI, and seeing the procedure as a standard test in much the same way as women are encouraged to view cervical screening and smear tests. As one participant mentioned; *"Er, and a lot of people are walking around with it young, I'm, I'm convinced that there's a lot of young blokes that get um, get the symptoms. Well then, they might not get the symptoms but then the bumps will be there. And if they can, you know, just overcome, you know, that fear of the old finger. It's all the embarrassment of it you see. Because, it's, it's nothing he's got a glove on and all that sort of thing. But seriously it might be a bit messy. But, it doesn't hurt. But if, if you find it soon*

*enough, and get the treatment soon enough, well it will be no trouble at all*". Participants felt that honest accounts of the procedure are needed if men are to be persuaded to have the procedure.

One participant described the varying attitudes of men in his support group toward discussion of prostate cancer. One patient didn't want others to know about his prostate cancer and didn't wish to discuss it. However after reluctantly joining the group, he found it very useful and became one of the most outspoken members, even approaching strangers and encouraging them to be tested. Attitudes toward the disease varied from one individual to another, but the men who did join support groups seemed to find them useful. Some men felt that the disease equated with death, and that discussion of the condition would show vulnerability or weakness. This was the attitude held by a Maori patient who was contacted by a participant during the time he was setting up a support group. Anecdotal reports from participants suggested that few Maori attended support group meetings. Whilst American epidemiological data clearly shows racial differences in the distribution of prostate cancer, statistics comparing the incidence of the disease for Maori and New Zealand European men are currently not available. It would be useful to explore the views of Maori toward support groups, and whether beliefs differed from those of European New Zealanders. It is also possible that there may be a difference in the health beliefs and behaviours of urban and rural Maori. Therefore further research in this area would be an advantage before planning advanced support services.

Ultimately, participants felt support groups should aim to raise the profile of prostate cancer at a national level, in much the same way as cancers of the cervix and breast have received media coverage. Participants noted the endorsement of mammograms and cervical smears by the medical profession, and were perplexed that the PSA had not received similar support. The debate surrounding the PSA was absent in the men's talk, suggesting participants were unaware of the contention. Therefore despite the publication of literature recommending caution, all participants were in favour of global testing for men over 40.

#### Social Interaction and the Community

Socialising, a pastime reported as being consequential to the coping process, was described as being particularly difficult for some men due to incontinence or fatigue; *"You know, I can't go out for an evening out"*. Several participants found they could no longer enjoy alcoholic beverages as lowered bladder control resulted in frequent urination; *"But, um, that was a problem I had, it, it was a problem, that leakage, from the bladder ... so that, that was one problem that came up pretty quick. As I said it's gradually got better but it's still a bloody*

*nuisance and what is, I'll tell you what is the worst thing out is, um, I quite like a rum now and then, but if I have too many rums HOLY SMOKE! I would say my limit would be three very weak ones. If I have any more than that, hell, and you don't, the point is you don't know you've, you're leaking you see. That's the worst thing about it, yeah".*

Several men discussed the loneliness and social isolation of cancer. A sense of being alone in the world became pronounced when peers past away and familiar faces at focus group meetings were no longer present. One man described his despair after treatment; "*You got to, you see that's the worst thing you see, if you're on you're own you get no human contact at all. You know, you don't even touch people, you don't talk to them or see them or anything you know. And that's terrible, that's half the problem really is you know, the um, er, you know, the lower you get you get lonely um, and that sort of thing but, you could go mad you see, you feel like a caged tiger in this place ...*". The emphasis on social contact may also be related to the age of onset of the disease. Prostate cancer tends to effect older men who may have smaller social networks than younger people. Thus the social isolation reported by participants may result from age related factors in addition to the effects of prostate cancer.

Some men found their relationships with others altered after treatment. One man discovered that initially many people would visit and offer support, however as the illness continued friends stopped visiting. It was as though he had already passed from their company. Without continued social interaction topics of conversation began to diminish;" *... I used to, when I wasn't very well, I used to get a lot of people coming to see me, then all of a sudden they've stopped ... you don't get the er, visitors you used to get before. They sort of knocked off you know, and I think that sometimes they don't know what to say to you, that's the impression I get sometimes. Which is a bit awkward, I suppose, you know, when someone is sick you're inclined to think that er, you know, 'what the hell can I say to them'?"*

The importance of retaining one's dignity and paying your own way within support group functions was emphasised. Even in social situations where free beer was made available, it was important not to "*Just hog it, ... because it was free*", but to behave courteously. Prostate cancer was not an excuse to be rude or self-centred. Belonging to the community also meant identifying as part of the group. One participant felt that the term 'cancer survivor,' as often used in the literature, was an appropriate term to use, and an accurate phrase for representing the way cancer patients felt about themselves. However, he added that the term "*current cancer survivor*" most likely reflects the reality for many men.

Several men felt a keen appreciation for people when part of a support group. It seemed that the community atmosphere brought out the best in people, and enhanced the sensation of belonging to a group and sharing the 'ups and downs' of cancer treatment. One man felt that

cancer changed not only his body, but his outlook as well. Despite the negatives of cancer and treatment, the experience enhanced the positive aspects of life making them appear more salient. Cancer left its mark on the character of the person, or as one participant described; *"they've got something there, they've got something there that other people haven't got"*. This experience opened individuals to other points of view and practices. The result was an environment of increased tolerance and understanding, where one could relax and be themselves. An environment where to have cancer was the norm, not the exception; *"I see them, I see all the girls from (the hospice), and um, you know, they don't go to the meetings or anything but I see them in town and they always come up and have a word, and they, they give you a big hug and that you know, and, and they're really alive once they've had cancer you know ... They just give you a big hug, and they're so, they're so good together over there"*. Such renewed vitality was not experienced by all participants however. One man felt that prostate cancer had turned him into *"an old pensioner"*. Vigour had been drained in a similar manner to the secondary cancer that had stripped strength from his leg. Social activity was therefore reduced, and solitary pursuits were followed including reading and gardening.

## The Personal

### Control

Mr A had survived the war as a combat fighter and bomber pilot, and had experienced many harrowing experiences as a top dressing pilot after the war, including having his plane burst into flames mid-flight. Mr A also recounted the details of a very full and exciting lifestyle, and was obviously familiar with high-risk situations. However, despite possessing a robust set of coping skills developed from these experiences, the impact of his wife's illness and his own diagnosis brought him to *"a very low point"*. A point where he felt as if he were *"out to it"* and was *"just going to step off the planet"*. Mr A was surprised at the enormous emotional strain he experienced with his wife's illness and the reality of his own mortality. Coping strategies cultivated from past experiences were ill prepared to deal with the unrelenting nature of cancer, and the terminal illness of a loved one. One explanation for the failure of these strategies is the lack of control inherent within these situations. Whilst previous experiences had generally occurred whilst the participant was at the controls of an aircraft, performing daring and heroic feats, there were no 'controls' for Mr A to manipulate during the ongoing degeneration of his body from a prosaic disease. The death of close friends and acquaintances occurred quietly and inconspicuously within the confines of parochial

hospitals and town houses. The lack of control and the nature of cancer to attack indiscriminately created a crippling panic, which only passed once order and poise had returned to the participant's life.

Regaining a sense of control was a central thread running throughout the participants accounts of their ability to cope with prostate cancer. Loosing control resulted in depression, a sense of hopelessness and lethargy. The short case study above provides some insight into the role of control within the experience of prostate cancer. Men able to cope with life threatening situations found the 'ordinariness' of cancer difficult to deal with. Cancer chose it's victims indiscriminately, and disregarded the current life events surrounding those men it affected. The disease killed slowly and quietly within people's homes and its path couldn't be avoided or altered by the efforts of sufferers. Participants therefore felt helpless against its onslaught, and sought to battle this state with proactive behaviour such as seeking information, treatment and support.

Some of the negative effects of treatment could result in loss of control over one's body. Loss of bodily function such as incontinence or impotence understandably had a large effect on those men whom it effected. Incontinence in particular resulted in depression for several men. However, losing control could also effect daily living and social situations. One man described a detailed plan designed to allow him to reach a public toilet should he lose bowel control in public. Public conveniences in town were noted so that embarrassment could be minimised. Loss of control of one's body interfered with the fundamentals of being a self-sufficient individual. Participants found they had to rely on props, aids and other people to function. The state of dependence could be demoralising and frustrating, especially for those men who were particularly active pre-surgery. The trauma of lost control could be immense, and participants described the Herculean efforts needed to cope with the associated frustrations and practical problems involved. This impingement on 'normal life' increased feelings of anxiety and depression. Loss of control therefore had far reaching consequences in the lives of participants; *"I still get trouble, you know walking sometimes I just never go out. And, and any rate, um, the worst, the worst effects I've had, I had, um, er, involuntary, er, defecation which means you shit yourself, and you know you can be in town and it just strikes you just like that you see, 'cause you've got no control, no control over your bowel, It just hits you. So in the first place I didn't know too much when I, um, first had it come out, er, any rate I'd, I'd be in town and I knew where all the toilets were naturally 'cause I'd you know, strategic. And one-day the nearest one happened to be McDonald's so I go bursting, bursting into McDonald's you know, to try to get there before, you know, I couldn't hold it any more and er, any rate I'd shit myself right in the middle of McDonald's and then I sort of had to hobble out the other door ... in front of all the people. So that wasn't too good, but I've had, I've had it several times since but I've got that under control now"*.

Controlling knowledge about the presence of the illness was also important for participants. Some men kept the news of their cancer from family or friends, as the additional stress of other's reactions may have been too much to bear. Once treatment was successful and the outcome of prostate cancer on their future predictable, participants were able to inform family on their own terms, with a sense of security and with the knowledge that 'everything was under control'. Regarding the areas of their lives that could be manipulated therefore, participants made use of their power, and gained a stronger sense of coping. Control acted as a foundation on which the men based their coping, thus as areas of control were lost, the men shifted weight to those regions that remained under their influence. Sharing experiences with others also gave the participants a sense of their own control. Experiences could be retold how the participant felt they should be explained, using their own terminology rather than that of the medical profession. Details could be omitted or included on the whim of the speaker, thus bolstering a sense of authority and power over the material.

A lack of information regarding operations and medical procedures caused some participants considerable anxiety. Without an illustrative account of what patients should expect before, during, and after the operation, participants faced a virtual black hole. The process of having surgery could be frightening, particularly as many factors regarding the extent of the cancer are generally unknown before surgery. Patients didn't know how successful surgery might be, whether they would be impotent and incontinent permanently, or even if they'd remain entire. Uncertainty therefore was a significant problem, and accompanied a feeling of having no control over the situation.

## Coping

Most men described coping as an attitude. To deal with the impact of cancer, participants stressed the need to accept the disease, rather than evading issues. Understanding the entirety of the situation and admitting to difficulties when they occurred was crucial if such problems were to be tackled effectively. A proactive approach to coping was therefore a necessity; *"If you er, if you're just going to put up with it, well you're going to be er, you're going to be a very worried sort of a person. But if, if you find out that um, see a lot of people get the idea 'oh, it can't bloody happened to me', you know. But if it does, and you, you take some sort of positive action, and it, and it sort of works for you and, and er, and sort of puts it on, puts the spread or the longevity of it on hold and er, you know you're able to walk around with a smile on your face, and, you know. Well, that's the way I view it anyway"*.

Participants maintained that in order to cope there was a need to accept that some control had been taken away, and with this loss of control came an inevitable sense of

powerlessness. This did not involve 'giving up' or completely resigning oneself to a lack of bodily control in a particular area, but an acceptance of what was and wasn't possible in terms of recovery of lost function. Power or control was reasserted through routines, pleasurable activities and via successful medications or aids, such as incontinence pads or powerful painkilling drugs. Regaining some control and ownership over one's body was an essential stage for successful coping on both a practical and psychological level. Participants moved through coping stages of cancer, leading to a point of acceptance and adaptation, a phenomenon also discussed by Carter (1993) in her research with breast cancer survivors. Phases were fluid, and included shock, information and support seeking, frustration, acceptance and 'work', and progression. Stages could be revisited by participants and experienced in parallel, a feature also discussed by Carter (1993) in her concept of "going through" cancer. Participants who were situated at the acceptance phase felt they 'just had to get on with it', and looked toward enjoying the rest of their lives as much as possible; "... oh, I've put it behind me but, I think you've got to accept it, and just sort of carry on with your life. You know you can't just sort of sit in a closet and um, hoping that it will go away, because it won't. Er, you've just got to sort of try and um, you know, look after yourself and er, do what you're told. I think you can enjoy it, er, life after". Some participants felt that they had moved a step further, to a stage where prostate cancer had no bearing on their lives whatsoever. In effect they felt 'cured'. Other participants believed that this level was in fact regression to pre-acceptance stages, and that men who claimed to be 'past cancer' were deceiving themselves; "Um, you have to accept it! You know, it's there, and it's there to stay. Er, I would say the majority of prostate cancer patients, um, they can get over it altogether, you know, their mind's gone a bit too far. You know, I was just reading a pamphlet not too long ago on um, my medication I've got and it said that, you know, if you watch yourself you can live for three or four years. Um, after, but it'll finally get you in the end"! The possibility of reaching a stage where one could feel that they were 'past cancer' was simply not available for all participants. Some men had secondary cancers that due to painful movement or stiffness in the joints, were a daily reminder of the presence of disease. Therefore the men who tended to reach a stage whereby cancer was seen in past tense, usually had orchidectomy operations that left bladder control intact, and minimised the chance of metastasis

After treatment, participants were confronted with the aftermath of their decisions. The impact of treatment was often far more severe than diagnosis, especially if participants had opted for radical prostatectomies. Those men whose cancer had metastasized to bone tissue also faced significant challenges and hardships. This period involved coming to terms with the practicalities of the disease, reducing pain to manageable levels and adjusting to changes in bodily function, such as impotence, incontinence and aching or painful movement. Views of masculinity also evolved for some men.

After a period of time all participants reached a stage where they felt they were able to continue with their lives to various degrees. Participants had found routines that suited their life styles and allowed them to adapt to cancer. One man with effective drugs to combat the pain of secondary bone cancer, felt that by following pursuits that didn't encourage pain he alternated between a level of acceptance, and a temporary stage of being 'past cancer'; "... *yes I think it has, you know, you, you've got to accept it. But I try to overcome that, or try to beat it by doing you know, things that I, wouldn't effect me like that. But um, oh no it just makes you tired ... but I don't know, if you accept it you can sort of grow out of it a bit, you think you can grow out of it*". Men with secondary cancers at this stage therefore, had received drugs or radiotherapy capable of reducing pain to acceptable levels, and had continued with enjoyable activities or had found alternative pursuits. Participants who had opted for orchidectomies adapted to life without sex, and prostatectomy patients, often faced with similar problems, regained some bladder control or found satisfactory alternatives in male incontinence pads. Therefore in all accounts, regaining a sense of control over one's body, led to 'peak' levels of coping. Control allowed participants to establish a sense of normality and to feel that some level of recovery was taking place. Progress was being made. Routine provided security, purpose, and a sense of self-sufficiency; "*Yeah well see I, I can walk down to the shops down here on, you know, on occasions and I take it very slowly because I walk down the hill and I get the Sunday paper, I do it on the Sunday, then I go down to Pumpkin Planet to walk and, and get the um, get my groceries you know, my um vegetables down at Pumpkin Planet, they're, they're cheaper down there and er, I walk down there you know. I've got the car but, I just like to walk now and again. Er, you know, if it's not too cold or raining or anything. I, I enjoy a walk*".

With successful coping came a renewed appreciation for life. All participants described an enriched value for the things in their lives that had been successful, and an intense pleasure from things that they found enjoyable, such as fine weather, or particular times of the day. As participants frequently mentioned, coping was an attitude. Dwelling on what could no longer be achieved only heightened depression, whilst enjoying life and focussing on positive experiences provided continued enjoyment of life; "... *it's just an attitude. A lot of people they hear the word cancer and they panic. But um, you know I'm pretty laid-back I mean say, you got it, you got it, and you've got to face it and everyday is a bonus really. Once you've, once you've gone through it, everyday is a bonus and you've got to make the most of it and it's no good you can't do anything about it, what happens happens. It's in the past, you can't alter that, you can't alter the operation, you can't alter anything*".

Generally participants felt that unless prostate cancer prevented everyday life or effected their health, it was no longer a concern. For most men, good health and being able to enjoy life were far more important than worrying about prostate cancer. Health enabled one to participate in enjoyable activities. It was a precious gift and to make the most of this

treasure, participants felt obliged to enjoy life. Emphasis therefor was on living for the moment, and for those men who were married, making the most of time together with their spouse. For several men advancing age was seen as a greater threat to future longevity than cancer. As most men felt they had lived a satisfactory life, old age was seen as a way of cheating or escaping cancer. Dying of old age was the 'right' way to go, and would equate with having 'beaten' cancer. Therefore getting on with life and appreciating it while it was available was essential.

The participants used a variety of resources in order to cope with cancer and treatment. Married men reported having a great deal of support from their wives. All participants mentioned the importance of social contact for adequate coping. Friends and social interests for instance, gave the participants opportunity to enjoy life by participating in activities outside the home; *"... we'd have a barbecue or a few beers, and it was good you know, people would get together to support each other, and you know, that's what keeps you going really you know, you've got to have an interest eh? If you, if you don't have an interest your, you know, well you go mad actually. You'd have to send for a head-shrink"*! Participants sometimes felt like enjoying themselves with other cancer survivors, without dwelling on morose topics, or becoming engaged in emotionally charged conversations. Some men resumed old pastimes or picked up new interests, such as computing or fishing. Social interaction therefore was regarded as essential in order to regain a sense of self and re-establish 'normality'. From the participants accounts it appeared that these were the two prime goals of successful coping. Whilst those patients who had accepted and adapted to cancer embraced these goals completely, those who felt they were 'past cancer' tended not to completely grasp their personal identity in relation to prostate cancer.

The stage of being 'past cancer' appeared to be a moment of self-deception or wishful thinking on the part of some participants. All men agreed that ultimately cancer was a permanent feature of their lives, reminded by the regular PSA checks. Changes to routine or problems associated with prostate cancer dispelled the state of being 'past' the disease. Therefore successful coping was regarded as facing reality and dealing with whatever problems arose. However for those men who occasionally fell into a 'past cancer' frame of mind, this state was a welcome relief from the concern and occasional anxiety of reality.

Participants used the resources at hand to cope with cancer. Humour was often used as a way of coping with otherwise grin and melancholy topics and as a way of sharing information with others, including self-disclosure. Participants found facetiousness made some personal issues 'safe' to discuss. Often uncomfortable or embarrassing procedures were described in jocular terms, with the humorous side to events being emphasised; *"... and now I refer to the orchidectomy operation as, have, um, having my orchids pruned! (Laughs) "*. For those that had it, health insurance was seen as invaluable. Insurance allowed patients to reduce

the length of time between diagnosis and surgery, and ultimately enabled men to get on with their lives in the quickest time possible. Conversely, those without private health care lingered in long waiting lists with the knowledge that their cancer could be spreading.

The process of coping was not necessarily a step by step unidirectional process. Some participants described moving to a previous 'stage' as new problems or situations arose, and the boundaries of coping 'levels' blurred when participants felt more comfortable with certain aspects of the disease than others. Routine and control appeared to facilitate the 'acceptance stage' of coping, as the participant found an order to his life that provided an affable quality of existence. A change in this routine however could highlight difficulties and the side effects of treatment or metastasis, thus pulling the participant back to a stage of mourning or sense of loss. Depression therefore could be a problem for some individuals. Men affected by depression sometimes found themselves alternating between thoughts regarding lost abilities and control, and being thankful for the positives of life around them; *"You suddenly think to yourself 'well, um, it is better to be alive than racing about the place', instead of worrying about whether you, whether you're leaking a bit. Um, you get a bit, well I do, you get a bit depressed. On occasions, on occasions, but you come back to er, you know, you sort of look out, go outside and you look around and it's a nice sunny day and you sort of come back to, to this world again you know. ... Um, so, I can live with it all right but it gets me a bit depressed sometimes and there's a few things you used to be able to do that you can't. So that's about it"*.

The rhetoric espoused by participants after treatment asserted a practical 'back to normal' approach. However, for some men, coping wasn't so simple. For several participants, prostate cancer remained in their conscientiousness, despite the struggle to 'get past it'. One man insisted that prostate cancer hadn't really affected his life but discussion continued to cover times when the participant felt particularly low, and the social activities he could no longer participate in; *"No, no, no it hasn't, well it hasn't effected me only in so far that I found that when I wasn't, for a period I, for a period there I wasn't, well I wasn't feeling well I had to sort of, well I resigned from one committee I was on, I resigned from that and er, and one or two of the things I normally used to attend I've sort of, I had to, well I had to give them away because I just didn't have the enthusiasm ... we used to, we used to go out regularly every Saturday night doing dancing but er, we had to give that away and er, and so, but I'm able to visit and things like that. But it hasn't, it hasn't effected me all that much really, no"*. Some men therefore felt that they weren't allowed to find prostate cancer difficult. One had to keep a stiff upper lip and battle on, keeping a focus on 'silver linings' and other objects of hope.

All participants mentioned a need to place emphasis on positive experiences and to avoid depression, or as one man put it, *"bringing himself down"*. Participants struggled to remain positive and fight against the cancer, the easier road being to slip into depression, which

could be a dangerous maelstrom of negative emotions and self-pity. Surviving cancer therefore is an ongoing process rather than a static state. As one participant saw it, he was a "*current cancer survivor*", living for the present. Depression and fatigue led to less successful coping, such as blaming the world, God, or snapping at one's wife and receiving even less support. Several participants reported feeling very lethargic and depressed immediately after treatment. For one man it took a year before he was able to get his "*get up and go*" back. Most men made a connection between not being able to lead a 'normal' life and depression. Obstacles in the way of a 'normal' life were primarily incontinence, impotence, exhaustion or physical pain and stiffness. Several participants found it hard to constantly remain positive. Remaining positive was energy draining, and so once one had become depressed, it was very difficult to emerge from that depression. Exhaustion was a large problem for some men, and for married men it became impossible to muster the strength to comfort spouses. Some participants found it easier to cope by controlling the amount of information that their family received regarding their condition. One man was actually relieved that he had no family at all to concern with his diagnosis, and invested heavily in the medical profession for support through reassurance of their medical expertise. Other single men tended to rely on one or two key individuals, friends or family members who could offer support without involving the extended family. Therefore although wives could offer a great deal of support to their husbands, some men also felt responsible for their wives coping.

Some participants found they had to cope on multiple fronts. One man struggled when he had to nurse his terminally ill wife as well as dealing with his recently diagnosed cancer. Another participant struggled with simultaneously comforting his wife, remaining positive, and dealing with his own grief and sense of loss. For those men with secondary cancers, even after treatment, a long and painful battle with the disease lay ahead.

Perhaps one of the largest threats to the men's ability to cope, was the uncertainty of cancer. Most participants described losing friends in support groups to cancer and the re-emergence of the disease even after treatment. Participants felt unsure of how far their own cancer would spread and reported that they felt a lack of control until a sense of security developed after several years. Even after this period several men mentioned that cancer was frequently "*at the back of (their) mind*", and that they had to take it "*a day at time*". One man mentioned that cancer was still present in his thoughts "*every morning*", and to an extent remained a significant part of his life. For this particular man, secondary bone cancer continued to cause significant problems on a day to day basis. Therefore, although prostate cancer per se had been treated, the resulting secondary bone cancer had become a problem in itself. It was this continual reminder that kept the participant from ever completely removing himself from the effects of prostate cancer. This condition spurred the participant

to campaign passionately for global screening and the use of the PSA test. A component of the coping process therefore, was work towards informing others and changing policy.

As participants regained their strength, energy, and enthusiasm for life, depression tended to become a less frequent problem. Several men found that once feelings of sickness and lethargy had passed, they felt they had been reborn into stronger and tougher people. Participants also felt that their marriages had been revitalised and strengthened by the process or as one man commented, it was like "*being in love again*". The ability to go from their lowest point and then return gave the men an increased vigour. However the experience was not a simple voyage, there were times when participants felt they would die of the disease. Ultimately however, this 'rite of passage' left men feeling their lives had been enriched in a way that was not always obvious to the outsider.

Prostate cancer could be unpredictable. As most participants explained, the disease is never referred to as being 'cured', but rather goes into a state of regress. Therefore participants were aware that treatment did not ensure survival from prostate cancer. As one man commented; "*nothing is ever a guarantee*". Even an operation as thorough as a radical prostatectomy could not affirm that the cancer had been completely removed. It could linger in the body if cancerous cells were missed. For several men the shadow of cancer continued to lurk in their conscientiousness long after surgery; "*... I'm able to do things now that I, I wasn't able to do twelve months ago but er, but it definitely effects you, you, you've got it at the back of your mind, you've got the whole thing at the back of your mind the whole time you're thinking 'well what if, what if, what if'?*" Uncertainty therefore often plagued survivors, despite lowered PSA results. Common coping strategies focussed on the present, taking each day at a time. Participants felt unable to look beyond their current condition for fear of getting to a stage where their mind had "*gone a bit too far*", and becoming dangerously ill when their guard was down.

Prostate cancer didn't respect the efforts of survivors to live a 'normal' life. Those that appeared to be coping well with the cancer could succumb earlier than those who seemed to be struggling. Without a frame of reference or obvious pattern in the way the disease led to death, there was a feeling of uncertainty and panic regarding the progression of the illness for individuals. Uncertainty and lack of control, a coalescent pair, seemed to feature prominently in the experience of prostate cancer. Participants emphasised that even youthful, otherwise fit men, could develop the disease. Some younger men actually passed away before older sufferers, thus it was hard to judge how the cancer would affect each person. One participant was checked regularly for fifty-four years as part of his licence to fly aircraft, and was always declared healthy and free of serious illness. However, as he discovered, prostate cancer can attack even active and physically fit people. The illness may develop for men at different ages, proliferate at different rates, and produce varying

symptoms and outcomes. Prostate cancer was also seen by some as something of a 'time bomb', the precise moment of its re-occurrence or spread unpredictable, yet it's eventual reanimation expected. The speed with which prostate cancer could strike meant that some acquaintances expired before participants had realised they were close to death. Within the support group community 'regulars' and 'veterans' quietly passed away, their eventual departure having been expected, yet the actual event often arriving suddenly. There were often no ceremonies, just a mention of the man's death and an empty seat. Loneliness therefore was a common problem amongst the survivors as their peers passed away around them. Prostate cancer was seen as an insidious and hidden disease, striking unexpectedly and with unforeseen severity.

Participants described their sense of loss when peers had died of the disease. Some acquaintances had passed away who had been treated at the same time as participants, whilst others continued to live a full life. The trauma of losing others added an additional burden to the men's ability to cope, and acted as a reminder of the participants own mortality. Deaths tended to trigger a 'who's next?' response within support groups, and increased the level of anxiety for several men. The time of diagnosis was perceived as critical, with earlier diagnoses enhancing prospects of survival. Seeing one pattern amongst the uncertainty therefore enforced the value of early detection, and the use of the PSA as a diagnostic instrument.

There was a mystique attached to cancer; *"(It is) still a bug, a bogeyman you know, it's still, the thought that you had cancer and the cancer could come back again. It certainly has an effect on your life"*. The possibility of a relapse therefore could never be discounted. Support services could provide some comfort, and positive talk helped participants to put aside their fears, even if only for a moment. Ultimately however, the survivors were conscientious of the disease. Cancer was an ever-present evil. Even after successful treatment it remained in the body like an arch villain from a daytime soap, battered and brooding yet ready to return in the next instalment; *"They, they don't give you, do an orchidectomy and say 'right, you're okay now, you, your testicles have been removed you're not producing any more male hormones so you're home and hosed, we've beaten it'. They never allow that, that they've beaten cancer because it's, always there"*.

### The Body & Conceptions of Cancer

Cancer was perceived as an invasive disease that lurked deep inside the body. The cancer wormed into the flesh to the extent that it actually fused with one's tissue, and became part of the person, *"it's in your blood"*. The individual therefore became irreversibly altered.

Personal identity evolved to incorporate 'self' with cancer. This conceptualisation was not limited to the psychological, but manifested in the physical. One man remembered being tattooed and marked in preparation for radiation treatment, leaving a permanent badge of cancer; *"They tattoo you in three places, you know, with a little dot"*. Fusion also made treating the cancer difficult without injuring healthy tissue. Participants were prepared to 'cut out' and remove the entrenched disease, even if it involved damaging their own body. The cancer had to go; *"... it come to me pretty quickly that if I had cancer of the prostate I didn't want it in my body ... I thought to myself 'holy smoke' you know, um, when you've got something like that you think 'God I gotta get rid of this immediately'"*.

Participants described a feeling of detachment from their bodies at times. The body had become an object, a machine needing repair by specialists. Patients were passive during this process, lingering in the 'waiting room' of their minds whilst allowing the 'mechanics' to get on with the job; *'... I went for what they call a trans-sectional ultrasound and biopsy, and that's er, that's something they, they do by, inserting something up your backside, and that and er, and er, another long thing goes through, course I couldn't see because I'm, I'm lying on me belly, I couldn't see you see"*. The keys of the body therefore, were passed over to the professionals. Total control was lost, and the rights to images of the body were forfeit. One man was disappointed after experiencing the arduous process of radiotherapy, not to have an image of his cancer; *" ... they're treating you through the, um, right through your body, and you see you just got that small kernel of cancer there, but see they've got to radiate through the rest of your body. And it damages the tissue in between, ... And then, um, you know, and then it comes out like that, as a synoptic chart like, like the weather chart really, ... And, um, it's in colour, and I wanted one to frame actually but they wouldn't give me one"*. Sometimes the process of diagnosis and treatment appeared effective yet crude; *" ... he took a biopsy and ... its the sort of thing they just poke up, and they put on your prostate and they grab a piece out of the prostate ... they just rake it out, well it's, it's a sort of a scoop, and they just hit it, and it just grabs a piece off all round"*.

Participants often reported that making a firm decision on their choice of treatment reduced their anxiety considerably. Once the choice had been made, participants left control in the hands of physicians; *"... somebody said to me you know 'it must have been a real worry when you found out you had cancer', well it was for about the first quarter of an hour, but after I decided I was going to have the operation and he said you'll be right after that, it didn't worry me a great deal"*. Sometimes however, this trust could seem ill placed. Some participants felt horrified by the results of treatment. The body could be 'returned' to the participant mutilated, or altered in ways which made it almost unrecognisable; *"Er, one of the first obvious impressions I got once the swelling had gone down enough to be able to see because I was grossly distended, um, was my penis. It had been reduced in size to about a*

*quarter of what it had been". The men felt powerless as major alterations or modifications took place; "They castrated him. Without an option".*

Conceptualisations regarding the origin of cancer varied. Participants stated that the disease wasn't transmissible so social contact was still possible. However, several men found that the reactions of others did not necessarily support this reality. Social isolation and stigmatisation led some men to consider the possibility of cancer as contagious. Their reality of cancer, born via the reactions of the world around them, was cancer as an infectious disease. Externalising the source of cancer also allowed the participants to forgive and accept their bodies. Cancer was not a malfunction of one's own body, but rather a fault of the 'other'. The disease therefore belonged to the population as a whole rather than the individual. One participant's account serves as an example of this processing. The notion of cancer evolves from its medical and factual conception, to a virulent infectious disease; *"A lot of people don't know you've got cancer of course. But um, those that do, I mean so, you can't catch cancer can you? I mean you know, it would be different if you could catch it. At one stage I thought it was a virus actually, but I, I'm bloody near convinced it is a virus actually! Because it gets into the cell, it gets into the cells. They don't know that it couldn't be a virus even you know. Because the cells carry it round. It could be like AIDS because it gets into the very cell you see".* Theorising adds weight to the argument of cancer as an infectious disease. Cancer *"gets into the cell"*, and is spread throughout the body and potentially to others, through blood. A virus by definition is an infectious agent. Therefore the increasing numbers of men diagnosed with cancer and the rising profile of the disease support the concept of an epidemic. Externalisation of cancer continued by including the role of environmental factors such as pesticides and known carcinogens; *"You see, okay, years ago, I don't think there was all that much cancer around. But, not like it is today, I don't know whether it's all the pesticides or whether it's er, the food, you know all the preservatives in food and everything giving people cancer but, you know cancer was pretty much unheard of when I was a kid ... In those days it was sort of a dreaded disease. But now of course it's very prevalent all round".*

### Sexuality & Masculinity

Feelings of masculinity and sexuality were very personal issues for each participant. The impact of impotence and the physical changes of treatment had their own meaning and significance for each man. Masculinity referred to the concept of being male, whilst sexuality related directly to sexual functioning, and participant's sexual identity. Thus despite the relation between concepts, 'being a man' did not necessarily relate directly to one's sexual self.

Some men found the physical changes they experienced after surgery surprising. One man was relieved that he retained the ability to have an erection, but found the sensation of ejaculation and orgasm had changed noticeably; “... I'm lucky really because although, you know, the function is still there, it's you know, it's very slow and um, it's quite painful really. But um, you know, it's just like er, um exaggerated, you know, when your, when your, ejaculation is, is quite painful the same pain, but, more sensitive. Yeah. I don't know whether that's, that's not a bonus actually because it's painful!” Whilst another participant found his sexual functioning altered but not completely absent; “.. um, you can have an orgasm, but it's a dry orgasm. Um, penetration, and erectional penetration is totally impossible”.

One man was relieved that he retaining sexual functioning and was able to enter into sexual relationships with women. As the participant's wife had lost interest in sex before passing away, he found a 'reawakening' of his sexual identity after treatment. “... I was married for, for 43 years. I've been all over the world actually, you know, you name it and I've been there and um, you know, I've met some really beautiful women, well that's what I missed you see when my, my wife ... she wasn't interested in sex for about 12 years and then she was in hospital. And er, you know, I, I missed it terribly but then when she died of course, um, it became, necessary again”.

Before marriage the participant had lived an exciting life as a debonair RAF pilot, and enjoyed the return to a bachelor-like lifestyle. Sexuality then, extended beyond simply being able to perform physically, but involved an entire social and personal aspect of his life that had been discarded. The participant re-discovered the process of 'chatting up' women, and identified a new or forgotten aspect of himself as a sexually attractive and eloquent man; “I meet some, I meet some women, but you know, I don't, I'm not looking for a relationship actually, because I couldn't stand it actually. You know, I'm used to my little house, and I keep everything in its place ... but, I sometimes strike lucky. I meet them in the pub or the club, you know, and, an' before that you know, I was, I was um, you know, I was um, you know I didn't approach women much you know while I was married. I didn't know how hard it was, or how easy. So I find it quite easy actually! There's a lot of them out there”.

The concept of the orchidectomy varied between participants. One man felt considerable relief at remaining “entire”. Castration was regarded as a universally recognised blow to men's masculinity; “... you know how that would effect you”, and the weight of such a transformation, too monstrous to contemplate; “I don't know how it would effect me actually”. Participants who actually experienced an orchidectomy also varied in their feelings. Some men regarded the operation as a necessary life saving procedure, and minimised the impact of their feelings in relation to masculinity by adopting a practical, 'just get on with it' approach; “So that's what happened and that's, that's the option I took”. These men felt

fortunate to have escaped cancer with a procedure as 'simple' as an orchidectomy, rather than experiencing the incontinence and other problems associated with treatments such as radiotherapy or prostatectomy; *"I more or less just had the, the er, orchidectomy and that was about it. Some of the others have had all sorts of other bloody operations associated with it, you know or leading up to it and all that sort of thing"*.

An orchidectomy resulted in a dramatic physical change, but also required a fundamental shift in the concept of 'maleness' and what made an individual 'male'. Some men therefore had to engage upon a personal odyssey where the fear of losing one's manhood was a palpable concern, and reassurance regarding the outcome of such an undertaking was unavailable. Aside from the participants ongoing 'war' with cancer, this challenge was yet another battle to be fought and won, and for some men increased the already substantial emotional burden. The men who survived this struggle however, felt 'entire' within themselves, their identities remained intact.

One participant felt the decision to have an orchidectomy was out of his control. It was just something that happened to a person, just as prostate cancer had occurred seemingly by chance. When asked how the orchidectomy had effected feelings of masculinity, the participant even described the choice as though it was made externally, by another group of people, and affecting another being than himself; *"Well that's a pretty good question, and I, and I, and it did hit me hard when they said they're going to have the orchidectomy"*. Later the participant mentioned that the decision was left up to him, but was something *"... that they're going to have to, you're going to have to have it done"*. It was therefore a kind of Hobson's Choice, rather than a treatment option selected after deliberation from several available options.

For some men, sexual functioning after treatment, such as erections and 'wet dreams,' could be pleasant and unexpected surprises. These events took on significance as symbols of hope and 'potency' and ultimately a return to normality. The men's concept of themselves as fully functioning males remained intact; *"But, there again you see, um, there was something that happened, um, about a month ago and I was laying in bed and sure enough I was asleep, and I had this wet dream! So, it can't be all that bad can it? And, an', you know, I was dreaming you know, and, an', I sort of woke up, - Hello!"*

Several participants experienced hot flushes. Apart from their inconvenience, and the discomfort experienced, flushes could also pronounce perceptions of being emasculated. The effect could be increased when combined with the need to use female aids such as women's incontinence padding, and having to forsake stereotyped male practices, such as being able to change a tire or using urinals; *"... One thing I miss is, you wouldn't think you'd miss this, but you go into a public toilet and instead of going to pull your zip down and fire at*

*the wall you can't you have to go into the stall toilet, because I've got a pad in see? It's a bloody nuisance."*

Physical changes after an orchidectomy such as loss of body hair, development of breasts, and reduced muscle tone also caused an uncomfortable state of fading masculinity; *"I've lost a lot of weight. I was a bit bigger than this now ... I've lost um, you know, a bit of body hair because you lose all your male hormones and that, and er, it's just one of those things ... and er, I think you to do develop from time to time female sort of um, you know, your breasts get bigger. It might happen so, but I think it does um, effect the male"*.

Concepts of masculinity also differed. Whilst some men related manhood to the ability to function sexually, other men defined masculinity in different actions. For one man 'potency' related to his ability to act as a useful member of society. The decision to have an orchidectomy was made in preference to medications, so that the participant could keep his blood 'pure' for the purposes of donation. Action in the community therefore, was central to the participant's view of himself as a man. Nobility and chivalry equated with masculinity, rather than physiological functioning. Correspondingly another participant found his sense of manhood ran deeper than anatomical completeness; *"When we had a special week for prostate awareness week or something, I don't mind telling, you know, some of the people who came to me after said 'I saw it, I saw your article in the paper the other day, it was very good'. And then another joker would come up and say 'Christ you certainly spilled your guts out, told them that you got, had your, your balls out' and all the rest of it. 'I could never talk like that' and then I said 'well you, it's the difference of when it happens to you, you learn that a lot of these old wives tales don't really mean anything in the end, and being a man is being, as far as I'm concerned, being a man is learning to live with it, with cancer really. If you can learn to live with cancer well you can, you'll be able to live with anything'.*

Participants reacted and adapted to their treatment in different ways. One participant described a particularly horrific experience whereby his penis was shortened considerably after surgery. The participant felt that he had lost *"the whole lot"*, due to cancer escaping the prostate. After the shock of these changes the participant was left with a profound sense of loss; *"Um, but it does worry you a little bit. No doubt, no doubt in my mind at all. As far as I'm concerned it does worry me. Um, I've always been a fairly active lover in, in all respects, I've had three wives! Um, so um, yeah there is, is, is a sense of loss there"*. Although not a substitute, enjoyment in other areas of life gained greater priority, such as pursuing interests or enjoying particular foods or beverages. Another man was very frustrated due to his impotence. An active sex life had been cut short by a radical prostatectomy. Although the participant found intercourse not as important as it had been earlier in marriage, at 70 the desire for sex remained. Continuing sexual desire for his spouse therefore could only be endured, and was considered a problem. In fact the participant felt that if removal of his

testicles would relieve him of this desire, he would rather have combined an orchidectomy with his prostatectomy; *"I still consider my wife quite good-looking and very attractive and quite sexy you see. This is the next problem that comes up. Um, you find out that your impotent as well. Ah that's, yeah that's a bit of a blow for a while, um, however I'm over 70, she's over 70, er ... Well even when you get older it, you know, it's nice to be able to um, sleep with your wife and that ... The thing with this operation is, although it makes you impotent it doesn't take the um, oh what do you call it? The drive away? yeah. I think what they should really do when they do that operation is take the testicles as well because they reckon that fixes it completely you're not worried about it at all. Um, which can be a bit frustrating at times"*.

In terms of treatment, all participants mentioned a point where the importance of continued sexual function was weighed against increasing chances of survival. Even those men who had renounced intercourse saw this as an important decision. Participants agreed that choosing treatments that provided a better chance of survival were preferable to those that offered reduced chances but spared function. However, not all men in one participant's acquaintance felt this way; *"Obviously some people don't. Um, (a patient) opted for radiation rather than the radical so that he could maintain his sex life. However um, from my wisdom, from what I understand, is that er, the radiation will eventually kill your sex life. So well, well it's given you a bit of time. Um, but it wasn't for me because I, I was concerned, how I'd exist, with cancer; don't want it, get rid of it. That, that was me personally, he's obviously looking at it from a different angle"*.

#### The Impact on Marriage & Role of Spouse

Married participants consulted their spouses on all aspects of the disease. The principal source of support, wives played an essential role in their husband's treatment choices and ability to cope. Men also reported that their partner instigated the request for medical attention on their behalf, even before diagnosis. Some participants described their wives as essential interpreters, or as spokespersons; *"Well I didn't think that there was anything wrong with me, I went down to the doctor with a crook back, of course my wife always comes in with me because she thinks I don't tell the doctor everything. So anyway while we're in there she said er, 'oh it's', to the doctor, 'oh it's been a fair while since I had a, er,' ... the blood test for prostate cancer. 'Oh', he said 'all right'. So he took, I had some blood taken"*. Wives therefore mediated conversation between patients and doctors, and had considerable influence on their husband's actions and understanding of the disease.

Participants felt that their marriages survived the strain of cancer via clear communication. Central to this harmony, was a commitment to honesty about one another's expectations and desires. This level of exchange was particularly important during the time participants were choosing treatment options. Expectations regarding sexual function for instance, were particularly important topics to discuss. One participant appeared to have coped with prostate cancer especially well, and had little problem adjusting to his orchidectomy and resulting impotence. The advanced level of coping undoubtedly resulted from a large number of factors, yet particularly prominent among these would be the participant's supportive marital environment, a possible advantage over those participants who had to deal with their cancer independently.

The impact of prostate cancer on marriages was described as having three primary effects. Notably sexual relationships often had to change or cease altogether. Also men might become incontinent, or need additional physical care that could be particularly draining, both physically and emotionally for their spouse or caregiver. Finally, frustrations regarding incontinence, pain, impotence and other factors could effect the behaviour and mood of the participants, leading to snappy remarks, irritability or depression.

The most significant impact on marriage for most participants was the end of a sex life. The loss of sexual relations effected each man differently, although the nature of this change is explored in greater detail elsewhere. However in regard to marriage, communication between spouses relating to their expectations, the importance of sex, and the possible outcome of surgery was very important. The views of both parties were respected, as ultimately the women's life could be significantly effected by her husband's treatment decisions. Participants described their wives as supportive and explained that their spouse had accepted the lack of sexual intercourse if impotence had resulted from treatment. Some couples had actually renounced sex well before the onset of cancer, and so in terms of their relationship, impotence was no longer an issue. Generally then, men considered that their wife either no longer desired sex, or was quite content to live without it. However some doubted the reality of this satisfaction, feeling perhaps that their spouse was 'putting on a brave face', and making the most of a bad situation for the sake of their husband; *"My, my wife's gone 'well that's it'. I'm fortunate in that way. Um, but it does worry you a little bit ... yeah there is, is, is a sense of loss there. Um, more for me probably than, than for (my wife), though, though I don't know whether she um, is just trying to, be nice or, or what I just don't know. But er, there it is"*.

If men doubted their wives contentment, all agreed that their own frustration was most likely more intense. As one man mentioned, impotence did not necessarily equate with a lack of libido. Concern regarding potency focused on a sense of manhood, identity and personal gratification. Most participants believed that the strain of celibacy would have been much

greater on their marriage if both partners were younger. Developing prostate cancer at a later stage in life therefore was preferable, when sexual intercourse may have played a less central role in the relationship.

Despite desires and frustrations, all men decided that ultimately the ability to experience intimacy without sex was essential. Most participants described an adaptation and progression of their relationship. Some men found that the trauma of prostate cancer drew them closer to their wives. Couples endured a tempering which resulted in their relationship emerging, in a stronger and more consolidated form. The process also encouraged individual development through the shared relationship. One participant explained; *"well, I think from my point of view we've come closer. You're um, it's like being given a death sentence and then live, and then you've lived through it together. If you, you're bigger and better people for it, you know"*. Several men mentioned that at their stage of life, sexual intercourse had taken a less central role before diagnosis anyway, and so felt very little loss. Intimacy was maintained by spending quality time together, and learning to enjoy one another's company. Pursuing shared interests or past times increased the participants feelings of growing closer to their wives, so that most men claimed their marriage had actually been enhanced by the experience. One man described this process as *"falling in love again"*.

After surgery, some couples discussed orchidectomies and impotence through the use of humour. Treating the topic with levity helped to reduce its threat and made talking about its implications to the relationship easier to manage. Anxiety regarding upcoming PSA tests, or frustration from impotence and incontinence could cause behaviour changes in some husbands however, such as snapping, short temper and depression; *"I'm probably a little bit more, abrupt, than I was before. Um, I get grouchy"*.

For those unmarried men, impotence coloured their views of future romantic relationships. One participant decided that there would be no point in getting married after prostate cancer, whilst another believed that some form of romantic relationship would still be possible, provided it was based on clear communication and a loving friendship.

### Religion and Spirituality

For the purposes of the research, I have made a distinction between religion and spirituality. Religious faith encompassed the doctrines of a particular institution and may have included attendance at meeting places, such as a church. Strength could be gained from the structure and community associated with a religion, rather than spiritual beliefs per se.

Likewise the concept of spirituality focussed on faith in a spiritual being, power, or order greater than the material world. Participants who felt they received comfort from their spiritual beliefs may not have been concerned with the trappings of a particular faith. Moreover individuals may have gained support from both concepts, or not at all.

Religious or spiritual beliefs were sensitive and personal issues for every participant. Several men described themselves as having no religious or spiritual faith. However, their attitudes toward the concept coloured their view of prostate cancer and coping. Despite not placing trust in a particular religion himself, one man suggested that the concept could serve a good purpose if it aided others to cope with the disease. Another participant felt baffled at the idea of a benevolent God, seeing the world as an unfair and sometimes cruel place; *"Ah, not a religious person. Um, I think if, I think if there was a good Lord up there nobody would get cancer so that's all we are into about that. Um, can't really, he's supposed to be so good and kind and everything else and then the next thing you read in the paper is some poor kid about five just about to die with um, a brain tumour or something like that"*. Prostate cancer therefore appeared as a completely random condition that no amount of wishful thinking could prevent.

Some men felt that prostate cancer had re-framed their lives, emphasising the importance of higher spiritual issues. One participant believed he had grasped an understanding of the disease within the context of his life. Faith in both a higher power and grand scheme provided a sense of calm and tranquillity; *"It's the galactic balance ... and the earth goes round at a certain speed, ... you see, and then people say 'oh it's all a coincidence'. Well, it, it isn't you know, when you, when you, when you delve into it, there's a big master plan there somewhere, and it was all designed. So, you've got to believe it, I, I believe it, ... I believe there's something behind it. Behind it all"*. Spirituality therefore, provided a safety net. Despite the apparent chaos of cancer, there was an order to life. If the participant was not able to gain control himself, he could invest in the strength of a higher being.

Energy and revitalisation could also be drawn from a spiritual entity, which offered protection and guidance. One man found that spiritual power was enough to boost his physical as well as emotional wellbeing; *"I knew there was somebody up there. Okay I, I never used to go the church or anything, I wasn't you know. But I knew all the time, I can, I can get, I can get um, energy. I can get energy. From outer space. I'm not, I'm not mad but, you know, I can, you know. It's not meditation but I, I, I've just got to um, you know, I just got to raise my hands and I can feel it"*. With the aid of higher external sources of respite, prostate cancer lost significance and became an easier condition to cope with.

Several men felt that their religious views had been comforting and supportive. Religion had provided a complete lifestyle and sense of community, which including social activities and

support. One man also felt that shared faith had brought him closer to his wife in their struggle against cancer; *"I've always had my religion and um, there's been no change whatsoever there you know, we are regular churchgoers every week and that sort of thing and um, and we er, we contribute to different ones, people in need and things overseas you know, and um, but no, er, but we always have had had our religion and er, we found it very, it was very comforting I think ... I think too, it's, it's brought (my wife) and I even closer together, you know"?*

For those men with a religious faith, prostate cancer had either increased their beliefs in a higher being, or left them unscathed; *"It hasn't, it hasn't made me bitter towards God as you might say. No, no, no I er, no, no, I'm not, I'm not bitter towards, I'm not the old expression 'why me Lord, why me'? But it's, it's, someone's got to be a statistic and, and it just so happens that I've been unfortunate enough to be um, to be classified as a statistic, so I've um, I just sort of got to accept what I've got and get on with life"*.

In conclusion participants did not feel that prostate cancer had significantly effected their beliefs or faith. Life was still to be enjoyed after cancer and depression from negative thoughts or inactivity could only be blamed on one's self. As one participant aptly stated; *"... God helps those who help themselves"*.

#### Beyond Prostate Cancer: Views of the Future

Participants concerned themselves less with the future, and more with the present. Their outlook was centred on dealing with current concerns, and making the most of their lives. Prostate cancer couldn't be trusted to allow a future life; *"The term they use er, um, whether it's the term they use in hospitals or what not I don't know. But I think that's quite a good way of looking it, of putting it; cancer survivors. Um, there's no real, other way of putting it. You're surviving at the moment, you don't know what is going to happen in the future. Well probably, we would be current cancer survivor"*! When thinking about the future then, most men placed their hopes in the fortunes of others, expecting that methods of diagnosis and treatments would continue to improve for new generations of prostate cancer affected men. Some participants allowed the possibility of a cure for cancer, although generally didn't expect this in their lifetime. Investing hope in others encouraged men to persevere with 'work,' and the cause of global screening.

For some men more pressing concerns overshadowed the possible return of the disease. Several participants felt that advancing age would be a more likely cause of death, whilst another man suffered from physical disorders that had a larger impact on everyday life. Others felt more secure in their futures. Three men were looking forward to new beginnings

and the many experiences waiting to be explored. One had taken up computing, whilst another was enjoying social life as a single man.

The experience of cancer provided participants with a sense of achievement amongst the loss. Surviving was an individual journey, which forged a stronger spirit. One man explained; *"You've been through it and, and you learnt to live through it and you, I think you're stronger because of it, and I think, because you believe cancer was a irreversible thing before now you've learnt to live with it, but death doesn't seem to be such a drastic thing any more, you can say you sort of looked death in the face and, it's not such a big thing any more"*.

Ultimately there was a sense of participants progressing through 'pages' in the story of prostate cancer. Reflecting on the 'stages' of coping described earlier, the 'story of cancer' was a similar process and did not necessarily have a conclusion or ultimate resolution. Carter (1993) describes a similar temporal aspect to "going through" cancer, although here I have made a distinction between 'the story of cancer', and coping stages. Whilst coping stages could vary almost on a day to day basis, 'the story' was a linear process on a grander scale, a reflection by the participant of their entire experience with cancer, past, present and future. 'Pages' were fluid rather than having discrete boundaries, yet continued forwards toward some hidden final chapter. The meaning of cancer therefore, continued to take shape and develop over time. It's final verse in this prose was obscure. Consequently, whilst some men felt that cancer was primarily in the past, and looked toward a future without the disease, all participants set aside some room in their futures for a possible reoccurrence.

## Conclusions

The experience of prostate cancer was a highly individual journey, which progressed through 'pages' or chapters toward an uncertain conclusion. Despite being a unique and sometimes lonely process, participants shared similar conceptions of the medical community, the 'cancer community' to which they belonged, and the role and possible improvement of support services. In addition participants moved between seven fluid stages of coping, similar to processes described in the literature regarding women's experiences with breast cancer. The process of 'work' however appeared to be a singular phenomenon amongst the participants and offers an interesting area of future research. Moreover the men's accounts present many topics for further investigation, including the relationships between doctors and patients, possible Maori/Pakeha differences in interpretation of prostate cancer, communication within the health system and the role and development of support services.

Whilst the research highlighted salient issues for these particular men, further investigation into the experience of prostate cancer survivors is essential in order to better understand the unique needs and experience of this population. Ultimately increased awareness of these issues within the medical community and allied fields can only improve the process of diagnosis, patient's treatment satisfaction, and future support services.

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## Appendix A

Table 1

### Semi-Structured Interview Sheet

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**Question**

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What is your view of the medical profession?

Has prostate cancer and its treatment effected your life?

How do you deal with prostate cancer and its treatment? Is it possible to cope?

Has prostate cancer or its treatment effected your relationships with others?

Has prostate cancer or its treatment effected your marriage in any way?

Has prostate cancer or its treatment effected your sexuality or masculinity?

What do you think about support services for men with prostate cancer?

Has prostate cancer or its treatment effected your outlook on life at all?

Has prostate cancer or its treatment effected your religious or spiritual views if you have any?

## Appendix B

Table 2

### Phenomenological Analysis Technique

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Step 1:	The transcriptions are read several times in order to get a sense of their total content.
Step 2:	Significant phrases or statements that directly pertain to the phenomenon being studied are extracted.
Step 3:	Formulated meanings are created from each significant statement. The meanings are then validated with a colleague experienced in phenomenological analysis.
Step 4:	The formulated meanings are aggregated into themes that are common to all protocols. The themes are validated by referring them back to the original protocols to be sure they exist there.
Step 5:	An exhaustive description of the phenomenon is written by integrating the statements, the formulated meanings, and the themes.
Step 6:	The exhaustive description is integrated and synthesised into a statement of the fundamental structure of the phenomenon. This step is validated with an experienced colleague.
Step 7:	Participants validate that the fundamental structure contains the essence of their original experiences.

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Notes: Table from Colaizzi (1978), cited in Coward (1994).