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## **Responding to localised prostate cancer : Lifeworld reconstruction during the first post-diagnostic year**

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**RESPONDING TO LOCALISED PROSTATE CANCER: LEIFELD  
RECONSTRUCTION DURING THE FIRST POST-DIAGNOSTIC YEAR**

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**This thesis is presented in fulfilment of the requirements for the degree of  
Doctor of Philosophy**

**Faculty of Computing, Health and Science**  
**Edith Cowan University**

**March 2005**

## USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

## ABSTRACT

This thesis investigated the experiences of men diagnosed with localised prostate cancer, as they reconstructed their lifeworlds during the first post-diagnostic year. With the exception of health related quality of life, a review of the psychosocial research literature revealed few studies that explored the psychosocial experience of men diagnosed with localised prostate cancer. Furthermore, the review uncovered no studies that explored the process of lifeworld reconstruction, and only three studies that considered the role of masculinity in the responses of men to the prostate cancer experience. Such a limited understanding, about the nature and process of lifeworld reconstruction, potentially compromises the provision of gender appropriate care by health care professionals. Therefore, providing an improved understanding of men's evolving responses to localised prostate cancer is important for the development of gender appropriate care that is lifeworld compatible. The purpose of this study was to contribute to an improved understanding of men's emotional, relational, and existential engagements with the prostate cancer experience, by providing an in-depth descriptive account of the process of lifeworld reconstruction.

A prospective longitudinal study guided by the constructivist inquiry paradigm explored eight men's experiences of prostate cancer from diagnosis through treatment, during the first post-diagnostic year. In this study in-depth interviews represented the main method of data collection. A total of 32 face-to-face, unstructured interviews were carried out with these men during the 12 months of data collection, each man being interviewed on four occasions. Data collection and analysis were guided by the hermeneutic-dialectic process. The interviews were transcribed verbatim, and the data coded using a procedure employing the method of constant comparison. The coding process was facilitated through the use of the ©QSR N6 software for qualitative data analysis.

The insights gained by this study suggest that lifeworld reconstruction is a heterogeneous, internal process that holds central importance in the response of men to the prostate cancer experience. Men reconstruct their lifeworlds silently, through a process in which they establish the cancer as a physical and social entity, minimise their emotional reactions, re-plot individually important reference points of a stable lifeworld,

and perpetuate lifeworld stability into the future. Furthermore, in keeping with the essential silence of lifeworld reconstruction, men do not seek emotional support beyond close relationships, and depend on the indirect process of inclusive synchronicity to elicit emotional support within close relationships. This study also suggests that social façades, such as institutional health care and hegemonic masculinity, act externally to homogenise the response of men, and to transmit the message that an increasingly ordered treatment trajectory is required for continued group membership. Men respond to such an imperative by introjecting hegemonic masculinity as a false identity, and use it as a temporary mechanism to protect the internal process of lifeworld reconstruction. This study concludes that even though maintaining the operation of lifeworld reconstruction behind social façades may benefit social institutions, and perhaps even men from time-to-time, there are also indications to suggest that the relative balance of such benefits requires further exposure and challenge.

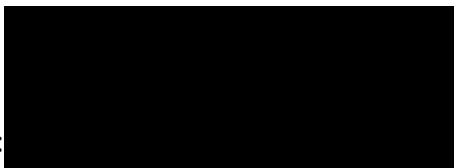
## DECLARATION

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## ACKNOWLEDGEMENTS

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Finally, and most importantly, I wish to offer my sincere gratitude to those men who allowed me to observe their lives, who shared their experiences of prostate cancer with me, and whose honesty and openness provided the material for this study. I thank them for their trust, for their generosity of spirit, and for the humbling experience. I hope sincerely that I have honoured their voices in the writing of this thesis.



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## NOTATIONS USED IN INTERVIEW TRANSCRIPTION

Each interview was transcribed verbatim. However, to provide some clarity when reading the text the transcripts have been edited. In editing, some words have been omitted or inserted but, where this has occurred, every effort has been made to preserve the context and meaning of the original text. Enabling sounds uttered by the researcher, repetitions, and hesitations have been omitted, unless they add meaning to the direct quotation.

The following notation is used in direct participant quotations:

Each participant is referred to by a pseudonym. The researcher is referred to by his name.

- ... Represents a pause by the speaker, where two or more groups of dots denote a proportionally longer pause.
- (...) Represents a portion of text that has been edited to improve the meaning or remove immaterial text.
- (word/s) Represents non-language responses, such as (chuckles).
- [word/s] Represents a word, or words, that clarify or add meaning.
- WORD** Represents an emphasis.

# CHAPTER ONE

## INTRODUCTION

### Introduction

Men, presented with a prostate cancer diagnosis, respond from within the diminishing security of a fragmenting lifeworld, potentially becoming stranded with feelings of confusion, uncertainty, disorientation, and fear. A reasonable statement, and yet such a description runs counter to the cultural stereotype, which contains the idea that men are strong, stoic in the face of adversity, and brave. As such, men are expected to cope with a prostate cancer diagnosis, with its potential to be life threatening, and with the treatment sequelae. Moreover, such a discourse, the discourse of hegemonic masculinity, implies that men have no need to talk about their experiences, or their feelings, and do not want the “fuss” of emotional support and understanding. Therefore, hegemonic masculinity has variably shaped the ways in which men have constructed their responses to prostate cancer. As such, I would suggest that men’s responses to, and within, the prostate cancer experience have been muted, obscured, and frequently displaced.

The same discourse has shaped, and limited, the ways in which the male response to prostate cancer has largely been described in the psychosocial prostate cancer literature. With some notable interpretive exceptions (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2001; Chapple & Ziebland, 2002; Clark, Wray, & Ashton, 2001; Faithfull, 1995; Fitch, Gray, Franssen, & Johnson, 2000; Gray, 2003; Gray, Fitch, Davis, & Phillips, 1997; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000b; Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002; Gray, Fitch, Phillips et al., 2002; Hedestig, Sandman, & Widmark, 2003; Moore & Estey, 1999; Pinnock, O'Brien, & Marshall, 1998) the psychosocial research literature has focussed, normatively and psychometrically, on aspects of the prostate cancer experience such as quality of life, and the variables associated with adaptation and adjustment or, interpretatively, on discrete and cross-sectional experiences of men and their female partners (See for example, Bacon, Giovannucci, Testa, Glass, & Kawachi, 2002; Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Bisson et al., 2002; Bjorck, Hopp, & Jones, 1999; Cassileth, Soloway, Vogelzang, Chou, & et al., 1992; Davison & Degner, 1997; Eton & Lepore, 2002; Joly et al., 1998). Even though such studies have elucidated important

issues for men with prostate cancer, they have provided limited insight into the depth and complexity of men's responses to, and within, the prostate cancer experience. This situation surfaces the need for a clearer, and more in-depth, understanding of the experiences of men in order to facilitate the provision of appropriate care, something that is especially meaningful in the context of the muted and obfuscated experience imposed by traditional hegemonic masculinity.

The central academic aim in conducting this study was to deepen and expand our understanding of the ways in which men respond to, and within, the prostate cancer experience. The central human aim, however, was to continue the process of clarifying the experience of men so as to prevent them from becoming stranded with feelings of confusion, uncertainty, disorientation, and fear without recourse to skilled and timely help.

This thesis presents the findings of a prospective, longitudinal, and formative study that examines the experiences of eight men, with localised prostate cancer, through from diagnosis until the end of their first year living within the prostate cancer experience. A prospective, longitudinal approach was judged most appropriate to capture the depth and complexity of the experience; and to expose and explore the themes, patterns, and variations contained within, and evoked by, the experience. Consistent with the character of constructivist research it is hoped that such an approach will provide a vicarious, although not exact, experience of living with prostate cancer. This introductory chapter will describe the background, significance, and purpose of the study, as well as provide an overview of this thesis.

### **The Background to the Study**

The incentive for this study arose from my work as a community based nurse-counsellor working with individuals, and families, experiencing a cancer diagnosis. In the course of this work, and apart from individual and family work, I facilitated a prostate cancer support group for men diagnosed with prostate cancer. It was in this context that I came to realise that the majority of men attending the group did not appear to want to talk about the emotional impact of the prostate cancer, or its sequelae, but wanted, instead, to garner as much information about the treatment for prostate cancer as they could. As a nurse I was able to provide this information but, as a nurse and a counsellor, I was curious about the manifest avoidance of, lack of insight into, and little interest shown in, the emotional impact of this potentially life threatening disease

demonstrated by these men. More significantly, however, I became increasingly aware that I was unable to discover a great deal about how these men with prostate cancer lived with, and within, such an experience from day-to-day. It was as if the experience had been rendered inscrutable.

Some of the literature suggested that I should not have been surprised; men reported using support groups as sources of information about the disease and its treatment, as opposed to sources for social support or coping skills (Breau, McGrath, & Norman, 2003; Breau & Norman, 2003; Gray, Fitch, Davis, & Phillips, 1996). Furthermore, other literature suggested that the provision of information to men with prostate cancer assisted in the reduction of state anxiety and an improvement in psychological health (Davison & Degner, 1997; Kunkel, Myers, Lartey, & Oyesanmi, 2000).

On the other hand, McGovern, Heyman, and Resnick (2002) reported that those men (n=14) with prostate cancer who attended support groups demonstrated more use of anxious preoccupation as a coping style, than men in a control group (n=37). The study did not identify if the coping style predisposed men to join a support group, or if it was a learned consequence of being a support group member (McGovern et al., 2002). Moreover, and importantly, McGovern et al. identified that over half the control group advised that they would not have attended a support group had the opportunity arisen.

Placed in the context of the discourse of traditional hegemonic masculinity, the findings of these studies become normalised. Indeed, such a discourse would support the prediction that men would be unlikely to seek emotional support in the public domain, while seeking information would be regarded as acceptable. However, what hegemonic masculinity obfuscates, and what these studies do not reveal, is why these men remain silent about their emotional experience. Moreover, studies such as these reveal little about the nature of the emotional experience, or about how men engage daily with the potential uncertainty and longevity of the prostate cancer experience.

As health care professionals, we engage with men experiencing prostate cancer from the inside of the health care milieu, using insider knowledge and with an insider's understanding of the disease and treatment trajectories. We endeavour to engage ethically, and with compassion, and with skill; and yet all too often we find ourselves on the outside of men's experiences, with limited insight into how we might engage more therapeutically. Standing on the outside of men's experiences we are confronted with



two choices; we can choose to remain on the outside, or we can choose to move towards a greater understanding of their lived experiences. If we choose the former, we can continue to provide competent care. If we choose the latter, we can provide care that approaches congruency with the lifeworlds of these men and, therefore, care that is more empathically attuned with their lived needs and experiences.

Therefore, my concern in undertaking this study was to gain a better understanding of the process men employed to construct their responses to the prostate cancer experience. That is, the process by which men made sense of their experiences, responded to the emotional content of their experiences, and reconstructed their lifeworlds over time.

### **Aim of the Study**

This thesis is based on the premise that if healthcare professionals are to provide care congruent with the lifeworlds of men encountering prostate cancer, an in-depth understanding of their evolving responses to the prostate cancer experience is imperative. As such, I sought to explore and clarify the lived experiences of men as they responded to localised prostate cancer during the first year following diagnosis. Therefore, the broad aim of this study was to:

*provide an in-depth descriptive account of men's responses to localised prostate cancer, so as to facilitate an improved understanding of the evolution of men's personal, emotional, relational, and existential engagement with the prostate cancer experience.*

### **Significance of the Study**

If, as previously advanced, we are to provide care that approaches congruency with the lifeworlds of men responding to prostate cancer, then we must do so on the basis of a clear understanding of their lived needs and experiences. However, in the context of the current world psychosocial literature, there is a paucity of longitudinal knowledge regarding the nature and evolution of men's responses to, and within, the prostate cancer experience. This prospective longitudinal study will move somewhat towards redressing this knowledge deficit. Furthermore, this study will augment the current body of knowledge by providing further insight into the evolving process of lifeworld reconstruction, as men live day-to-day with the prostate cancer experience.

It is anticipated that the findings of this study will contribute towards health professional's understanding of the day-to-day experience of men with prostate cancer. With this new understanding, it is further anticipated that health care professionals will re-engage with men situated with their experiences of prostate cancer, in an effort to provide increasingly empathic and congruent care.

Moreover, it is hoped that the findings of this study will contribute to men's understanding of their individual experiences. That is, by way of giving voice to many shared experiences and feelings, it is hoped that the inscrutability of the prostate cancer experience will be mitigated, and that the sense of isolation imposed by the discourse established by hegemonic masculinity will be greatly diminished.

Finally, it is anticipated that the longitudinal findings of this study will contribute to future knowledge by directing attention towards the longitudinal nature of the prostate cancer experience, its heterogeneity, and its complexity. Therefore, it is hoped that the process of adjustment to cancer will be re-examined, with less attention given to discrete variables, and more attention given to an understanding of the evolution of a mosaic of context-driven responses to experience.

### **Definition of Terms**

Within the context of this thesis, the following terms are defined as:

#### ***Lifeworld.***

Edmund Husserl (1859–1938), the originator of the term the lifeworld (*lebenswelt*), described it as the lived experience. The lifeworld has also been described as the symbolic world incorporating the structural components of culture, society, and personality (Habermas, 1981). Therefore, within the context of this study, the two terms are conflated so that lifeworld (*lebenswelt*) is assumed to contain the structural components of culture, society, and personality.

#### ***Peri-diagnostic Period.***

The peri-diagnostic period represents a span of time leading up to the point when men received a diagnosis of prostate cancer, incorporates the point of diagnosis, and ends three months following the diagnosis of prostate cancer.

### ***Post-diagnostic Period.***

The post-diagnostic period represents a continuous and ongoing span of time commencing three months following a diagnosis of prostate cancer.

### ***Cohesive Self.***

The cohesive self describes the relatively coherent structure of the typical self that functions normally and healthily; “typical” and “normal” being self-referenced. This stands in contrast to the fragmenting self that can be experienced on a continuum from mildly anxious disconnectedness to the panic of the complete loss of the structure of self (Wolf, 1988).

### ***Localised Prostate Cancer.***

Localised prostate cancer is prostate cancer contained within the prostatic capsule, and includes tumours from stage T1a to T2b (Ohori, Wheeler, & Scardino, 1994).

## **Overview of the Thesis**

This introductory chapter has provided the background, purpose, and significance of this study, as well as an overview of this thesis.

Chapter Two reviews some of the psychosocial research that has previously been carried out with men diagnosed with prostate cancer. It is worth noting that, with the exception of health related quality of life, the world research literature examining the psychosocial aspects of prostate cancer is not extensive. Moreover, the bulk of the existing work is categorised as quantitative, and therefore does not best reveal the lived experiences of men. Some literature relating to the epidemiology and diagnosis of prostate cancer has also been reviewed, so as to provide a clearer understanding of the pathophysiological context of the prostate cancer experience.

Chapter Three explicates the research paradigm and method. The underlying philosophy of the constructivist paradigm is examined, and the application of the constructivist methodology, in the context of this study, is described. The approach and methods used to protect the quality of this study are also delineated.

Chapters Four and Five represent the experiences of a group of eight men as they reconstruct their lifeworlds during their first year of living with, and within, the

prostate cancer experience. However, the men in this study did not tell their stories in a strict chronological sequence, nor did they necessarily emphasise or reflect on their experiences in a contemporaneous manner. Indeed, part of the process of lifeworld reconstruction involved these men in moving backward and forwards, in an iterative way, between chronologically disparate experiences, as they endeavoured to make sense of, and assimilate the whole. However, to provide a sense of progression in portraying the men's experiences, they will be delineated chronologically in Chapters Four and Five. Therefore, Chapter Four presents as its focus what I have called the peri-diagnostic period. The chapter describes the experience of these men as they respond to the diagnosis, begin to appreciate the reality of the prostate cancer, and endeavour to identify solid reference points in the context of a shifting lifeworld. Chapter Five describes the post-diagnostic experience, and the ways in which the men in the study respond to treatment, reformulate and perpetuate a stabilising lifeworld, and attempt to move forward in the context of an altered lifeworld.

In Chapter Six I explore what I call the “critical beyond portrayal”. That is, although I recognise the importance of allowing the portrayal of the experiences of the men in this study to represent itself, I also believe it is appropriate to examine the underlying social contexts that shape lifeworld reconstruction, as the men in the study respond to the prostate cancer experience during the first post-diagnostic year. Consequently, the underlying social contexts are examined using a critical analytic approach. Finally, in Chapter Seven, the main insights gained from the study are summarised, and the implications of these insights for health care practice and for research are identified. The implications for men with localised prostate cancer are also presented, using an ethnographic fiction (Gray, 2004) that draws on the portrayal of the men's experiences presented in this study.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **Introduction**

Prostate cancer is, in general, a slow growing cancer; thought to start at about 30 or 40 years of age, and capable of growing over many years before it generates symptoms (Giatromanolaki, Sivridis, & Syrigos, 2001). Prostate cancer is a disease that generally becomes symptomatic in elderly men who, according to Barista (2001), have short life expectancies. Although the patho-physiology of, and treatment for, prostate cancer is well represented in the bio-medical literature, the same literature under-represents the psychosocial experiences of men with the disease. As an example, a specialist medical textbook purporting to be a “single” and “comprehensive” source of information about prostate cancer (Syrigos, 2001) contains two chapters about psychosocial issues; one short chapter about quality of life, and an even shorter chapter about psychological and sexual problems. Although the information provided in these chapters is contextually relevant, these writings make no mention of the emotional or lived experiences of prostate cancer.

Furthermore, Bjorck, Hopp, and Jones (1999) suggest that the psychosocial prostate cancer literature appears to focus on categories such as quality of life or emotional functioning as measures of coping. Few studies have examined, for example, the coping process, or the affect of gender on the prostate cancer experience, or the effect of cultural schemata on adjustment, or the day-to-day experience of living with the disease and its treatment sequelae. Fewer studies have provided an interpretive longitudinal exploration of the process of responding to the prostate cancer experience. Indeed, in a biopsychosocial review of prostate cancer, Sestini and Pakenham (2000) identified that no comprehensive longitudinal understanding exists with respect to the physical or psychosocial experiences of men with prostate cancer. To put this into some kind of time perspective, Green (1987) (accepted for publication 1985) carried out a 20 year literature search and was unable to produce a single article, in any language, about the psychosocial consequences of prostate cancer.

These deficits notwithstanding, I begin this review by outlining the diagnosis of prostate cancer because it forms an important context at the beginning of the prostate

cancer experience. More particularly, the diagnostic process involved with prostate cancer impacts on treatment choices made by men, and therefore on the longer term experiences of living with prostate cancer. While lived responses to the prostate cancer experience are unequivocally central to this study, it is important to acknowledge and incorporate the idea that men, prostate cancer, and their experiences coexist in an integrated and mutually generative relationship. Equally, in setting the tone of this review, the order in which the literature is presented represents an artificial sequencing of this relationship, rather than the temporal representation of putative reality.

Given this context, three areas of the psychosocial prostate cancer research literature associated with responding to, and within, the prostate cancer experience are then reviewed: Health Related Quality of Life, The Coping Response, and the Experience of Localised Prostate Cancer. I am hopeful that this review will provide a tentative set of boundaries that assist in containing the complexities of lived experiences of prostate cancer until such time as the narrative begins to speak for itself. It is by engaging with the narrative that the reader will achieve the richest understanding of the insights provided by this study.

### **Epidemiology and Diagnosis of Prostate Cancer**

Prostate cancer is the most common cancer found in Australian males, with a lifetime risk of developing the disease before the age of 75 of one in 11, and it is the second most common cause of male deaths from cancer after lung cancer (Australian Institute of Health and Welfare [AIHW], 2002a).

A significant development in the diagnostic technology associated with prostate cancer, the prostate specific antigen (PSA) assay, resulted in an increase in the number of men acquiring a diagnosis of prostate cancer between 1990 and 1994 (AIHW, 2001). Although the incidence of prostate cancer has since fallen back towards the underlying level, perhaps as a result of the detection of the prevalent cancers, the mortality rate has declined much more slowly (AIHW, 2001). However, there are currently a significant number of men in the population who have a diagnosis of prostate cancer, and have been treated, or who will have such a diagnosis and treatment in the future.

The peak incidence of prostate cancer occurs between the ages of 60 and 84 years (AIHW, 2002b) with 89% of cancers occurring at or after the age of 60 years (82% between the ages of 60 and 84 years). The mean age of men with this disease is 72

to 74 years (Grönberg, 2003). Results of autopsies show that most men older than 85 years display histologic prostate cancer (Grönberg, 2003), with histologic prostate cancer exceeding clinical prostate cancer by approximately eight times (Giatromanolaki et al., 2001). Potosky et al. (2000) point out that almost 90% of new cases are localised to the prostate gland. Indeed, men with asymptomatic prostate cancer may die from other causes before their disease comes to their attention and requires treatment (Barista, 2001).

Although the incidence of prostate cancer is greatest in Western countries, there is evidence of a rising trend worldwide (Grönberg, 2003); with Parkin, Bray, and Devesa (2001) predicting that in 15 years prostate cancer will be the most common male cancer. Steginga et al. (2001) suggest this rising trend, and the significant iatrogenic morbidity associated with treating prostate cancer, represent a major public health concern. Given the incidence data previously described, prostate cancer is clearly a disease experienced principally by older men, at a time in their lives when their social productivity is declining and ending. Furthermore, given the post-mortem evidence of *in situ* prostate cancer (Grönberg, 2003), and the potential iatrogenic and social consequences of treatment (e.g. impotence, urinary incontinence, impact on relationships etc.), there is a sense of inevitability about the diagnosis of prostate cancer, its treatment, and the iatrogenic consequences of its treatment. However, as much of this sense of inevitability has derived, I would suggest, from the development of the PSA assay, it is worth examining the impact of this “screening” instrument in the context of the diagnosis of prostate cancer.

The previously mentioned rise in the incidence of prostate cancer during the past fourteen years has been attributed to three factors (Barista, 2001); the increased use of PSA screening, an increase in the awareness of prostate cancer, and possibly an increase in life expectancy. However, of these three, PSA screening, in the context of the diagnosis of prostate cancer, has become the most confusing, and most contentious issue confronting health care professionals and men alike. Routine screening for prostate cancer using the PSA assay is not centrally sanctioned in Australia; the Australian Health Technology and Advisory Committee (AHTAC) (AHTAC, 1996) advised against the screening of asymptomatic men. However, de facto screening occurs (AHTAC, 1996) as a result of men going to their family doctor (GP) and asking for a PSA test. De facto screening also occurs as a result of men going to their GP for some other reason and having the PSA test prescribed on the basis of their age alone.

However, the available evidence suggests that only 16% of men with localised prostate cancer, detected by screening, benefit from radical treatment, because their disease would not have otherwise compromised their life expectancy or quality of life (Frankel, Davey-Smith, Donovan, & Neal, 2003). Put another way, in this group of men 84% of radical treatments are carried out with no prospect of benefit (Frankel et al., 2003). For example, albeit that radical prostatectomy for localised prostate cancer will obviate the chance of death for many men, it is perhaps difficult to justify such an approach in an asymptomatic group. This is an especially relevant point to consider when only nine percent of men diagnosed with localised prostate cancer are likely to die of prostate cancer within 15 years (Albertsen, Fryback, Storer, Kolon, & Fine, 1995). Moreover, the iatrogenic burden of radical prostatectomy is potentially severe and permanent; up to five percent of men develop severe urinary incontinence (Weldon, Tavel, & Neuwirth, 1997) and up to 90% of men become impotent (Siegel, Moul, Spevak, Alvord, & Costabile, 2001; Stanford et al., 2000).

Therefore, many men who find themselves in the post-fifty age group are confronted with the confusing issue of making a decision to engage (or not engage) with de facto screening in the absence of clinical disease, and in the context of insufficient evidence to connect asymptomatic diagnosis with an increased life expectancy. However, as Partin and Wilt (2002) identify, health information about prostate cancer, at least in the public domain, does not provide a message about uncertainty, but rather encourages annual prostate cancer screening for men from the age of 50 years.

### **Health Related Quality of Life and Localised Prostate Cancer**

The previous section makes it clear that a diagnosis of localised prostate cancer places men in a position where they are required to make treatment choices. Subsequent to these choices, these men experience the outcomes of their chosen treatment or treatments; outcomes that potentially impact on their health related quality of life (HRQoL).

The literature represents HRQoL as a person-centred variable, measured using surveys or questionnaires (instruments) that may be self or third party administered (Penson, Litwin, & Aaronson, 2003). HRQoL instruments are organised around scales, where each scale measures a different domain of HRQoL; domains may be either general (generic) or disease specific. General domains address aspects of well-being that are considered to be common to all people, whereas disease specific domains emphasise



those areas of concern impacted on by a particular disease (Penson et al., 2003). The six disease specific domains in prostate cancer have been identified by Penson et al. as anxiety about cancer recurrence, hot flashes, bladder irritability, urinary incontinence, bowel dysfunction, and erectile dysfunction.

HRQoL has been defined as the physical, mental, and social consequences of disease for daily living and the impact of these consequences on well-being, satisfaction, and self-esteem (H. J. Green, Pakenham, Headley, & Gardiner, 2002). Da Silva (2001) adds that HRQoL refers to a quotient of an individual's actual status over his or her expected status, and Turini, Redaelli, Gramegna, and Radice (2003) suggest it is a subjective evaluation as opposed to an objective measure. Therefore, based on these ideas, I would suggest that HRQoL represents a subjectively referenced construct that has been used to assess the consequential impact of disease on the functional, physical, and emotional components of people's lives.

In reviewing the prostate cancer HRQoL literature, it was evident that many HRQoL studies have focused on the measurement of treatment outcomes and efficacy. More particularly, many prostate cancer outcomes studies, using HRQoL, have focussed on the disease specific domains of bowel, urinary, and sexual functioning (Braslis, Santa-Cruz, Brickman, & Soloway, 1995; Jonler, Nielsen, & Wolf, 1998; Litwin, McGuigan, Shpall, & Dhanani, 1999; Perez et al., 1997), based on the assumption that they have a deleterious impact on quality of life (Bacon et al., 2002).

These observations about focus notwithstanding, HRQoL research has assisted greatly in acknowledging the importance of understanding the impact of disease and treatment on the lives of men with prostate cancer, across a range of dimensions. Furthermore, in the absence of a consensus about the best treatment for localised prostate cancer, HRQoL has provided men, and health professionals, with a mechanism for understanding the consequences of treatment choices that does not depend on an estimation of survival (Eton & Lepore, 2002). Indeed, HRQoL has become increasingly important, not just for the men with prostate cancer, but also for institutions involved in planning, providing, and monitoring health care (Pietrow, Parekh, Smith, Shyr, & Cookson, 2001; Turini et al., 2003).

In this section, I review some of the HRQoL literature that has examined both disease specific (urinary and sexual function) and general domains in men treated for localised prostate cancer.

## *Disease Specific Domains of HRQoL*

### *Urinary Function*

According to Freedman, Hahn and Love (Freedman, Hahn, & Love, 1996), 98% of men with localised prostate cancer receive treatment with either radical prostatectomy (RP) or external beam radiotherapy (EBR). Younger, healthier men receive radical prostatectomy, with men after the age of 70 (or in men with noteworthy comorbid medical conditions) receiving external beam radiotherapy. As previously identified, the estimated prevalence of severe urinary incontinence following treatment with radical prostatectomy is up to five percent (Weldon et al., 1997).

In general, cross-sectional studies suggest that men treated for localised prostate cancer, experience an increased burden of urinary related problems when compared with age matched men without prostate cancer (Bacon et al., 2002; Joly et al., 1998; Litwin et al., 1995). Indeed, in a review of the comparative literature Grise (2001) estimated urinary incontinence following RP to be two times more common than following EBR.

For example, in a comparative cross-sectional study of men treated for localised prostate cancer (Litwin et al., 1995), a sample was recruited from a managed care programme (n = 214) to study HRQoL outcomes. The sample consisted of a group of men treated with RP (n = 98, mean age = 69.7 years), EBR (n = 56, mean age = 76.2 years), and observation (OB) alone (n = 60, mean age = 75.2 years); and then compared against a group without prostate cancer (n = 278, mean age = 72.5 years). Utilising a number of generic and disease specific instruments, Litwin et al. identified that across all four groups the men treated with RP experienced the worst urinary function ( $F_{(3, 483)} = 33.9$ ;  $p < 0.001$ ).

Studies comparing RP against EBR or Brachytherapy (BT) revealed a similar picture; those men who received a RP experienced more urinary problems than men treated with EBR or BT (Brandeis, Litwin, Burnison, & Reiter, 2000; Eton, Lepore, & Helgeson, 2001; Fowler, Barry, Lu-Yao, Wasson, & Bin, 1996; Lim et al., 1995; Tefilli et al., 1998). For example, Eton, Lepore, and Helgeson (2001) recruited a sample of men with localised prostate cancer from a clinical trial (n = 256, mean age = 65.0 years, age range = 45 – 80 years) and, using a cross-sectional design, compared the early HRQoL, using the Prostate Cancer Index (PCI), of three sub-samples treated with RP (n = 156), EBR (n = 49), and BT (n = 51). Measures of HRQoL, perceived support, social

constraints, self-efficacy, and self-esteem were used. The researchers identified poorer urinary function in the radical prostatectomy group and significant treatment related differences on the urinary function scale of the PCI were found ( $F_{(2, 251)} = 78.7$ ;  $p < 0.001$ ). Moreover, a supportive social environment ( $r = 0.15$ ;  $p < 0.05$ ), high self-efficacy ( $r = 0.25$ ;  $p < 0.001$ ), and high self-esteem ( $r = 0.29$ ;  $p < 0.001$ ) predicted better HRQoL. Although these findings provide some information about factors associated with health related quality of life, the magnitude of the correlations are relatively small, indicating a fair degree of unexplained variance. The need for further research to explicate factors associated with HRQoL more fully appears warranted. Limitations notwithstanding, this study was interesting because the researchers appeared to be moving away from restricting measures to HRQoL or mental functioning, and towards including intra-personal factors as variables that potentially mediated between treatment and HRQoL outcomes.

These cross-sectional studies provided useful information about the status of HRQoL at particular points in time. However, as with all cross-sectional studies, these studies are unable to provide information about how urinary function changed over time. Moreover, because the studies did not provide baseline measurements of HRQoL, it is difficult to know how much HRQoL has changed from pre-treatment levels.

Longitudinal studies, on the other hand, assist in revealing what Eton and Lepore (2002) refer to as the trajectory of disrupted urinary function. That is, longitudinal studies allow for the tracking of changes in the HRQoL of men with prostate cancer over time. A number of longitudinal studies have demonstrated that even though the exacerbation of urinary function is common during the first few months following RP, improvement may occur within one year of treatment (Litwin, McGuigan et al., 1999; Lubeck et al., 1999; Potosky et al., 2000; Stanford et al., 2000). In the study conducted by Litwin et al. (1999), for example, 61% of men ( $n = 90$ ) treated with RP had recovered their pre-treatment urinary function by the end of the first post-operative year (T2). Also, by T2, between 86 and 97% of men had recovered their baseline function domains of general HRQoL.

Importantly, what these longitudinal studies have revealed is the presence of a temporal and reciprocal relationship between urinary function and HRQoL and, more generally, the importance of understanding the changes in the disease trajectory that alters HRQoL over time. Incorporating narrative idiographic data would help to reveal

the detail of such a reciprocal relationship and, more specifically, the contextual features of individual lives that intervene to affect the relationship, positively or negatively, in the moment and over time.

Furthermore, in the Prostate Outcomes Study, a 24 month longitudinal community based cohort study, Potosky et al. (2000) compared two year HRQoL outcomes in a group of men treated with RP (n = 961) and EBR (n = 373). The study established that men receiving RP experienced more urinary complications, at 24 months, than men receiving EBR ( $p < 0.001$ ); the RP group were found to be 3.3 times more likely to report urinary incontinence, and 6.6 times more likely to report being bothered by it, than men receiving EBR. Perhaps more importantly, this study also revealed that men who received a RP, and who had poorer baseline urinary function, experienced some recovery during the second year. On the other hand, older men who received EBR continued to demonstrate a decline in urinary function during the second year. Potosky et al. concluded that treatment choice, baseline function, and age were the principal causal factors involved in changes to disease specific HRQoL during the first two years following a diagnosis of localised prostate cancer.

Potosky et al. (2000) provide salient information about the important variables causally involved in changing disease specific HRQoL during the first two post-diagnostic years. However, the mechanisms of interaction between these variables have not been identified. Because the mechanisms are almost certainly more complex than a main effects relationship would suggest, re-examining the experience of the study cohort from an idiographic perspective would begin to reveal the contextual nuances important to a more in-depth understanding.

In summary, longitudinal studies are able to demonstrate improving trends in urinary function, as measured by disease specific HRQoL instruments. Such information provides men with useful information about outcomes, and the treatment and recovery trajectories that enable them to make informed choices about treatment at the time of diagnosis. There is a sense, however, in which it would be equally important for men to understand the ways in which general HRQoL declines and improves during the treatment trajectory. That is, it would be important to demonstrate the interrelationships between, say, urinary function and role function, or urinary function and emotion, in order to provide men with greater insight into the potential cumulative consequences of treatments such as RP and EBR. Finally, the utility of such information

could be enhanced if it were selectively associated with, and qualified by, the emic perspective gained through longitudinal narrative studies.

### ***Sexual function***

The prevalence of male erectile dysfunction (MED) (or erectile dysfunction [ED]) in men with localised prostate cancer is not clear and varies between studies. As an estimation, the prevalence rate of MED is between 30 and 70% (Geary, Dendinger, Freiha, & Stamey, 1995), and may be as high as 90% (Siegel et al., 2001; Stanford et al., 2000), even with nerve-sparing surgery. A recent multisite, longitudinal, community based study (Stanford et al., 2000) shows a prevalence rate of MED of 59.9%, with a nerve sparing procedure, at 18 or more months post prostatectomy. Although MED in men receiving EBR may not be as immediate, it still occurs in as many as 30% of patients during the first couple of years following treatment (Robinson, Dufour, & Fung, 1997).

Perhaps not surprisingly, HRQoL cross-sectional studies demonstrate that men treated for localised prostate cancer report more problems with sexual function than do age-matched men without localised prostate cancer (Fransson & Widmark, 1999; Helgason et al., 1997; Helgason et al., 1996; Litwin et al., 1995). Moreover, men treated with RP demonstrate the highest prevalence of MED (Fowler et al., 1996; Helgason et al., 1997; Helgason et al., 1996; Lim et al., 1995; Meyer, Gillatt, Lockyer, & Macdonagh, 2003; Shrader-Bogen, Kjellberg, McPherson, & Murray, 1997; Yarbrow & Ferrans, 1998).

In a recent cross-sectional HRQoL study Meyer et al. (2003) used a MED specific quality of life (QoL) instrument, the “ED effect on QoL” (ED-EQoL) (MacDonagh, Ewings, & Porter, 2002), to assess the psychosocial impact of MED on the QoL of a group of men ( $n = 89$ ; mean age 61 years) a median time of 92 months after RP. Of those men who were potent before surgery ( $n = 74$ ), 56 were not potent following the RP. Overall, even some considerable time after surgery, 72% of the group of 56 impotent men reported a moderately or severely affected HRQoL due to their MED. Importantly, however, the results showed that many areas that compose HRQoL were moderately or severely affected by ED; these areas included self-esteem, guilt, blame, happiness, and anger.

The use of the ED-EQoL demonstrated an important shift towards recognising the relevance of the psychosocial issues associated with MED (and therefore prostate cancer and its treatment). Also, the description of responses to the questionnaire (e.g. “a third of the group felt that other people were ‘quite a lot’ or ‘a great deal’ happier because they were sexually fulfilled”, and “73% of men felt a failure because of their ED”) provided greater insight into the range of consequences associated with MED. However, in the context of this thesis, it is equally important to use the longitudinal narratives of men, as a means of capturing and elucidating the ways in which they construct their day-to-day experiences of living with MED.

The longitudinal HRQoL localised prostate cancer literature generally identifies that sexual function following RP declines rapidly, and that men experience great difficulty in regaining pre-treatment levels of sexual activity (Litwin, McGuigan et al., 1999; Lubeck et al., 1999; Potosky et al., 2000; Stanford et al., 2000). Also, some longitudinal studies (Lubeck et al., 1999; Potosky et al., 2000) show that men treated with EBR experience similar sexual problems, although the findings are confused somewhat by the observation that the men in these studies demonstrated poor baseline sexual function. However, results from the Prostate Cancer Outcomes Study (PCOS) (Potosky et al., 2000) do suggest that men treated with RP demonstrate more sexual “bother” at two years, than men treated with EBR.

The assessment of “bother”, as used in the PCOS (Potosky et al., 2000), represents an important attempt to qualify the dimensions of HRQoL (eg. urgency of urination or bowel movements), by recognising a psychosocial impact, associated with dysfunction, on men experiencing treatment for prostate cancer. A number of longitudinal studies have utilised bother scales in assessing HRQoL (See for example, Cooperberg et al., 2003; Dale et al., 1999; Litwin, Flanders et al., 1999; Litwin, Pasta, Yu, Stoddard, & Flanders, 2000; Litwin, Sadetsky, Pasta, & Lubeck, 2004; Lubeck et al., 1999; Namiki et al., 2004; Visser et al., 2003; Walsh, 2000; Wang et al., 2000). The use of bother scales is important, as they contribute to a qualitative picture of the health-related functioning of an individual (Litwin, 1994), using validated scales. Moreover, used in longitudinal studies, bother scales provide a quick mechanism for monitoring, albeit superficially, the psychosocial domains of HRQoL over time.

Therefore, as with urinary function, HRQoL longitudinal studies associated with sexual function are able to remove some of the problems linked to the absence of

baseline measures seen in cross-sectional research. Longitudinal studies are also able to provide some sense of the changes in HRQoL over time, when comparing one treatment modality against another. However, longitudinal studies do not provide information about the meaning of the experience or the contextual realities involved in living with MED on a daily basis. Furthermore, there is no evidence to show that the MED HRQoL literature has been incorporated into programmes aimed at assisting men to manage MED in a time and context appropriate manner.

### *General Domains of HRQoL*

General HRQoL measures incorporate overarching issues that concern many types of patients, sick and well (Litwin, 1994). For example, the European Organisation for Research and Treatment of Cancer (EORTC) Core Quality of Life Questionnaire (QLC-C30) includes five functional scales that measure physical, role, emotional, cognitive, and social functioning as well as one global status/QoL scale (Borghede & Sullivan, 1996). However, not all general instruments include the same scales.

Substantially, cross-sectional studies have not demonstrated any general HRQoL differences across treatment groups in men with prostate cancer. That is, men treated with RP have shown similar general HRQoL to those men treated with EBR (Lim et al., 1995; Shrader-Bogen et al., 1997; Tefilli et al., 1998; Yarbrow & Ferrans, 1998). However, even though longitudinal studies have demonstrated problems in some domains of general HRQoL, by and large these problems improve during the first treatment year (Lubeck et al., 1999). For example, Litwin et al. (1999), identified that between 86 and 97% of men (n = 90), treated with RP, regained their pre-treatment levels of physical well-being, role-physical well-being, general health, role-emotional well-being, and social well-being by the end of the first treatment year.

These longitudinal studies, using general HRQoL instruments, have provided useful data about changes over time, and certainly have added to the quality of description when compared with the concept of a bother scale. Moreover, I would suggest that general scales have facilitated access to psychosocial elements that, although based on self-referenced progress, are capable of being widely interpreted and understood.

I would further suggest that dimensions of general HRQoL are well positioned to facilitate recognition of the psychosocial factors (PFs) relevant for a wider, deeper,

and more comprehensive understanding of the prostate cancer experience. However, Lev et al. (2004) point out that these PFs have rarely been examined in the context of HRQoL, and even less so in men with prostate cancer.

This observation notwithstanding, in a recent prospective longitudinal study Van Andel, Visser, Hulshof, Horenblas, and Kurth (2003) examined HRQoL and PFs in a group of men ( $n = 138$ ), some of whom had localised prostate cancer ( $n_{RP} = 58$ ;  $n_{EBR} = 25$ ). The study utilised a general and disease specific HRQoL instrument, as well as a range of psychosocial psychometric instruments (including measures of coping style, psychological distress, expression of emotion, and impact of events). The authors only published the baseline results, which showed some age and socio-economic status differences between the RP and EBR groups, some differences in HRQoL, but no differences between groups on the baseline measures of PFs. The psychosocial measures were evaluated using univariate ANOVA and covariance, but were not reported. However, the analyses of HRQoL and PFs were adjusted for age and socio-economic status, which were recognised as confounding variables.

Nevertheless, the authors concluded that the inclusion of PFs was important, even though they recognised that PFs were not considered to be an integral part of the assessment of HRQoL in oncological research (Van Andel et al., 2003). Furthermore, Van Andel et al. (2003) identified that there have been recent studies of the relationship between HRQoL (general and disease specific) and PFs, suggesting that HRQoL is affected by a number of PFs (See for example, Aalto, Uutela, & Aro, 1997; Eton et al., 2001; Goodwin et al., 2004; Luscombe, 2000; Visser et al., 2003). Clearly, the addition of PFs adds another important dimension to the longitudinal study of HRQoL in men with prostate cancer.

### ***Conclusion - HRQoL***

Although HRQoL has revealed important information about the prostate cancer treatment trajectory, to date, the emphasis of the research has been on functional and physical variables, and has excluded or under-represented the psychosocial variables. Moreover, many studies have used generic instruments to assess HRQoL in men with localised prostate cancer; instruments that do not incorporate domains relevant to the impact of prostate cancer. As well, the prostate cancer specific instruments that exist (approximately nine) have generally focused on the symptom-specific domains of HRQoL; these domains are not consistent across instruments, and no single instrument



has been used to assess HRQoL across the range of ages or disease stages (Sommers & Ramsey, 1999). These ideas are supported by Clark, Bokhour, Inui, Silliman, and Talcott (2003), who observed that although precise attention has been given to the potential for physical post-treatment dysfunction (e.g. urinary, bowel, sexual), minimal attention has been given to the emotional, interpersonal, and behavioural changes generated by a diagnosis of localised prostate cancer.

Thus far, HRQoL studies have not examined intervening variables involved in moderating the response between the diagnosis and treatment of prostate cancer, and the outcomes described by HRQoL studies. Longitudinal HRQoL studies could be augmented by the inclusion of this type of data, adding further to knowledge about these variables. Furthermore, the addition of qualitative information describing the experience of prostate cancer would facilitate increased relevance by providing a context within which to locate HRQoL outcomes.

### **The Coping Response**

HRQoL provides useful information about the outcomes of prostate cancer and its treatment, information that can be used in a predictive manner to help men with prostate cancer understand and make choices about treatment. However, HRQoL reveals nothing about the coping response, or the psychosocial resources that contribute to the quality, and success or failure, of the coping response in the context of prostate cancer and its treatment. This is important, as it is the coping response that potentially gives rise to outcomes such as adjustment, maladjustment, or psychopathology. Therefore, the next logical step in this review is to consider the coping response, and those psychosocial resources that act to mediate or moderate men's responses to prostate cancer and its treatment. As such, it moves the discussion away from end points, towards one that begins to acknowledge a symbiosis between person and environment, and the psychosocial variables that mediate in such a relationship.

There are two factors that have limited what is currently known about the coping response in the context of prostate cancer. One factor is the paucity of literature that has examined coping with prostate cancer; the other factor involves a lack of clarity about what constitutes coping and how to measure it (Sommerfield & Curbow, 1992). Parle and Maquire (1995), for example, have suggested that the diversity of definitions of coping found in the literature have caused problems of interpretation when different studies have used different meanings of the term. From within the life stress paradigm (see

below), the seminal work of Lazarus and Folkman (1984) has helped to reduce the ambiguity by identifying the different elements associated with coping. That is, they identified four sets of variables: stimulus, appraisal, response, and outcome (Lazarus & Folkman, 1984). Importantly, using a transactional model, these authors argued that coping responses change according to the changing contexts that trigger appraisal and re-appraisal (Lazarus & Folkman, 1984). As such, responding to changing contexts refers to a complex interaction between individual and situational variables, including appraisal variables. Indeed, it is the appraisal variables that have been neglected in the literature, especially with respect to coping with cancer (Parle & Maguire, 1995).

What some researchers refer to as appraisal variables (Carver et al., 1993; Watson et al., 1991), others refer to as resource variables (Curbow & Somerfield, 1995). Curbow and Somerfield suggest that resources facilitate the acquisition of some positive end point or outcome, or assist in the avoidance of some negative end point or outcome. As an example of psychosocial resources Walker et al. (1996), in referring to studies about adjustment in men following treatment for prostate cancer, identify variables such as social support, role function, self-esteem, and individual differences (e.g. coping style, locus of control, attribution, and optimism etc.).

Much of the earlier work involved with psychosocial resource variables occurred within the life stress paradigm, recognising as it did a relationship between life stress (life events) and distress (Ensel & Lin, 1991). Out of this paradigm came the work of theorists such as Lazarus and Folkman (1984), who suggested that psychosocial resources were mobilised, as a result of appraisal, in order to buffer or mediate the harmful affects of stressors. More recently, Ensels and Lin have put forward the Resources Theory (Ensel & Lin, 1991) in which psychosocial resources are viewed as elements of the external and internal environments. As such, psychosocial resources either discourage distress or mediate (counter) the potential harmful consequences of difficult life events. Moreover, Ensels and Lin classify resources as either psychological or social. Psychological resources are possessed by, or are intrinsic to, an individual, but social resources are embedded in the individual's social environment.

With these ideas in mind, in the remainder of this section I review some of the quantitative psychosocial literature that has considered the resource, or other appraisal, variables that potentially influence the coping response to prostate cancer. In particular, I will review some of the literature that has examined individual and social coping.

### *Individual Coping*

It has generally been acknowledged that the period between receiving evidence of an elevated PSA level and receiving a diagnosis of prostate cancer can be stressful for men who, according to Burke, Lowrance, and Perczek (2003), are confronted with the uncertainty of prostate cancer and the unknowns of treatment and its side-effects. However, as these same authors point out, little research has been undertaken with respect to men's emotional adjustment to prostate cancer (Burke et al., 2003). Furthermore, there is a paucity of literature that examines, or refers to, the coping response, intrinsic psychosocial resources, or other appraisal variables in the context of prostate cancer.

What much of the literature has referred to is the idea of psychosocial distress as an outcome. A number of non-prostate cancer psychosocial studies (See for example, Carver et al., 1993; Gilbar, 1999; Kelly, Ghazi, & Caldwell, 2002; Manne, 1999; Manne & Schnoll, 2001; Manne et al., 2004; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001), and a smaller number of prostate cancer psychosocial studies (See for example, Balderson & Towell, 2003; Banthia et al., 2003; Bisson et al., 2002; Malcarne et al., 2002; Perczek, Burke, Carver, Krongrad, & Terris, 2002; Roth et al., 1998; Taylor, Shelby, Kerner, Redd, & Lynch, 2002; Zabora et al., 2001) have examined the concept of psychosocial distress in this way.

However, I would observe that many of these studies have demonstrated a similar limitation as that described by Parle and Maquire (1995) in the context of coping research. That is, the range of operational definitions, based on the psychometric measure or measures of distress used in the various studies, have caused problems of interpretation when different studies have used different or multiple psychometric instruments. Indeed, Zabora et al. (2001) point out that over 40 standardised instruments have been used to measure psychological distress in cancer patients, although seven emerge with the highest frequency of use (see Table 1). The same authors advise that the Brief Symptom Inventory (BSI) and the Symptom Checklist 90-R (SCL-90) are adequate measures of distress (Zabora et al., 2001).

Table 1

*Scales of psychological distress by frequency of use in the cancer literature*

Scale	Number of Items	Measures
Profile of Mood States (POMS)	65	Affective states
Psychological Adjustment to Illness Scale (PAIS)	46	Adjustment to illness
Brief Symptom Inventory	53	Psychological distress
Symptom Checklist 90-R	90	Psychological distress
State-Trait Anxiety Inventory	40	Anxiety
Centre for Epidemiological Studies Depression (CES-Depression)	20	Depression
Beck Depression Inventory (BDI)	21	Depression

*Note.* From “The prevalence of psychological distress by cancer site”, by J. Zabora, K. Brintzenhofeszoc, B. Curbow, C. Hooker, and S. Piantadosi, 2001, *Psychooncology*, 10, p. 21.

Balderson and Towell (2003), in a study examining the prevalence and predictors of psychological distress in men with prostate cancer (n = 94) (age range = 51 - 86 years), identified a prevalence rate of 38% using the Hospital Anxiety and Depression Scale (HADS), as well as a HRQoL of instrument. Balderson and Towell provided no analysis regarding the association between appraisal variables and outcome, and were therefore only able to speculate about a difference between their prevalence rate of 38% and that identified by Roth et al. (1998) of 13% (n = 121) (age range = 52 - 88 years), in a similar study using the HADS. Moreover, at least according to Zabora et al. (2001), the HADS is not an adequate measure of distress because it focuses on only two elements of the concept; anxiety and depression.

Nevertheless, the study was important for three reasons. Firstly, the study identified distress as an issue, and potential outcome, confronting men with prostate cancer. Secondly, the study opened the way for other research directed towards examining the role of the appraisal variables, and the longitudinal variation of distress.

Finally, the study examined the role of dimensions of HRQoL as predictors of distress. In all these ways, the study provided an important segue between prostate cancer outcomes research, and research that sought to examine coping as a process.

With respect to the appraisal variables, one issue associated with coping with cancer in general concerns the ability of individuals to match resources with the demands imposed (Gotay & Stern, 1995). Gotay & Stern suggest that such an idea has been considered most generally with respect to optimism.

In a longitudinal study, Perczek et al. (2002) followed a group of men ( $n = 101$ ) (Mean age = 66.7 years;  $SD = 7.44$  years) across a four week period from biopsy until two weeks following diagnosis. Using measures of optimism (Life Orientation Test), coping (COPE), and distress (POMS) the study addressed the role of optimism and coping styles in adapting to a prostate cancer diagnosis. Adaptation was considered in terms of emotional distress.

No relationship was shown between reduced distress and active coping style. That is, at or around the time of diagnosis the active coping style appraisal variable (eg. fighting spirit) did not appear to have an effect on the experience of distress. On the other hand, independent of the biopsy result (37.6% received a diagnosis of prostate cancer; 62.4% did not), the avoidant coping style appraisal variable was shown to be predictive of increased distress ( $r = 0.33$ ;  $p < 0.01$ ). Optimism was not significantly correlated with avoidant coping ( $r = -0.11$ ). Generally, then, the study did not find that active coping was predictive of distress levels. However, the authors suggest that active coping may not be an appropriate response at such an early stage in the experience (Perczek et al., 2002). Indeed, Stanton and Snider (1993) identified, in a study of women with breast cancer, that active coping responses may not be required during periods of accommodation.

If this is so, and as little is known about the way in which men respond and adapt to a prostate cancer diagnosis (Perczek et al., 2002), this study points clearly towards the importance of understanding the contribution of the situational and appraisal variables during the peri-diagnostic and post-diagnostic periods. Moreover, the value of interpretive longitudinal studies is apparent, and can provide important information about which of the appraisal variables might be most appropriately examined during the peri-diagnostic experience, and how men describe the phases of the experience.

While Perczek et al. (2002) concluded that active coping was not predictive of distress, the opposite was observed by Bjorck, Hopp, and Jones (1999), in a small cross-sectional study. The study assessed the interrelationship among a number of psychosocial variables (optimism, mental adjustment to cancer, appraisal, and emotional functioning) in a group of men ( $n = 30$ ) (mean age = 75 years) diagnosed with prostate cancer, one to 20 years after the diagnosis. Bjorck et al. hypothesised that fighting spirit (an appraisal variable) would be related to positive emotional functioning, as defined by higher scores on self-esteem and lower scores on depression and anxiety.

With respect to active coping style, the study reports that fighting spirit (mean score = 3.06; SD = 0.34; range = 1 – 4) was positively correlated with self-esteem ( $r = 0.36$ ;  $p < 0.05$ ). Also, self-esteem (mean score = 43.96; SD = 5.88; range = 10 – 50) was inversely related to helplessness ( $r = -0.53$ ;  $p < 0.01$ ). Therefore, the researchers suggest, men with higher self-esteem have the ability to adopt a fighting spirit towards prostate cancer because they perceive themselves as capable of influencing the outcome. This conclusion may, or may not, be the case. Because there was no baseline measurement of self-esteem it is not possible to know the extent to which fighting spirit (or self-esteem) was actively increased or decreased as a result of the impact of other appraisal or situational variables, or as a consequence of time since diagnosis and treatment. As well, the small sample limits conclusions. Furthermore, the study did not examine the moderating affects of contextual factors (Andrykowski & Brady, 1994). As such, a longitudinal study would have been better placed to identify the transactional nature of coping by measuring the changing frequencies of responses, using the same variable set, over time.

There have also been a small number of studies that have examined the impact of a range of other individual or interpersonal variables on the coping response in men with prostate cancer. These studies include the affect of dyadic strength and marital satisfaction (Banthia et al., 2003; Ptacek, Pierce, & Ptacek, 2002), and cognitive appraisal (Ahmad, 2000). However, only one quantitative study has attempted to associate aspects of masculinity with the process of coping with, and adjustment to, prostate cancer. Masculinity represents an important, albeit changing, variable that provides good information about the ways in which men interpret the prostate cancer experience and respond to it.

Helgeson and Lepore (1997) construed prostate cancer as a victimisation experience in which the masculine self was threatened by prostate cancer. In a cross-sectional study of men's adjustment to prostate cancer (n=162) (age range = 48 – 84 years), they examined the personality traits of agency (a positive male gender-related trait) and unmitigated agency (characterised by reflection on self to the exclusion of others). Helgeson and Lepore hypothesised that unmitigated agency would be associated with poor adjustment, but agency would not; that unmitigated agency would be associated with problems in expressing emotion, but agency would not; and that problems in emotional expression would mediate the association of unmitigated agency to poor adjustment.

Measures included the agency (Cronbach's alpha = 0.69) and unmitigated agency (Cronbach's alpha = 0.75) scales from the Extended Version of the Personal Attributes Questionnaire; and the global quality of life instrument, the Health Status Questionnaire (HSQ) (Cronbach's alpha ranged from 0.62 – 0.91).

The results appeared to support the hypotheses. Adjustment was measured against the outcomes identified by the HSQ. On this basis, unmitigated agency was associated with poor adjustment for six of the eight HSQ domains, and also associated with the mental health composite score (MCS) ( $r = -0.37$ ;  $p < 0.001$ ). In contrast, agency was associated with better functioning for four of the eight HSQ domains, and significantly associated with the MCS ( $r = 0.21$ ;  $p < 0.05$ ). With respect to mediation, unmitigated agency was associated with greater problems in expressing emotion ( $r = -0.31$ ;  $p < 0.001$ ), and agency was associated with fewer problems expressing emotions ( $r = 0.27$ ;  $p < 0.001$ ). As such, the researchers concluded that comfort in expressing emotions could be considered as a mediator of both agency and unmitigated agency to adjustment.

Notwithstanding the limits of cross-sectional designs, this was an important study because it was able to link a cultural and social construct with adjustment to prostate cancer. Furthermore, the study linked gender attributes, in this case agency and unmitigated agency, with the emotional expressiveness of men, and with the effect of that expressiveness in the context of relationships. In this way, the study was also able to highlight the importance of emotional and communicative support for men (See also, Lepore & Helgeson, 1998).

However, the study was not designed to examine the contextual responsiveness of the masculinity construct, both in the moment and over time. Moreover, I would suggest that use of gender related traits implies a stability of the masculinity construct that is almost certainly inaccurate, supporting as it does an essentialist notion of masculinity (Wall & Kristjanson, in press). Therefore, a longitudinal study would have helped to clarify the changing nature of the masculinity attributes studied, and an interpretive component to the study would have assisted in understanding the nuances of the intricate interaction between masculinity and other contextual variables.

### *Social Coping*

Resource variables include the characteristics of an individual, or their environment, that become involved in the repair or maintenance of adjustment when confronted with difficult circumstances (Curbow & Somerfield, 1995). Social resource variables refer to those resources external to the individual. Therefore, the purpose of invoking either intrinsic or social resources is to facilitate or augment coping with, and adjustment to, the experience of prostate cancer and its treatment.

Ptacek et al. (2002) point out, quite correctly, that the dominant model of stress and coping, for 20 years, has been the transactional model put forward by Lazarus and Folkman (1984), and that psychosocial research has emphasised the individual rather than the social. In this context, the social appraisal or resource variables have contributed less to an understanding of coping and adjustment, perhaps because the social variables have contributed less to an understanding of individual differences. That is, the social and individual domains have remained relatively isolated from each other, at least with respect to psychosocial research (Ptacek et al., 2002), even though there has been some literature that has linked adjustment to social support (See for example, Greenglass, 1993; Schreurs & de Ridder, 1997; Thoits, 1986). Ptacek et al. suggest this paucity of literature may have resulted from the plurality of ways in which social support has been measured; a similar situation to my previous observations regarding the study of coping and distress.

On the other hand, the claimed paucity of literature does not apply to all cancer groups. Both Poole et al. (2001) and Ptacek et al. (2002) observe that the benefits of social support for women with breast cancer has been well represented in the literature. However, these authors further observe that the ways in which support, coping, and outcome processes operate in men with prostate cancer (Ptacek et al., 2002); and the



effects of support group attendance on outcomes for men with prostate cancer (Poole et al., 2001), are poorly understood. The importance of these observations are amplified by a study carried out by Roth et al. (1998), which revealed that a number of distressed men with prostate cancer remained undetected and untreated (emotionally) because (social) identification systems were not in place. Furthermore, Gray, Fitch, Davis, and Phillips (1997) identified that few support services were available to those men with prostate cancer who were experiencing anxiety, and that little support was provided during the process of making decisions about treatment. Both these studies suggest a poor understanding about the support needs of men with prostate cancer.

A recent cross-sectional survey (Steginga et al., 2001) examined the support needs of a group of men with prostate cancer ( $n = 206$ ), drawn from seven self-help groups. Steginga et al. used the Supportive Care Needs Survey (SCNS) (scale Cronbach's alpha ranged from 0.87 to 0.96), to identify areas of unmet (support) needs. Albeit that the study sample was a self-selected group, and the instrument was not prostate cancer specific, the results suggested that supportive care interventions were required in the areas of sexuality and psychological concerns, as well as the health system and information domain. The information domain included items relating to wanting more information about the disease, and its treatment and side-effects.

Of particular import to this thesis, Steginga et al. (2001) observed that the men in their study reported moderate to high unmet needs in the supportive care domains of sexuality and psychological concerns. Regarding sexuality, the authors identified changes in sexual relationships, feelings of loss of masculinity, and changes in sexual feelings, as the items of concern. The psychological items were fear about cancer returning, fear about the cancer spreading, and concerns about the worries of those close to the participants (Steginga et al., 2001).

These represent important exploratory findings, and help in highlighting the relationship between the construction of masculinity and sexual functioning. However, even though Steginga et al. (2001) refer their findings to Andersen's (1999) earlier observation that sexual self-concept is a predictor of sexual morbidity after cancer diagnosis and treatment, the study does not identify the nature of the help needed. Moreover, the cross-sectional design limits the usefulness of the findings because the men in the sample were between one month and five years since diagnosis ( $29\% < 1$  year and  $51\% \geq 1$  year and  $\leq 5$  years), and therefore represented a heterogeneous group

with respect to support needs. The study would have benefited from being longitudinal, and from examining the social support needs of the various groups at different points in the illness trajectory, especially at and from the point of diagnosis. Equally, the inclusion of qualitative data would have provided descriptive insights into the experience of support at different moments, and insights into the ways in which masculinity engaged progressively with the support experience.

In the context of gender differences, coping, and social support, Ptacek, Pierce, Ptacek, and Nogel (1999) point out that the cancer support literature has, by and large, focused on women with breast cancer. As a consequence, I would observe that the amount of support men seek has been measured against the amount of support women seek, even though such a comparison makes no allowance for gender differences or other contextual variables. That is, as social support is differentially valued by men and women (Ptacek, Pierce, Dodge, & Ptacek, 1997; Shye, Mullooly, Freeborn, & Pope, 1995), using the experience of one population (e.g. women with breast cancer) to compare or explain the behaviour of another population (e.g. men with prostate cancer) may be inappropriate.

For example, in a retrospective cross-sectional study ( $n = 57$  men and their wives; mean age of men = 72.4 years,  $SD = 5.12$  years) Ptacek, Pierce, Ptacek, and Nogel (1999) set out to examine how men remembered coping whilst they were undergoing treatment. The men had all received EBR for localised prostate cancer, and had completed treatment a mean time of 13.15 months earlier ( $SD = 7.59$  months). The authors predicted men who used problem-focused coping, and received social support, would report better adjustment and relationship satisfaction. Ptacek et al. used various measures of stress, coping, social support, relationship satisfaction, and psychological adjustment to identify the amount of convergence between men and their partners.

The results suggested men remembered experiencing moderate levels of stress, which they coped with by seeking support ( $\bar{X} = 11.53$ ;  $SD = 3.71$ ) and using problem-focused coping ( $\bar{X} = 24.13$ ;  $SD = 7.41$ ). Adjustment was measured using the Mental Health Inventory (MHI) and, when compared with the population mean on which the MHI was based ( $\bar{X} = 59.16$ ;  $SD = 12.16$ ), the sample mean was found to be higher ( $\bar{X} = 66.93$ ;  $SD = 8.27$ ). Ptacek et al. (1997) concluded that the group of men was well adjusted. However, with respect to convergence of perceptions between men and their

partners, the study failed to find agreement in either stress perceptions or coping strategy use.

Concerning gender, Ptacek et al. (1997) reported surprise in the amount of reliance the men in the study placed on support seeking given their gender. These authors explain the basis of their surprise in two ways. Firstly, they refer to previous literature (See for example, Ptacek, Smith, & Dodge, 1994; Ptacek, Smith, & Zanas, 1992) that suggests younger men emphasise problem-focussed coping strategies. Secondly, they point out that sex differences in coping have predominantly shown up in the context of support seeking; the research clearly exhibiting that women use more support seeking than men (See for example, Hobfoll, Dunahoo, Ben-Porath, & Monnier, 1994; Vingerhoets & Van Heck, 1990). Moreover, Ptacek et al. account for their finding on the basis of an age effect, and by suggesting that a shift towards greater support seeking may indicate a shift in sex-role orientation; that is, men adopting more traditionally feminine roles.

I would suggest that such an interpretation reflects a bias towards an essentialist view of gender (Sabo & Gordon, 1995); that is, a view of gender in which male and female roles are seen to derive from a set of fixed characteristics, unresponsive to local contexts. My sense is that such reasoning is faulty and detracts from the importance of understanding the individual characteristics of men that respond dynamically to changing contexts. Moreover, this reasoning diminishes the important finding that emotion-focused coping (especially self-blaming, wishful thinking, and avoidance) results in more distress. This observation reveals the limitations imposed by the cross-sectional nature of the study, and accentuates the importance of using ipsative qualitative data to provide insight into the individual and longitudinal response to prostate cancer.

### ***Conclusion – The Coping Response***

The studies reviewed have extended our understanding of the psychosocial variables beyond the identification of outcomes described by HRQoL research. Moreover, these studies, by considering relationships between appraisal and situational variables, have provided important evidence for the conceptualisation of coping as more than a simple response to prostate cancer and its treatment. However, a paucity of literature, and a variation in methodological approach, has not assisted in the development of a comprehensive and coherent understanding of coping as a process.

That is, the relevance of a process orientation has been insinuated but not well developed.

It is relevant, in this context, to note the limiting nature of the apparent dominance of the cross-sectional design in the psychosocial literature reviewed. It is also noted, however, that many of the studies cited in this section were ex post facto/correlational studies. As such, they are susceptible to a self-selection bias; suggesting some of the effects on the dependent variables of interest may be the result of pre-existing situational or individual differences. This suggests some of the associations identified in the above studies may be better explained in alternate ways.

Furthermore, even though Ptacek et al. (2002) have suggested that the theoretical approach described by Lazarus and Folkman (1984) has dominated coping research during the last 20 years, I would suggest that this model has not been utilised consistently in the development of the prostate cancer psychosocial coping literature. However, what has been consistent is the utilisation of standard measures of coping and distress.

I have made the point previously that the use of standard measures, within studies, has tended to limit our understanding of the coping response to that measured by the instrument or instruments used. Leventhal and Nerenz (1985) have identified that standard measures are useful only to the extent that they define and incorporate the major coping responses utilised in the situation being investigated. On the other hand, I would suggest that the ability to generalise the findings has been compromised by the number of different types and dimensions of coping utilised across studies using, for example, the same measure of coping or distress (Aldwin & Revenson, 1987; Endler & Parker, 1990). Furthermore, Lazarus and Folkman (1984) have pointed out that the use of traits or styles, in the context of investigating the coping response, underestimates the complexity and variability of coping responses observed in situ.

It would also be reasonable to observe that the limited number of quantitative studies that have examined coping and adjustment, in the context of prostate cancer, have tended to focus on the macro issues or main effect relationships. Such an approach has provided limited insight into the complexity of the relationships, between these main effect variables, that almost certainly drive the individual coping response.

In reviewing the literature associating psychosocial resources with the response to prostate cancer, it is relevant to observe that the samples studied have demonstrated heterogeneity with respect, for example, to the stage of the disease (TNM stage, as well as localised and advanced descriptors) and type of treatment. Moreover, it is not clear if findings from psychosocial resource studies based on other cancer groups generalise to men in the prostate cancer population in general (Fife, Kennedy, & Robinson, 1994; Thompson & Pitts, 1993; Walker et al., 1996), let alone to men with localised disease in particular.

It is also important to sound a note of caution when considering the relative contributions of these resource variables to outcomes that have been associated with prostate cancer, or coping, or adjustment, or psychosocial morbidity. That is, it is important to recognise that coping, adjustment, and (prostate) cancer are multifaceted, and that measurement must incorporate this idea when attempting to identify the relationships between them (Parle & Maguire, 1995).

Furthermore, a number of these studies continue to treat men with prostate cancer as a homogenous group, and fail to control for age effects, and disease stage, or changes over time. The effect of this is to compound the problems associated with cross-sectional studies. However, these studies do highlight those variables that begin to speak of individual differences and that mediate in some way between the disease process and coping outcomes. This point is important because, as Meyerowitz, Heinrich, and Schag (1983) suggest, cancer is not a single stressor but a number of different and difficult situations and problems. What this observation implies is that individuals cope with prostate cancer by responding to particular situations, rather than to prostate cancer as a global entity. Therefore, research that examines men's responses to individual situations, singly and in combination, and emphasises the complex and dynamic nature of the variables concerned, stands the best chance of revealing the coping response in a way that better reflects men's constructed realities. As such, there is a clear mandate for the inclusion of qualitative studies that are able to extend the findings of such research, by illuminating the contextual experiences and relationships that are played out in the process of the coping response.

### **Experiencing Localised Prostate Cancer**

The studies in the previous sections foreground those individual and social variables that moderate or shape the responding process, thereby limiting or enabling

individual responses to prostate cancer. However, what these studies are not designed to uncover or describe are the cultural, social, and individual contexts that shape and facilitate the possible ways of responding. As such, the possible limits of responding experienced by men (and their families) as they live with the disease process do not emerge. There is a sense in which the individual nature of responding potentially becomes obscured by an over-focus on either moderator variables defined by theory or empirical work, or by an emphasis on main effects. Therefore, although I agree with Mischell et al. (2003), who suggest that to understand the relationship between treatment, moderating characteristics, and outcomes, moderator variables must derive from theory or empirical findings; I would emphasise the importance of doing so based on empirical data derived from interpretive research.

My sense is that the role of the interpretive literature is to reveal the experience of men with prostate cancer, by allowing the words of individual men to speak, as it were, for them. It is also the role of the interpretive literature to take the quantitative literature and seek for the meanings of its findings in the context of these individual lives. Therefore, I would suggest, it is the purpose of the interpretive literature to transmute the contextual experience of some individuals into a form that may be understood by many individuals, and to do so in a way that preserves the integrity and dignity of the original. These ideas accepted, in this final section I review some of the interpretive literature that has described the experiences of men with prostate cancer in such a way. In the process of this review, it is my intention to elucidate the ability of the interpretive literature to assist in manifesting the lived realities of individuals, rather than necessarily to explore specific findings.

Heyman and Rosner (1996), in a cross-sectional descriptive study, set out to gain an understanding of prostate cancer and the meaning given to it by men with the disease and their partners (n = 20+20). More specifically, they wanted to know about their perceptions of the experience of prostate cancer, and the meaning ascribed to it. The researchers described two phases, an early phase involving diagnosis and treatment, and a later phase defined as living with the cancer and the effect of treatment. The issues described in the early phase appeared to relate to the impact of diagnosis and making treatment choices, a state described as emotional numbness in which men felt a loss of control, a feeling of vulnerability, and a sense of themselves as being victims. At this point, gathering information became very important but, as men felt immobilised, they relied heavily on their wives to ask the questions. Men appeared to experience vicarious

agency via this strategy. In addition, at this stage, men sought out health professionals who “cared”, and judged them on this basis. In the later phase, both men and their partners felt a loss of control over their lives, with feelings of loss of “manhood” in the men. These feelings generated an intense sense of loss and grief as the men struggled to cope.

In a similar study concerned with patients’ and partners’ coping and marital adjustment, Lavery and Clarke (1999) aimed to describe individual and interpersonal coping strategies adopted in response to appraisals of prostate cancer by men and their partners (n = 12+12), and the impact on marital relationships. Coping was described in two ways, individually and interpersonally. Individually, couples reported using diversionary tactics (allied to cognitive avoidance), work, life-style change, positive attitudes, stoic acceptance, religious faith, and information seeking. Interpersonally, couples used open communication, free expression of emotion, working as a team, and protective buffering. Generally, the reported coping strategies helped couples to accept the diagnosis.

Picking up on the gender theme, a descriptive longitudinal study (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000a) identified a growing body of evidence suggesting, in relation to health, that men may be disadvantaged as a function of gender. Their study aimed to describe the experiences associated with diagnosis and surgical treatment for men with prostate cancer and their spouses. The core category that emerged was named “Managing the Impact of Prostate Cancer”. This category emphasised the importance of control, and the playing out of agency, as a way of minimising the impact of the cancer and its treatment. Five major domains were identified: dealing with practicalities, stopping illness from interfering with everyday life, keeping relationships working, managing feelings, and making sense of it all. It appeared men worked hard to control their emotions and vulnerability. This was related to traditional hegemonic masculinity that places men in a psychological bind, preventing them from expressing emotion or seeking emotional support.

Expanding on the masculinity construct Gray, Fitch, Fergus, Mykhalovskiy, and Church (2002) used a narrative approach, in a longitudinal study (n = 18), to demonstrate the linkages between masculinity and the experience of prostate cancer. However, in their paper the authors presented the narratives of three men from the study who complied with the hegemonic masculinity profile (e.g. stoicism, enactment of

relations of domination, aggression, and competition etc.). The results identified that the men in the study defined their masculinity in a diametric way to that of the traditional female, depended on their partners entirely for support, and disclosed little to other men. However, the importance of this study, in the context of its narrative design, has to do with the manner in which it presented the narratives of the three men. Gray et al. (2002) clearly identified their intention to reveal what they called the “performances” of prostate cancer (See also, Gray, 2003; Gray, 2004) as a way of avoiding the reproduction of an essentialist perspective of masculinity.

In providing the performances of these three men, Gray et al. allow the lives and experiences of the three men to reveal the limiting nature of hegemonic masculinity, and the ways in which it restricts their coping efforts, for example, to the vicarious use of their partners in the coping process; a way of minimising the chances of revealing to the world that they are afraid or not strong enough to manage the emotional burden. Although Gray et al. identify the limits of their study with respect to generalisation, my sense is that the transferability potential more than accommodates for any perceived loss. Moreover, I am struck by one of their conclusions that suggests the responses of men to illness are influenced by their historical contexts; that is, by their lives and experiences prior to prostate cancer.

In a further paper (Gray et al., 2000b), using data obtained from the above study (Gray, Phillips, Labrecque, & Fergus; 2000a), the researchers considered the further dimension of information sharing; men’s decisions about sharing information (or not) with people other than their partner. What emerged was most of the time, most of the men in the study, wanted to avoid talking about their cancer (other than with their partner), and tried hard to control any anxiety they experienced. The data also suggested men were uncomfortable receiving support, especially emotional support. Men rarely acknowledged their vulnerability, and showed some fear of stigmatisation; especially related to death, sexuality, and pity.

Although the findings of Gray et al. (2000b) appear to contradict those of Ptacek et al. (1997) the longitudinal nature of the Gray et al. study helps to appreciate the strength of the interpretive study in illustrating the meaning of “most of the time”. That is, the interpretive study begins to expose the effect of context on the ways in which the men in the study differentially accepted or did not accept emotional support at different moments in time.



Boehmer and Clarke (2001) in a cross-sectional study using retrospective focus groups, looked into communication between men and their partner (n = 20+20), about prostate cancer. The partners observed that the men were able to talk about physical changes, but were not comfortable talking about feelings. Partners tended not to interject in case it caused problems or stirred things up. To this extent, there was reciprocal silence. On the other hand, the men said they were uncomfortable and embarrassed about the physical changes, and not comfortable talking about these feelings. As in other studies discussed above, men downplayed the impact of the prostate cancer and its treatment. As a response, the women colluded with this silence, a strategy described as protective buffering. The problems associated with cross-sectional studies notwithstanding, what this study reveals again is the complex nature of the relationships, and the dynamics of those relationships, as men and their partners attempt to traverse the prostate cancer experience.

### ***Conclusion – The Experience of Localised Prostate Cancer***

Methodologically, some of the studies described in this section have been cross-sectional in design and, as such, only describe the moment. Furthermore, some of these studies cross a range of treatment types, and different stages of disease, and may be hampered by a self-selection bias. It is also apparent that the samples chosen may not have been representative, missing out different cultural groups, and only including heterosexual relationships when discussing coping.

However, the above studies begin to describe the meanings associated with experiencing prostate cancer, and the ways in which men interpret their feeling states. Moreover, this work suggests that coping with prostate cancer may be limited by gender characteristics, and subject to a discourse of collusion that allows men to minimise the impact of the cancer and its treatment.

Nevertheless, the few studies reviewed here reflect two important limitations associated with the qualitative prostate cancer psychosocial literature. Firstly, they reflect the paucity of qualitative studies that have examined the experience of living with prostate cancer. Secondly, and perhaps more importantly, this review reveals the way in which the reporting of qualitative studies limits the quality of interpretation. That is, there is a sense in which the selective nature of reporting constrains the ability of the study to represent fairly the original experience and the contextual nature of responding to the prostate cancer experience. Even in my review of the narrative study, carried out

by Gray et al. (2002), I limit the power of the story because there is not the space to present the words of the participants, and allow them to represent the experience in the consciousness of the reader. This reporting limitation notwithstanding, there is no doubt that the studies reviewed begin to describe the categories of responding that are implicit to the experience, and infer relationships between people as opposed to those between variables. As such, this thesis intends to add to the paucity of the qualitative literature that describe the prostate cancer experience and, although still being selective in the experiences presented, will endeavour to maintain the integrity and dignity of the original experiences by including relevant exemplars from each man's narrative.

### **Conclusion**

Other than HRQoL, there is a dearth of literature examining the psychosocial experience of men with prostate cancer. Even though these studies appear to embrace the main aspects of responding and coping (viz. outcome measures, individual and social variables, and descriptions of experience etc.), there are a number of gaps in, and limitations to, the reviewed works.

Coping with prostate cancer has mostly been studied in a way that emphasises outcome measures such as quality of life or emotional functioning. A contemporary understanding of coping with prostate cancer is, therefore, not well informed by the individual process of meaning making, or by the affects of cultural schemata (such as gender) and social context. Indeed, apart from the study by Helgeson and Lepore, (1997) discussing the effect of agency and unmitigated agency, and a consideration of hegemonic masculinity by Gray et al. (2002), little has been said about the role of cultural and social schemata in the process of responding to prostate cancer.

This represents a significant gap in the literature because it fails to ask men what it is about being male that causes them to respond and cope as they do, especially as they often respond emotionally to prostate cancer in ways that are potentially harmful. This study aimed to add to an understanding of how men respond to prostate cancer by asking how they understood what was happening to them, what individual, family, and cultural factors shaped their responding and coping and, most importantly, how the individual process of meaning making informed the manner in which they responded as men.

## **CHAPTER THREE**

### **RESEARCH PARADIGM AND METHOD**

#### **Introduction**

I have entitled this chapter “Research Paradigm and Method” because I believe it is important to recognise from the outset, the language of constructivism. Guba and Lincoln (1994) identify a paradigm as a set of basic beliefs used to guide action, and include ontology, epistemology, and methodology under this rubric. I adopted the constructivist paradigm (Guba & Lincoln, 1989; Lincoln & Guba, 1985) as the guiding framework for this study because, in my role as researcher, it approximated with my world view and my understanding of the construction of social reality. Also, and concurrently, I judged the constructivist paradigm to be congruent with the aims of this study.

It was therefore important to identify an inquiry paradigm that provided a way of accessing and describing the constructions of men, and the contextual complexity of their moment-to-moment experiences and relationships as they engaged, from within their lifeworlds, with prostate cancer and its treatment. It was equally important to involve an investigative paradigm that privileged the voices of the participants, while concomitantly recognising my human presence as the investigator and role as the instrument for data collection and interpretation. The constructivist paradigm met these requirements. Indeed, Harris (1992) clearly suggests the constructivist paradigm is suitable for exploring lived experiences situated in complex social contexts.

In this chapter, I describe the constructivist paradigm, its ontology, epistemology, and methodology. More particularly, however, I am interested in outlining the development of this constructivist study with respect to using the methodology suggested by the constructivist paradigm, and described by Guba and Lincoln (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985).

#### **The Constructivist Paradigm**

The constructivist paradigm represents a set of beliefs that guides disciplined inquiry (Guba, 1990). The beliefs relayed by an inquiry paradigm, are described based on its proponents’ responses to three basic questions; questions characterised as

ontological (what is the nature of reality?), epistemological (what is the relation between the knower and the known?), and methodological (how should knowledge be gathered?). Answers to these basic questions represent the givens that define what constructivist (or any) inquiry is and how it should be practiced (Guba, 1990). But Guba recognises that paradigms are the product of human constructions, and therefore exposed to the same defects characteristic of all human enterprise. Stringer (1996, p. 41) clarifies the meaning of the term constructions, by describing them as “created realities” or “sense-making representations”.

In constructivism, the basic beliefs that form the constructivist paradigm, the beliefs that arise from the three basic questions, have been produced in response to the perceived failings of positivism (and post-positivism). The constructivists (see for example, Guba, 1990; Guba & Lincoln, 1994; Lincoln & Guba, 1985) believe that positivism (and post-positivism) is flawed in four main areas. The first identified flaw concerns the theory ladenness of facts. The constructivists suggest that positivism (and post-positivism) do not accept that facts are only facts in the context of the theory that defines them, and are therefore not independent of such a framework. The second flaw refers to the under-determination of theory. The constructivists argue that no theory can ever be fully tested because of the problem of induction. That is, the existence of many potential theories to explain a single event limits the possibility of unequivocal explanation. The third flaw is linked to the value ladenness of facts. This area of concern is based on the premise that it is not possible for inquiry to be value-free. So, if it is only possible to view reality through the lens of theory, it is equally only possible to see reality through the lens of value. Thus, many constructions of reality are possible. The final flaw concerns the interactive nature of the inquirer and inquired-into dyad. That is, without objectivity the outcomes of inquiry are always a product of an interaction between the inquirer and the inquired-into. These ideas establish knowledge as a human construction, and make any distinction between ontology and epistemology obsolete.

If these responses to positivism (and post-positivism) are framed in the context of the nature of paradigms, and considered under the ontological, epistemological and methodological rubric, then the concerns expressed by the constructivists start to give shape and meaning to a constructivist paradigm. Although, as mentioned above, constructivists have essentially combined ontology and epistemology, the tripartite organisation will be retained in this thesis for the sake of clarity and completeness. The

ontology, epistemology, and methodology of the constructivist paradigm will briefly be discussed.

### ***Constructivist Ontology***

Ontology, as a branch of philosophy, is concerned with the nature of existence and being (Guba & Lincoln, 1989). The ontological question concerning scientific inquiry asks about the nature and form of reality, and what can be known about it (Guba & Lincoln, 1994). Constructivist ontology takes a pluralist and relativist position, which assumes that realities exist in the form of multiple mental constructions (Guba, 1990) produced by the individuals and groups that hold them. These constructions, in being socially and experientially situated, can change according to context and over time, and can therefore give rise to new realities (Guba & Lincoln, 1994).

Given multiple constructions of reality, the potential for constructions to conflict is high, even though each construction is potentially meaningful (Schwandt, 1994). However, the constructivists believe that constructions do not hold any absolute truth value, but are momentarily more or less true, according to the prevailing level of consensus about which construction is most sophisticated or best-informed at the time (Guba & Lincoln, 1994; Schwandt, 1994). Therefore, in this sense, truth and reality are relative to the socio-historical context (Schwandt, 1994). However, with precise clarity, Guba and Lincoln (1981) suggest it is the interrelatedness of multiple realities that form patterns of “truth”, and it is these patterns that the process of inquiry seeks to understand.

### ***Constructivist Epistemology***

Guba and Lincoln (1994) advise that the answer to the epistemological question is necessarily constrained by the ontological position adopted. Even so, the epistemological question seeks to understand the relationship between the knower and the known. The constructivist inquiry paradigm adopts a transactional and subjectivist epistemology (Guba, 1990; Guba & Lincoln, 1981, 1994). That is, a transactional relationship is established, between the inquirer and the participant(s), that provides for a process of joint construction in which the findings of any inquiry are mutually created (Schwandt, 1994). However, constructions are subjective and reside nowhere other than in the minds of individuals (Guba & Lincoln, 1989). Therefore, even though the subject(s) of inquiry are socio-historically situated, so too is the inquirer, and together they form a new socio-historical context in which an inquiry relationship is transacted.

As such, my sense is that it is in the complex intermental process of mutual construction that consensus is achieved, and that the distinction between ontology and epistemology disappears (Guba & Lincoln, 1994).

### ***Constructivist Methodology***

The constructivist methodology, as a way of finding out what can be known, is hermeneutic and dialectic (Guba, 1990). It is relevant to point out that, because of the subjective nature of mental constructions, it is necessary for an inquirer to engage in an intermental, and therefore social, process to elicit the constructions of participants (Guba & Lincoln, 1994; Schwandt, 1994). Furthermore, it is only through such an intermental process that the elicited constructions can be iteratively analysed and refined, so as to obtain a joint construction of reality that achieves consensus. This iterative process is hermeneutic in character because it has an interpretive emphasis; and is dialectic because it compares and contrasts one construction against another, so as to achieve consensus and a synthesis of the elicited constructions (Erlandson, Harris, Skipper, & Allen, 1993). The conclusive pragmatic criterion for this iterative methodology is that it facilitates progress towards a more sophisticated understanding of social reality (Guba & Lincoln, 1989).

### **The Constructivist Methodological Process**

The purpose of this section is to outline the practical flow, or development, of the methodology with respect to this study. With regard to the particular methodological specifications identified by Guba and Lincoln (Guba & Lincoln, 1989; Lincoln & Guba, 1985), this section will discuss the entry conditions and the hermeneutic-dialectic process.

### ***Entry Conditions***

There is a set of four specifications, or entry conditions, which must be met if a study is to be considered meaningful in the context of the constructivist inquiry paradigm. Firstly, constructivist inquiry is required to take place in the natural setting because of the relationship between context and meaning. Secondly, the inquiry instrument must be human because such an instrument is capable of responding and adapting to indeterminate contexts, and able to identify what is important in the emic views of participants. Thirdly, to facilitate an emergent design, and to respond dialectically to constructions in context, the human instrument must be able to access

and use tacit knowledge. Finally, because the instrument is human, the most appropriate methods to use are qualitative (Guba & Lincoln, 1989; Lincoln & Guba, 1985). The nature of these entry conditions, in the context of this study, will now be discussed.

### *The Natural Setting*

In calling for inquiry to be situated in the “natural” setting, Lincoln and Guba (1985) make the point that any event (or phenomenon) under investigation will always take as much meaning from its context as it does from itself. That is, how reality is constructed, and what it is constructed to be, cannot be separated from the environment within which it is experienced (and investigated). Therefore, reality constructions are time and context dependent (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985).

In the context of this study, the natural setting represented the homes of the eight individual men and, to that extent, the places in those homes where we sat and talked about their experience of prostate cancer. Therefore, the geographical context for these men was represented by the places where they lived, the rooms they walked through, the objects of material culture with which they surrounded themselves, and the neighbourhoods within which their homes were situated, and through which they moved. Even though all these men lived in houses, there was nothing that might be described as common about their physical environments. That is, each man constructed his physical environment in a way that reflected the social mores of his society, the embedded values of his culture, and the practical, aesthetic, and idiosyncratic inclinations of the individual, or individuals, contained within, and by, the physical space.

Each man lived in the context of a family, and an extended family. Most of the men in this study lived with at least one member of their immediate family, biological or blended; one participant did not, being separated from his wife. Therefore, the natural setting for most men also consisted of the day-to-day interaction that forms communal living: the verbal exchanges of communication, the atmospheres that shape the nature of that communication, and the implicit rules that contain all behaviours. Within these contexts, each man was affected by the complex relationships defined by the hopes and dreams, the personalities and temperaments, and the established roles of each individual as they interacted within the physical and cultural space of the family. Moreover, all these contexts shifted with time, becoming variously more or less complex, and

variously more or less imperative to the stability of the space within which the family resided.

As the men sat and talked with me in their natural setting, they sat in familiar chairs, chairs from which they almost certainly had watched members of their family, and the family itself, begin and develop, grow and learn, fight and laugh, leave and return. From the vantage of their chairs, they could be contained within the familiar histories of their lives, and the cohesiveness and continuity of their relationships, variously stable and unstable, which had developed and survived, or ended, within their sight. Each man's space contained him, and each man contained his space.

However, for the men in the study, their natural setting was further defined, or maybe infiltrated, by the added context of a prostate cancer diagnosis. That is, the prostate cancer became superimposed upon, and eventually merged with, the natural setting. To that extent, the natural setting became unusually disrupted and, to varying degrees, uncertain. I was reminded, as I talked with the men, that it was the human response of projecting onto their environment that contributed towards the instability of family systems, causing them to become disrupted and less safe. Therefore, for a time at least, the natural setting became a context in which the uncertainties of a cancer diagnosis were acted out in the family space, or the empty space, in the absence of the family. In this time shifted natural setting, the space was filled with talk of disease, of surgery, of radiation, of things not done, and of possible death. Contemplation of journeys to make, plans for retirement, and business yet to complete, took the place of everyday events and filled the family space, forcing out the sounds and feelings of "normality". Another time shift and the natural setting took on a more familiar feel as the treatment phase passed and the men who received treatment began to assimilate the changes. Therefore, the natural setting was also a resilient space, a buffering space, a normalising space, an adaptable space, and a space that managed to contain the worst of times.

Consequently, in calling for inquiry to be situated in the natural setting, my sense is that the constructivist inquiry paradigm presents, and is presented with, a challenge to emphasise the longitudinal dimension of inquiry. To do otherwise would be to miss, and misunderstand, the time shifts that create a state of contextual flux. Moreover, there is also a sense in which only describing the natural setting in the context of the physical or geographic features of an environment, seriously limits the



potential for understanding the in situ experience. That is, there is no *a priori* sense in which a setting can be known before it is experienced and, in experiencing it, the natural setting is changed. These observations bring into focus the nature of the researcher as instrument, which will now be discussed.

### ***The Researcher as Instrument***

The previous section foregrounds the indeterminate and complex nature of the natural setting. In the context of such indeterminacy, constructivism claims that the researcher represents the instrument of choice for constructivist inquiry (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985). One of the reasons for this directive relates to an idea about the responsiveness of the researcher-as-instrument. That is, the researcher is perceived as being able to respond to, and make sense of, the many cues contained in the natural setting. More than this, however, the researcher is believed to be able to identify meaningful boundaries so as to render the field of study explicit and, presumably, contained.

The adaptability of the researcher-as-instrument is also seen to be important. As such, the researcher, even given a context of human imperfection, is viewed as being able to adapt infinitely to changes in cues, levels of meaning, and situational nuances. Moreover, the researcher's ability to extract what is meaningful from an interaction and to summarise it meaningfully in the moment, provides for immediate feedback, clarification, and amplification. Indeed, constructivists identify this as "processual immediacy" (Lincoln & Guba, 1985, p. 194), defining it as the ability to process and use information in situ.

Other important features of the researcher-as-instrument include the ability to view situations and events as complex wholes, the ability to operate with both propositional and tacit knowledge, and the capability to recognise and explore the idiosyncratic (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985).

Although I have no doubt about the relevance and importance, and indeed accuracy, of these observations, and their place in substantiating the role of the researcher-as-instrument, I would like to add a few thoughts about subjectivity and investigator effects. In particular, I would like to mention the idea of constructed meaning. There is a sense in which the researcher takes on the responsibility for recognising, in any researcher-participant interaction, that one of the functions of

narrative is the divination of meaning, as a way of making sense of experience. Though this may be obvious, what is less obvious is that the construction of meaning occurs in the inter-subjective space between the participant and the researcher as both instrument and other human subject (Rapley, 2004). Therefore, even though it is not the function of the researcher-participant dyad to generate a therapeutic space, there is a sense in which a transitional space may be created that provides for the telling, and retelling, of stories that are neither entirely objective nor entirely subjective (Day Sclater, 1998).

It is not the role of the researcher-as-instrument to manipulate such a transitional space, but it is the role of the researcher to recognise his/her contribution to both the function, and creative nature, of such a space. In so doing, I believe it becomes possible for the researcher to avoid the problem of re-framing joint constructions in ways that patronise the participant. Therefore, I would add to the useful features of the researcher-as-instrument the ability of, and need for, the researcher to work with the structure of the story and not the inner world of the participant (Rapley, 2004), even though the inner world of both human subjects inevitably informs the construction of meaning.

There is a sense in which some investigator effects might be eradicated if it were possible to reveal all that is known about the investigator, a simple process of subtraction leaving the participant's experience and meaning in stark relief. Of course, this is not possible. Indeed, Fergus, Gray, Fitch, Labrecque, and Phillips (2002) wisely advise that researchers cannot escape the human state of being reflexive, culture bound individuals interpreting a self-interpreting participant. Patton (2002), however, believes that part of the credibility of the qualitative researcher-as-instrument relies on revealing information about him or herself. Although I entirely agree with the principle of surfacing the relevant, I am not sure, for example, how revealing that this study grew out of my experience as a Counsellor, adds to my credibility as a researcher. Allowing that such information provides the reader with some sense of my motivation for undertaking the study, it says little about how my particular presence played itself out in the context of the study. On the other hand, with respect to equalising power relations, it was important that I identified to each participant my background as a Counsellor, and emphasised that there was no therapeutic intent associated with the interviews.

With respect to my particular human presence in the natural setting, however, there was indeed a sense in which I had the capacity to affect the context and quality of the inter-subjective space, and therefore the process of data collection and co-

construction. In this regard I agree with Holstein and Gubrium (2004) who argue that (social) participants co-produce the context they inhabit, by way of their interaction. I also agree with Drew and Heritage (1992) who emphasise that context is locally produced, incrementally developed, and transformable at any moment. As such, I made an effort to establish the foundations for co-construction by normalising my presence, by spending time at the start of each interview building a common context. I achieved this by dressing casually, by using first names, by spending time sharing recent experiences or news, by sharing humour and laughter, and by following the participant as he gradually moved towards and into the telling of his story.

More generally, the above ideas emphasise the importance of the trustworthiness of the researcher-as-instrument. Lincoln and Guba (1985) clearly identify that the trustworthiness of the researcher-as-instrument is equally as assessable as a paper-and-pencil instrument, and just as capable of refinement given appropriate supervision. Therefore, in the context of the trustworthiness of this study, it is relevant to acknowledge that, as a Counsellor, I had a great deal of experience interviewing individuals in the context of the therapeutic alliance. However, it was important for me to recognise the difference between addressing issues of the inner world and using the structure of the story in the process of data collection, analysis, and interpretation. As such, it was important to review the transcripts of my interviews with participants and with my supervisor to ensure that my interviewing technique, and the content obtained, remained trustworthy and methodologically appropriate.

### ***Tacit Knowledge***

Constructivists believe it is appropriate to acknowledge the role of tacit knowledge in the research process. In referring to tacit knowledge, Guba and Lincoln (1989) suggest it to be those things that we know but are unable to articulate, and differentiate it from propositional knowledge, which are the things we know and can articulate. In their understanding of tacit knowledge, Guba and Lincoln follow Polanyi (1967) who also suggests, and perhaps more meaningfully for the constructivist endeavour, that we already know tacitly the things we seek to learn (Polanyi, 1967, p. 22-23). However, my sense is that tacit knowledge depends on experience, that is, on some form of experiential interaction with the kind of reality being investigated, even if only tangentially or from within a similar class of experience. Therefore, all investigators use tacit knowledge. What is most relevant for the constructivist, however, is the idea that the human instrument is capable of accessing and processing tacit

knowledge in situ, and of using it, *a posteriori*, to develop and communicate propositional knowledge. This phenomenon has been well described with respect, for example, to the reflective practitioner (Schon, 1987).

In the context of this study, it would be incorrect to assume that tacit knowledge was the same as forgotten knowledge, or knowledge that was remembered but not used, rather like the difference between the spoken and written lexicon. It would also be incorrect to assume congruence between tacit knowledge and the type of clinical or research experience that is available in propositional form, or between tacit knowledge and attitudes or biases, and so on. Therefore, little would be gained by acknowledging my biases; or my previous clinical and research experience; or what I know about prostate cancer and the prostate cancer experience; at least not in the context of tacit knowledge. That is, tacit knowledge is not available to me until I know it to be relevant-in-use and, if it were available *a priori*, it would no longer be tacit. What is relevant, however, is that I acknowledge the importance of tacit knowledge, accept it as an entry criterion for constructivist research, and remain open to its emergence-in-action.

### ***Qualitative Methods***

Qualitative methods of inquiry are identified as being the most appropriate for constructivist research (Guba & Lincoln, 1989; Lincoln & Guba, 1985). Appleton and King (1997) suggest that methods refer to specific data collection and analysis techniques. The constructivists clearly make the point, however, that the preference for qualitative methods is in no way anti-quantitative, but rather is because qualitative methods better approximate “normal” human communicative activities (eg. looking, speaking, and listening) (Lincoln & Guba, 1985). The data collection method used in this study was in-depth individual interviewing, and is discussed below in the section detailing the data collection process.

### ***The Hermeneutic-Dialectic Process***

Achieving the entry specifications represents the end of the first phase, and leads the inquirer into a second phase described by Guba and Lincoln (1989) as the hermeneutic-dialectic process. The purpose of the hermeneutic-dialectic process is to identify the constructions held by participants (Koch, 1994). The process consists of four continuously interacting components: purposive sampling, the continuous interplay of data collection and analysis, the grounding of the findings in the data, and the refinement of the design (Guba & Lincoln, 1989).

The value of such a process lies in its ability to explore and compare contrasting constructions, held by the same or different individuals, and to use the information gained in the development of constructions that are consensus driven. That is, the hermeneutic-dialectic process is equally valuable when analysing and re-analysing an individual transcript, or similar themes in transcripts belonging to different individuals. It is in this way that the process enables the elicitation of increasingly sophisticated joint constructions. In the following sections, the application of the hermeneutic-dialectic process in this study is discussed.

### ***Purposive Sampling***

The sample population for this study was comprised of men diagnosed with localised prostate cancer. Men were invited to participate in the study on the basis of the following criteria:

1. The participants spoke English.
2. The participants had received a diagnosis of localised prostate cancer within four weeks prior to their recruitment to the study. Four weeks was chosen as a timeframe to capture participants who were considering treatment options.
3. The participants were from either metropolitan or country areas of Western Australia.
4. The participants' ages were between 40 and 85 years. This age range was chosen in an effort to capture a wide age range of individuals; given the reported variations in the age related disease and treatment trajectories.
5. The participants were willing, and agreed, to be involved in the research process.

According to Patton (2002) the purpose of sampling in qualitative research is to expedite in-depth understanding, rather than empirical generalisation. Denzin and Lincoln (2000), on the other hand, more generally make it understood that decisions about sampling in qualitative research are conditional on the inquiry paradigm, on the research design, and on the required sampling unit (e.g. case or process). As such, Denzin and Lincoln argue that, although each case or process will always exhibit

features of the general class of case or process they belong to, no two cases or processes will ever be the same. For these reasons, so these authors suggest, many qualitative researchers choose purposive sampling methods, and seek out settings, groups, or individuals where, and for whom, the processes they are interested in are likely to be found (Denzin & Lincoln, 2000). Therefore, for these reasons, and because Guba and Lincoln (1989) identify maximum variation purposive sampling (Patton, 2002) as the sampling method of choice for a constructivist study, such an approach was adopted for this study.

Although Guba and Lincoln (1989) also advocate that samples should be selected serially, (that is, data collection with the next participant should not commence before data collection with the previous participant is essentially completed) and be selected contingently, (that is, the next participant interviewed should reflect the in-the-moment needs of the study), this was not possible. The men in this study were recruited as they presented to an urologist for the diagnosis of localised prostate cancer, and subsequently entered the biopsy-diagnosis-treatment-recovery trajectory; this process was not controllable. Therefore, men were contacted soon after they were recruited, and interviewed on four occasions as they traversed their first post-diagnostic year. Maximum variance in the sample was achieved by recruiting men of different ages, from both rural and metropolitan areas, who received a range of different treatments or no treatment at all.

### ***Participant Recruitment.***

Participants were recruited through two metropolitan based urologists, and one country based urologist. I met with each of the urologists to discuss the purpose of the study, to describe the recruitment procedure, and to seek their help in recruiting men to the study. All three urologists agreed to talk with those men they considered to be appropriate for the study and, for those who matched the selection criteria, provide them with an information sheet (Appendix One). The urologists further agreed to seek permission from the men to communicate their telephone numbers to me. All the men selected by the urologists agreed to me contacting them.

I subsequently contacted each of the men referred to the study, and briefly explained the aim of the study and who I was. I then arranged to meet with each individual in his home to discuss the nature and scope of the study, outline the consent process and its meaning, and answer any questions that might arise. This meeting also

afforded me an opportunity to discuss my background and clarify, as mentioned above, that the purpose of the interviews would not be to provide counselling. Issues of confidentiality were discussed and the point clearly made that men could withdraw from the study at any time without let or hindrance. Prior to leaving at the end of this introductory meeting, I gave each man a second copy of the information sheet, a copy of the consent form (Appendix Two), and a demographic questionnaire (Appendix Three) that would enable me to describe the study sample. I afforded each man a period of one week to consider my request and to discuss the study with his family if he wished. To facilitate the provision of further information, should questions arise, I provided my telephone details and encouraged men to contact me. Participants were recruited in this way, over a period of nine months, as they were referred by the urologists.

Of the 12 men referred to the study by the urologists, eight agreed to participate. Of the four men who did not participate, one man was diagnosed with advanced prostate cancer and therefore did not match the study criterion of localised prostate cancer. Two men had agreed to participate when asked by their urologists, but subsequently recanted their decisions for undisclosed reasons. The fourth man was unable to participate because of the acute onset of a severe cerebrovascular accident.

Of the eight men who did participate, each man was interviewed on four separate occasions. Ideally, recruiting would have continued until saturation of the data was achieved. However, the realities of recruiting for this study meant that I was restricted by the rate and number of referrals from the urologists. Nevertheless, the longitudinal nature of the study, and the use of multiple unstructured interviews, provided an appropriate range, depth, and quantity of emic data about men's responses to localised prostate cancer and its treatment.

### ***Profile of Participants.***

Eight men diagnosed with localised prostate cancer participated in this study; their demographic characteristics are shown at Table 2. The youngest man in the study was 48 years old, married with four children (two living at home), and employed full-time. The oldest man in the study was 76 years old, married with three children, retired, and living in the same house he had occupied for more than 45 years. All but one man lived with a partner, and all but two men lived in the metropolitan area.

Table 2

*Demographic Details of Participants*

Pseudonym	Age (years)	Marital status	Highest level of education	Support group member	Treatment
Gerry	48	Married	Year 12 High School	No	Radical Prostatectomy and Neo-Adjuvant Therapy
Dixon	54	Married	Trade or TAFE*	No	Radical Prostatectomy
Robert	57	Married	Year 10 High School	No	Radical Prostatectomy
Winston	61	Married	University - diploma or degree	No	No Treatment (Own Choice)
Cecil	70	Married	Trade or TAFE*	No	Radiotherapy and Neo-Adjuvant Therapy
Otto	70	Married	Trade or TAFE*	No	Radiotherapy and Neo-Adjuvant Therapy
Richard	70	Separated	Completed Primary School	No	Radiotherapy and Neo-Adjuvant Therapy
Herbert	77	Married	Trade or TAFE*	No	Hormone Ablation Therapy

\**Technical and Further Education (TAFE)*

***Collection of Data***

As previously identified, data were collected by the researcher using in-depth, unstructured individual interviews. According to Lincoln and Guba (1985) the use of the unstructured interview is of most value when the researcher is unsure about what he/she is wanting to discover. Given such a context, and the exploratory nature of this study, unstructured interviews were considered to be most appropriate.

However, in describing the unstructured interview, Fontana and Frey (1994) suggest it provides an attempt to understand the complex nature of human (social)



behaviour without limiting discovery by imposing pre-determined categories. The operative phrase in this statement is “an attempt to understand”. I was very clear, in interviewing participants, that even though I had not imposed *a priori* categories, I was going to impose unconscious categories as a consequence of my role as researcher *qua* human. That is, I was attempting to understand the constructions of the participants through unconscious, and situational, filters that would inevitably affect both the data I collected and the way in which it would be interpreted. Albeit that Marcus and Fischer (1986) view such a situation with concern, I agree with Jack Douglas (1985) who suggests that unstructured interviews take place in the everyday world of real people. As such, I would suggest, meaning is always constructed in a context of intersubjective difference that, far from being confounding, is one of the processes that drives understanding. Furthermore, I also agree with Rapley (2004), who suggests that interviewing does not incorporate extraordinary skill, but rather is a straightforward process in which one individual, *qua* human, interacts with another individual, *qua* human, so as to understand his or her experiences, opinions, and ideas.

Practically, the interviews were recorded using a small digital recorder that was unobtrusive, and which was quickly accepted by the participants. I interviewed each man on four separate occasions, at approximately three month intervals, during their first post-diagnostic year. The duration of each interview varied from 45 minutes to two and half hours. Although I was able to undertake an initial interview with most of the men who received treatment ( $n = 7$ ), prior to its commencement, I was unable to interview one man for the first time until two weeks after he had received a radical prostatectomy.

Participants were interviewed, on each of the four occasions, in their homes. I have talked above about the natural setting, and of context, and of the researcher as instrument. Here I refer to the more practical aspects of approaching the interviews in situ. In line with Lincoln and Guba's (1985) thinking about interviewing, I explained again to each participant the nature of the study and the purpose for which the collected data would be used, and repeated this rubric on the occasion of each interview. I reminded each man that I would treat all data with absolute confidentiality. I also sought permission, on each occasion, to carry out the interview, and gave the participant an opportunity to clarify or ask questions about any issues from previous interviews. I was cognisant at the time of each interview, that discussing the experience of prostate cancer represented a potentially difficult addition to the disease and treatment burden.

However, while I did not set out to generate a cathartic response, nor did I attempt to avoid strong emotion or difficult feelings, especially in the contexts of relationships and sexuality; this position being commensurate with my earlier comments about the inter-subjective space.

The early interviews were focussed on establishing an investigative alliance. That is, I was concerned to provide each man with a sense that what he had to say was of value, and that I had the capacity to try and understand his experience in his context, with his help. This process entailed making interpretive mistakes, and in seeking clarification on a number of different levels, from the practical (what did it look like?) to the emotional (what did it feel like?). My emphasis, however, was on helping each man to tell (reproduce) his evolving story, which necessarily entailed the re-visiting of information obtained in earlier interviews, in an effort to clarify particular events. In the process of re-visiting earlier experiences, it was possible to establish a sense of continuity between the experience and the feelings generated, a psychodynamic link, so-to-speak, which allowed each man to describe his constructions in a way that approximately incorporated the original experiential context. Moreover, revisiting earlier material assisted in maintaining the trustworthiness of the study.

### ***Management of Data***

The data from this study consisted of interview transcripts and, to a lesser extent, fieldnotes that were written following the completion of each interview. The digitally recorded interviews were transcribed, verbatim, as soon after the interview as possible. Most transcripts were transcribed by me as the researcher, but approximately 25% of the transcripts were transcribed by a professional transcriber. These interviews were checked for accuracy, by the researcher, against the original digital recordings. All the data were entered into ©QSR N6, which was used to store, and analyse the non-numerical and unstructured data generated by the study. Demographic details were stored in a secure and encrypted database.

### ***Continuous Interplay of Data Collection and Analysis***

I identified above the difficulties experienced in this study with achieving serial and contingent sampling. This approach to sampling logically supports the second and third elements of the hermeneutic-dialectic process (the continuous interplay of data collection and analysis, and the grounding of the emergent findings in the constructions of the participants). Therefore, even though it was not possible to apply the second and

third elements in the step-wise manner originally described by Guba and Lincoln (1989), it was possible to apply the essence of the principles implied.

I would observe that data collection and analysis continued to be messy and indeterminate until late in the study's trajectory. Data collection and analysis did not proceed in a linear manner, and therefore it is difficult to describe the process in such a way. Guba and Lincoln (1989) depict the process as starting with a single participant, and a general question about the nature of the issues, with the expectation that the participant will reveal matters of importance. Such matters are subsequently tested against the next participant, and so on, with the expectation that joint constructions will emerge out of the data. The process, of course, depends on the immediate analysis of the current interview prior to interviewing the next participant.

I accept that all retrospection tends towards simplifying the process and context of action, and hence it is always difficult to obtain a sense of the complexity of interaction between different constructions-in-use. However, I was aware, during each interview, other than the first, of at least four sets of data that reflexively engaged in the inter-subjective space between the participant, and me as the researcher. One set represented my lifeworld, another represented the lifeworld of the participant, and yet another was the selected and imported remnants of the lifeworld, or lifeworlds, of the previous participant/s. The final set represented the immediate co-constructed narrative, developed in a co-constructed context, using all the aforementioned data. It was in the midst of such complexity that a synthesis occurred between disparate constructions of the prostate cancer experience, which provided the data for analysis (Erlandson et al., 1993; Guba & Lincoln, 1989; Lincoln & Guba, 1985; Schwandt, 1994).

Therefore, data analysis occurred between the participant and researcher during the interviews, and between the researcher and the data (the transcripts and the emergent categories) following the interviews. Moreover, as the study proceeded, data analysis moved back and forward between the past, in the context of prior transcripts and different participants, and the present. Hence, data were always situated in a socio-historical context that informed interpretation.

Analysis of the data was facilitated through the use of the method of constant comparison described by Glaser (1978), Glaser and Strauss (1967), and operationally refined by Lincoln and Guba (1985). As such, each transcript was read line by line, and units of meaning identified (Unitising) and coded as free nodes in ©QSR N6. As data

collection proceeded, and the number of transcripts increased, units of meaning (free nodes) were coded onto major categories of meaning (Categorising), and identified as tree nodes in <sup>©</sup>QSR N6. These unrefined categories were subsequently presented to other participants as promising constructions, for validation and clarification.

This process of data analysis continued following the completion of data collection, with the method of constant comparison continuing to facilitate the emergence of increasingly inclusive constructions that were grounded in the experiences of all the participants. That is, all the categories (tree nodes) were re-examined and memos written that identified rules for inclusion. In this way, units contained in some categories were merged with other categories, which became major categories; and other categories were subsumed by these major categories, therefore creating sub-categories. The aim, in refining these categories, was to maximise both internal homogeneity, and external heterogeneity (Lincoln & Guba, 1985). Furthermore, the process of moving backwards and forwards between the data and the identified categories, and the rules that defined the categories, was an iterative process. As such it continued into the writing of the thesis when, in organising the prostate cancer experience into a coherent whole, the process of writing revealed inconsistencies in the data and new relationships not previously identified. Indeed, I believe it was not until I began to write the analysis chapters that I was properly able to appreciate the constructions of the men in the study as they responded to the prostate cancer experience.

I am aware that constructivists (Erlandson et al., 1993; Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985) apply the concept of consensus to constructions, and I have indicated tacit agreement with this concept in other parts of this thesis. However, my sense is that the achievement of joint constructions is a far more subtle and intricate process than the word “consensus” implies, and a far more nebulous process than simply following a “method” suggests. What I believe the analysis chapters reflect, apart from my interpretation supported by the words of participants, is the presence of a sub-text that refers to a tacit process of human understanding. This process, I suggest, is less about consensus and more about the sharing of a common experience. Therefore, I am sure that the point at which I chose to write the analysis had something to do with the practicalities of the study, and with redundancy of data. However, the decision to write the analysis also had much to do with a tacit understanding that this was the right

moment to present this interpretation about how men reconstructed their lifeworlds during the first post-diagnostic year.

### ***Emergent Design***

This final element of the hermeneutic-dialectic process is based on the premise that the researcher starts out with a lack of clarity about what it is he/she should know, but seeks to refine the study design as and when clarity improves (Lincoln & Guba, 1985). In this sense, the design emerges as data are collected, and joint constructions are refined, as a consequence of multiple iterations of the hermeneutic-dialectic process.

Much of what constitutes the emergent design of this study has been described in previous sections. However, to summarise, within this study prolonged engagement in the field, and the unstructured nature of the interviews, helped me to become aware of the issues and experiences shared by the men in the study. In the process of becoming aware, and in the process of better understanding the contexts of their experiences and my investigation, it became possible to discover the appropriate questions to ask. That is, these strategies provided me with a context, an emerging framework within which to think about the experiences and constructions described by the men in the study. Equally, the continuous interplay between sampling and analysis, and the grounding of the findings in the data, helped me to identify and consolidate appropriate constructions that meaningfully captured, and delineated, the responses of men to the prostate cancer experience.

### **Leaving the Field**

Leaving the field was a gradual process that was staggered according to the different points at which data collection ended with each participant. However, by the time data collection finished, I had known each man for a period exceeding one year, and had spent a total period of time in the field of some 21 months. More importantly, I had spent many hours in the men's homes, accepting their hospitality and trust, as I inquired into deeply personal experiences that potentially left them exposed and vulnerable. Nevertheless, we all had known from the outset of the study that the end of data collection would mark the end of our time together.

Therefore, leaving the field progressed naturally enough into the next phase of the study, and did not manifest in any traumatic consequences for any of us. I believe it is important to make this point because even though, as previously identified, we did not

operate on the basis of a therapeutic relationship, there were various times when the inter-subjective space took on a transitional form that helped to contain moments of fear and uncertainty. It was important for me to thank the men for their trust, honesty, and courage, to allow them to summarise the journey they had made as a form of closure, and to make sure they had my contact details in the event of any future questions.

### **Ethical Issues**

Prior to the commencement of this study, ethics approval was obtained from the Edith Cowan University Human Research Ethics Committee. This section describes the general strategies that were used to safeguard the rights of the individual men who participated in this study, with particular emphasis being given to informed consent and confidentiality.

Informed consent, according to Ryen (2004), means that research participants have the right to know they are being researched, the right to know the nature of the research, and the right to withdraw from the research at any time. In this study, all participants were provided with a written information sheet (Appendix One), detailing the nature of the study, prior to obtaining a written and signed consent (Appendix Two). However, it is important to reiterate that due to the emergent design of this study oral consent was sought before each interview. Participants did not gain directly from their participation in the study, although the possible future benefits to others were identified. Participants were not remunerated, involvement in the study being strictly voluntary, and the men were advised they could withdraw at any time without consequence. If the men became concerned or upset during the interviews, the researcher elicited consent to continue the interview before progressing.

Confidentiality, the protection of the participants' identities and personal information, was established as an imperative from the outset of the study. Each participant was given a pseudonym, used in all transcripts and this thesis, as well as a code number that was allocated as the file name for encrypted files containing the digital recordings and original interview transcripts. The researcher was the only person to know the password for the encrypted files and the identities of the participants. All paper-based materials, such as transcripts and other print-outs, were kept in a locked filing cabinet in the researcher's office. All this material will be securely stored in this way for a period of five years, at which time it will be destroyed unless still required. Regarding individuals mentioned by participants, when referring to a physician the

name was replaced with the designation “doctor” or “urologist”, and the names of family members of the participants were replaced with generic terms such as “wife”, “daughter”, or “son”.

### **The Quality of Inquiry**

Within the context of constructivism three approaches are identified that demonstrate the quality of a constructivist inquiry: trustworthiness, the nature of the hermeneutic process, and authenticity (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985). This section examines these approaches and describes how they were applied in the context of this study. However, in approaching this section of the thesis, I feel obligated to identify my agreement with Reid and Gough’s (2000) position regarding evaluative criteria. That is, Reid and Gough disagree with the value of applying criteria used to evaluate quantitative research, to qualitative research, based on the premise that both sets of criteria are analogous, or parallel one-another. Reid and Gough further suggest that the commensurability of these two sets of criteria should be contested (See also, Emden & Sandelowski, 1998).

#### ***Trustworthiness***

The conventional (positivist) criteria for judging the rigour of inquiry include internal validity, external validity, reliability and objectivity (Guba & Lincoln, 1981). Koch (1996), however, suggests the issue of rigour (reliability and validity) in qualitative research has persisted as the hegemonic patrimony of the positivist paradigm. Even so, Koch further identifies that while there is no consensus about the idea of rigour (in qualitative research) (See also, Popay, Rogers, & Williams, 1998), it is nevertheless imperative to ensure that knowledge derived from study findings are trustworthy and believable (Koch, 1996).

The trustworthiness of a constructivist inquiry is based on four components, believed to parallel the rigour criteria described by the conventional paradigm. These components are credibility, transferability, dependability, and confirmability (Guba, 1981; Guba & Lincoln, 1989; Lincoln & Guba, 1985). Recognising these components, I have previously identified that this study essentially complied with the methodology described by Lincoln and Guba (1985). However, I am mindful of the advice offered by Koch (1996), who suggests the inquirer is responsible for selecting or developing appropriate criteria for their study, and the reader is responsible for deciding if the study

is believable. Given these important ideas, this section examines the trustworthiness criteria as used in this study.

### ***Credibility***

Credibility references the size of the match (a subjective judgement) between the constructions of study participants and those identified, in the findings of the study, as belonging to the participants. Guba and Lincoln (1989) identify a number of techniques they believe assist in achieving credibility: prolonged engagement; persistent observation; peer debriefing; negative case analysis; progressive subjectivity; and member checks.

#### ***Prolonged Engagement and Persistent Observation.***

The idea of prolonged engagement suggests that substantial involvement at the inquiry site assists in preventing distortion, misinformation, and presented facades, while also facilitating rapport, trust, and the understanding of context (Guba & Lincoln, 1989). Moreover, persistent observation is said to assist in revealing the constructions of participants in a detailed and contextual manner. That is, persistent observation adds depth to the scope obtained by prolonged engagement (Guba & Lincoln, 1989).

Within the context of this study, I spent a varying period of time with the participants in their homes, on each of four occasions over the period of one year. In this sense, I can report the use of prolonged engagement and persistent observation. As such, and to the extent that I was able to establish an investigative alliance with each participant, I was able to access his emotional and experiential world. Therefore, I was able to reveal, or co-construct, a number of constructions that provided meaning to the participants' experiences of prostate cancer. However, I would suggest that my continuing ability to be aware of the ontological and epistemological givens, located in the investigative alliance, was perhaps of more relevance than either prolonged engagement or persistent observation *per se*. That is, I would suggest that distortions, misinformation, and facades are indigenous to the contextual inter-subjective space, and therefore highly relevant, rather than being confounding artefacts of investigation to be converted or somehow transmuted into "understanding".

#### ***Peer Debriefing.***

Given the emergent design of this study, peer debriefing constituted an important and valuable approach to facilitating trustworthiness (via credibility).



However, I interpreted peer debriefing as a process of supervision, that is, as an interpersonal interaction, between my supervisors and me, which aimed to improve my effectiveness in the process of inquiry. As such, it was possible to parallel the intersubjective space between the participants and me, and therefore to have my emerging analyses of the participants' constructions challenged. In this sense, I must also recognise the unconscious supervision provided by the participants, who constantly contributed feedback that helped to correct or affirm my understanding of their constructions in situ. This process of checking, between my supervisors and me, was not confined to the analysis of data. Checking also helped to clarify the emerging design of the study; to reveal the value judgements I imposed on the data and its analysis; and to monitor the coherence between the participants' transcripts and the constructions developed in this thesis.

### *Negative Case Analysis.*

Negative case analysis aims to reveal alternative interpretations of the data, especially where they refute the researcher's reconstructions of reality (Erlandson et al., 1993). Therefore, the fundamental purpose of negative case analysis is to safeguard the achievement of joint constructions, which represent the patterns in the data, by identifying and eliminating the exceptions to these patterns (Lincoln & Guba, 1985; Patton, 2002). Also, according to Patton (2002), credibility is achieved in reporting negative cases because such reporting acts to indicate that the researcher is not analytically predisposed to a particular interpretation.

In the context of constructivist ontology, as mentioned previously, multiple mental constructions are produced by the individuals (or groups) that hold them, and are momentarily more or less true according to the prevailing consensus about which constructions are best-informed or most sophisticated. Also, these socially and experientially situated constructions can change according to context and over time, and therefore can give rise to new realities. To this extent, the process of negative case analysis appears to be supported by constructivist ontology.

However, I am concerned that negative case analysis may in fact be no more than a tautology for a process that usually occurs when using the method of constant comparison. That is, I would suggest that the iterative process of analytic induction, used during data analysis, enables the development of constructions that become increasingly sophisticated, inclusive, and consensual as analysis proceeds. Therefore, I

did not set out with any deliberate intent to discover negative cases. Rather, I set out to privilege the range of constructions that described the responses of a particular group of men to the prostate cancer experience, in a particular socio-historical context. In so doing, I was trying to acknowledge that “truth” is indeed temporary and context bound.

### ***Progressive Subjectivity.***

According to Guba and Lincoln (1989), progressive subjectivity represents a process that monitors the researcher’s developing constructions, to ensure that the emerging constructions are jointly produced. Guba and Lincoln emphasise that the researcher’s constructions must not be privileged over those of the participants. The process depends on the researcher recording his or her constructions prior to any engagement with participants (i.e. expectations of findings etc.). The process further involves periodic debriefing, in which a debriefer checks that the researcher is paying attention to the developing constructions of participants.

Even though I fully agree with the importance of debriefing, and used this process with the assistance of my supervisors throughout data collection, data analysis, and in the writing of this thesis, I disagree with the logic of revealing prior constructions. My concerns, premised on an assumed benign investigative alliance, are these. In the course of discovering the constructions of participants, an iterative inter-subjective process, the researcher’s constructions are only privileged over those of the participant in-the-moment, but the participant’s constructions are privileged in the next moment, and so on. This must be so, otherwise the progressive resolution of perceptual differences, and the achievement of joint constructions, is impossible. Therefore, the constructions of the researcher, prior to engaging in such an inter-subjective process, become immediately obsolete the moment the first iteration is completed because of the nature of joint (re)construction.

### ***Member Checking.***

Member checking, according to the constructivists, represents the most important technique for determining credibility (Guba & Lincoln, 1989; Lincoln & Guba, 1985). These authors believe that member checking provides the most certain test in verifying the multiple constructions presented by the study participants, and further believe that it should occur continuously throughout the process of the study, both formally and informally.

However, Koch and Harrington (1998) suggest that nurses have adopted the parallel criteria (Lincoln & Guba, 1985) for assessing the trustworthiness of qualitative studies somewhat uncritically, and point to member checking as an example of this uncritical adoption of a rule based approach. Furthermore, there is an argument put forward by some qualitative researchers suggesting rigour should be driven by epistemology rather than by methodology (Avis, 1995; Koch & Harrington, 1998; Schwandt, 1996), a move that would surface, and privilege, the political and moral imperatives of inquiry (Schwandt, 1996). Epistemologically, the constructivist inquiry paradigm adopts a transactional and subjectivist position (Guba, 1990; Guba & Lincoln, 1981, 1994), suggesting that the findings of studies are transacted through a mutual process of construction.

In practice, what was jointly constructed, and partially analysed, was the interview data, which was subsequently (meta-)analysed to form the constructions synthesised from that data. As such, I was able to assess formatively my understanding of constructions, in situ and in-use, by offering punctuating summaries of the dialogue between participants and me, throughout the course of each interview. Moreover, I was able to test the accuracy of many of these synthesised constructions, retrospectively, during the course of subsequent interviews with other participants without, of course, revealing their sources. So, up to that point, it was possible to apply the methodological rule of member checking.

However, there was a point at which the individual constructions of the participants became subsumed by the synthesised categories (See, Koch & Harrington, 1998), as a result of the process of data analysis used. Therefore, other than the direct quotes used to support the analysis, it would have been difficult for participants to identify their own constructions. At that point, what I believe became more relevant than direct member checking was the mutuality of construction, and the inter-subjective relationships I had established with the participants. That is, simply put, I believe that the participants trusted me, as research-instrument, as other human subject, and as joint constructor, to represent “our” constructions honestly, and authentically. My sense is that it was in this way that I was able to exercise what Blumenfeld-Jones (1995) refers to as “fidelity” (See also, Sandelowski, 1993), which, I would suggest, begins to address the issue of the moral imperative suggested by Schwandt (1996).

### ***Transferability***

The constructivists use the criteria of transferability to establish the extent to which the findings of a study might apply in contexts that vary from that of the study. To this extent, the judgement of transferability rests with the reader of the study making contextual comparisons, in order to establish the degree of similarity between what Lincoln and Guba (1985) refer to as the sending and receiving contexts. The responsibility of the researcher is to provide a “thick description”, or sufficient descriptive data (Guba & Lincoln, 1989; Lincoln & Guba, 1985), to facilitate such a judgement of transferability.

Regarding this study, description of the natural setting and the participants, as well as the research process, has provided an “open window” through which to observe and consider the context of this inquiry. Most importantly, however, the inclusion of the participants own words, as supporting evidence for constructions, provides a means by which the reader, and potential transferrer, can vicariously experience the lifeworlds of the participants. My sense is that it is only through this interactive process of immersion that the reader can move beyond perceived facts, and into the experiential context of the participant’s world, where a judgement of transferability becomes possible.

### ***Dependability and Confirmability***

Dependability refers to the stability of the data over time (Guba & Lincoln, 1989). According to Erlandson et al. (1993) dependability is conferred if the findings of a study can be replicated with the same (or similar) participants, in the same (or similar) context. Confirmability, on the other hand, is about judging if an inquiry is the product of the realities conveyed by its participants, and not the biases of the inquirer (Erlandson et al., 1993). That is, confirmability is assured when the data, analysis, and findings of a study are seen to derive from the contexts of the participants and not the imagination of the inquirer (Guba & Lincoln, 1989). Erlandson et al. (1993) qualify this description of confirmability by adding that constructivists are not concerned if observations are contaminated by the inquirer, as they place their trust in the confirmability of the data. By this they mean the ability to track data, and the logic used to produce interpretations, back to their sources (Guba & Lincoln, 1989).

To the extent that dependability and confirmability are possible, or even desirable in the context of a qualitative study, then both have been demonstrated throughout this thesis, by a clear description of the methodology. Moreover, a clear

audit trail has been left linking the process, and logic, by which constructions were identified during the analysis, with their original data sources.

### *The Hermeneutic Process*

The hermeneutic process has been well described in the context of the above discussion regarding the hermeneutic-dialectic process. However, Guba and Lincoln (1989) suggest that the hermeneutic process acts as its own quality control, thereby limiting the opportunities for undetected error. It has been suggested above that the mitigation of error is achieved through the constant interplay between data collection and analysis. Indeed, Guba and Lincoln suggest that the biases and prejudices of the inquirer can virtually be negated, provided hermeneutic and dialectic principles are upheld. I do not entirely agree with this assumption. Notwithstanding the negative connotations attached to phrases such as “biases” and “prejudices”, I observe that it is probably neither appropriate, nor possible, to rule out the constructions of any study participant, including those of the inquirer. To be blunt, I would suggest that such background constructions form an integral part of the context of inquiry, and should be surfaced rather than hidden or eradicated by methodology.

### *Authenticity Criteria*

The authenticity criteria described by Guba and Lincoln (1989) appear to be a reaction, in the first instance, to the parallel criteria, with their positivist origins, and to their methodological focus. Guba and Lincoln's concern is that the parallel criteria, with their emphasis on methodology, may not privilege the rights of participants, by which they mean that participant constructions may not be faithfully collected or represented. Guba and Lincoln's second reaction concerns the hermeneutic process, which, they suggest, remains implicit and therefore not persuasive to those wanting to see explicit evidence of quality. Therefore, in addition to the criteria of trustworthiness and the hermeneutic process, Lincoln and Guba believe that the authenticity criteria of fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity should be considered.

Although I fully agree with the development of quality criteria commensurate with the ontology, epistemology, and methodology of any inquiry paradigm, I believe that the authenticity criteria, at least in the context of this study, were problematic for two reasons. First, the constructivist paradigm contains no reference to action, at least not in the transformative or dialogic sense of, say, critical theory. While I recognise that

the conclusive pragmatic criterion for constructivism is that it facilitates progress towards a more sophisticated understanding of social reality (Guba & Lincoln, 1989), a more sophisticated understanding does not presume action (or change), *ipso facto*. Yet, catalytic and tactical authenticities refer directly to empowerment and explicit action. Second, there is some evidence that the authenticity criteria were added as a result of earlier criticism of constructivist methodology (See, Guba & Lincoln, 1989, p. 245), and then applied to the specific case of fourth generation evaluation. Because there is a clear sense in which the logic of evaluation research presumes action (to induce change), it follows that the catalytic and tactical authenticity criteria apply absolutely. Equally, however, given the formative and non-transformative nature of this study, the catalytic and tactical authenticity criteria do not apply.

In the context of this study, the remaining authenticity criteria (fairness, ontological authenticity, and educative authenticity) do apply, in some measure. However, I would suggest that the methodology, ethical issues, and trustworthiness criteria described in this thesis have adequately addressed the potential concerns suggested by these remaining authenticity criteria, and I will therefore not describe them again here. Nevertheless, in fairness to the participants I would add that the process of investigation did contribute to the sophistication of their self-understanding (ontological authenticity) and to their understanding of other men (educative authenticity), as they responded to the experience of prostate cancer.

### **Limitations**

Even though I have a vested interest in declaring the relevance of the constructivist inquiry paradigm in the context of this study, I also have some responsibility to consider its limitations. More generally, I would observe that the relativist ontology privileges a contextual view of the experiential realities of participants. As such, it becomes difficult to present a properly “thick” description, as so much understanding is embodied in the contextual and experiential nature of mutual construction, which is difficult to access. Although I am sure this process represents lived reality, and adds to tacit knowledge; what might be more explicitly privileged are the contexts of inquiry and experience, and how these constructs mutually shape the meaning of experiences, and act as bridges between experiences, over time.

More specifically, I would observe that the sampling method acted to restrict the range of participants because of an over-reliance on recruiting participants through

urologists. Therefore, even though I was able to include one participant who adopted an “alternative” therapies approach to treatment, this was a chance event; and I was not able to include any men from other cultural groups (e.g. men of colour, indigenous men, or men in homosexual relationships). This approach to sampling also limited the sample size because of the prolonged period of time it took to recruit eight participants. Nevertheless, even though the sample size was small, I am hopeful that the depth of analysis that follows will allow the reader to make an adequate judgement regarding transferability.

### **Conclusion**

This chapter has outlined the constructivist inquiry paradigm, its ontology, epistemology, and methodology, as described by Lincoln and Guba (Guba, 1990; Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985). I have tried to describe the methodological process as clearly, and honestly, as possible because it provides access to the methodological decisions that underpin the quality of this study. In the process of doing so, I have also tried to demonstrate the aspects of the methodology that did not comply with the intentions or process of this study. Moreover, I have tried to acknowledge that ontology and epistemology are not “sacred cows”, but rather are social constructions that should be open to review, especially given the context of an emergent design and the reciprocity involved in construction. Nevertheless, regardless of the imperfect nature of inquiry and reporting, I am confident that the following chapters will provide a useful window into the lived experience of men as they respond to the prostate cancer experience, in an effort to reconstruct their lifeworlds during their first post-diagnostic year. As such, I am hopeful that this study will help to reduce the paucity of information about a very important life event in the lived experiences of men.

## **CHAPTER FOUR**

### **RESPONDING TO THE PERI-DIAGNOSTIC EXPERIENCE**

#### **Introduction**

For men, a diagnosis of prostate cancer is commonly a serendipitous experience. For all but one man in this study the initial consultation with their GPs occurred either for reasons unrelated to prostate cancer, or because the man had recently heard about prostate cancer and the PSA test from a secondary source. Only one man in this study had been tested yearly from the age of 50 years; and none of the men were aware of the controversy surrounding the PSA test, or screening for prostate cancer, until after they received a diagnosis of prostate cancer.

Most of the men were consequently unprepared for the possibility of prostate cancer, let alone a positive biopsy and the ensuing discussion about treatment and its sequelae. Nevertheless, the men in the study were ultimately presented with a prostate cancer diagnosis and expected to make informed and appropriate decisions about treatment, even though there was (and is) little clarity in the literature about the effectiveness and efficacy of treatments (Selley, Donovan, Faulkner, Coast, & Gillatt, 1997). Paradoxically, given the relative suddenness of diagnosis, there was little direct evidence of the emotional turbulence reported in those receiving a prostate cancer diagnosis (Roos, 2003).

Therefore, at least as they experienced the period surrounding the prostate cancer diagnosis (the peri-diagnostic experience), the men in this study found themselves separated from what had very recently been a stable, predictable, and familiar environment. Within this context of instability and uncertainty, each man was presented with an imperative to reconstruct his lifeworld.

Given this context of reconstruction it is relevant to observe that a diagnosis of prostate cancer represented an experience that was essentially meaningless, and therefore an experience that could not easily be contained within the boundaries of each individual man's lifeworld. My sense is that the meaninglessness of the prostate cancer experience generated a context of uncertainty, even though the men in this study did not necessarily identify or describe the experience in such a way.



Nevertheless, there was an early and pressing need for the men in this study to respond to the cancer in a way that would absorb the immediate impact of the prostate cancer diagnosis and the uncertainty it generated. Therefore, the work of the men in this study was to reconstruct their lifeworlds so as to re-contain safely the experience of prostate cancer, thereby converting the meaningless into the meaningful.

However, the process of achieving a contained and meaningful experience did not demonstrate a linear trajectory. In interpreting the experience of men responding to prostate cancer I am aware that I have done more than observe or report a simple sequence of events that follows the chronology of the original experience. Indeed, I would observe that the nature of analysis and interpretation acts to disconnect the experience from its original form, if not from its original context. This disconnection notwithstanding, what I am putting forward is a portrayal of many different moments from the experiences of the men in this study. This portrayal will provide both the essence of the experience and its context; enough for readers to be able to construct their own vicarious experience of responding to prostate cancer.

### **Responding to the Prostate Cancer Diagnosis**

Responding to the prostate cancer diagnosis describes the immediate concrete and abstract tasks carried out by the men in this study. Each man responded exigently; converting his immediate cognitive and emotional experiences into a form able to be contained by the social, cultural, and personal realities of his lifeworld – a response to the immediacy of diagnosis.

### ***Seeking a Diagnosis***

For most men in the study seeking a diagnosis comprised of little more (at least superficially) than a series of practical assessment procedures, a process devoid of emotional content. The practical nature of the diagnostic process was paralleled by the absence of emotional reactivity, and the matter of fact way in which men described seeking a diagnosis and attending the GP's surgery.

[It] was only through my in-laws that I thought just have a check-up, and I spoke to a few of my other friends and they said their doctors had been doing a bit as a normal course, you know you go for the six month or annual check-up and they do various tests sort of thing, and PSA is one of them. Well my doctor hadn't done one and, that's why I thought well, knowing about my in-law [who had been diagnosed with prostate cancer], I thought well have it done, see what's ... if anything's there sort of thing, and sure enough there was. (Cecil)

On the other hand, Herbert, the 77-year-old, had seen an urologist four years earlier when his PSA level was considered to be above the normal range. He had been told to do nothing, “The doctor I was going to at the time said it was better just to leave it.” (Herbert), and therefore he did not have a biopsy to confirm a diagnosis. Herbert followed the advice given by his GP, and continued to do so even in the context of persistent uncertainty. He had known for some time that his PSA level was significantly raised, he wondered if he had prostate cancer, but he chose not to act.

It was always in the back of my mind that I probably had it [prostate cancer] ... and [I] always thought I should do something about it but ... (Herbert)

Only one man in the study, Robert, had monitored his PSA level over a prolonged period of time, not because of a commitment to the early detection of prostate cancer *per se* but because of a prior diagnosis of post traumatic stress disorder (PTSD). For Robert the decision to seek a diagnosis was pre-determined by the PTSD; it was imperative to prevent uncertainty from occurring in his life.

It's been the last five years that I've had an annual check-up um and also I want to maintain fitness level; initially um I had blood pressure cholesterols, and my PSA was 4.5ng/ml. The doctor was quite- wasn't concerned about it he said it's probably at the maximum for that age but we'll monitor it each year unless you have some problems, because at that stage he'd done a digital examination, and he'd done a scan over the bladder and at that stage I think he said the prostrate (sic) was about 5cm, the diagnosis came back from the radiotherapy bloke who done it that said there was a slight bit of um calcification on one side but other than that it was normal; so for the next year we went and done the tests it was still 4.5ng/ml. The following year again 4.5ng/ml; last year it was 4.6ng/ml, I go in this year and it had gone from 4.6ng/ml to 5.6ng/ml. He still wasn't concerned nor had I any symptoms whatsoever um I did have a problem in relation to starting urinating but I put that down to my stress because if I could go away on my own I could urinate as strong as anyone, um but once I started I was quite good; that was about the only symptom I had um so he was aware of that I was aware of that, he said look I'll- because it's risen one I'll send you to the specialist and we'll eliminate- find out early if it's cancer, he didn't think it was but he said we'll eliminate it, so that was when uh the decision was made to go and see the urologist. (Robert)

Another man, Dixon, went to see his GP because of problems with nocturia (passing water at night), at which point the GP suggested measuring the man's PSA level. There was no reference, direct or otherwise, to seeing the GP because of concerns about prostate cancer; he went because of urinary symptoms.

For as long as I can remember I had what I maintained to be a Japanese bladder, you know 4 o'clock at night going to the toilet and I lived with that for years and years and just from there because of my age that- I decided to have a PSA test, that was from my local GP here; he said because of the age perhaps we should have a look at the PSA, it came back a little bit high, I waited again and confirmed the readings and then we decided perhaps it was time I went to a urologist and he also mentioned at the time that because of it, the frequent urinating that there are tablets out there and I'm on some tablets now. They're called Flowmax and they're just great, and I've never ever slept through the night before for years and years and I've just found them excellent, and so it's only from there on that uh the urologist- and had a biopsy I think was some time in April, it may have been earlier than that, and it came back localised prostate cancer. (Dixon)

Similarly, Gerry visited his GP because of a gastro-intestinal problem. During the consultation the GP decided to carry out a digital rectal examination (DRE) for prostate cancer, even though Gerry had not intended to seek advice regarding prostate cancer.

I went to the GP because I had a crook stomach and I didn't know what was wrong with it; in the end he didn't know what was wrong with it either, but um he had to do- he said I've got to check your back-passage, I said OK, this is for my stomach, he said while I'm there you're of the age that prostate cancer is a possibility we'll do that as well (...) (Gerry)

Another man, Richard, who did have some knowledge about prostate cancer because his wife was a retired nurse, sought the advice of his doctor because of symptoms of benign prostatic hyperplasia (BPH). He did not visit the doctor because he was concerned about prostate cancer. Indeed, a diagnosis of prostate cancer was made on the basis of the histo-pathology of the tissue excised during a trans-urethral resection of his prostate (TURP).

(...) I was in trouble because I couldn't, couldn't pass water. I was getting rid of 25ml maybe 30, pain, burn, and as I said to my wife and you know it's going to hurt, you hold it back and that's what I was doing. And she said, "Well we'd better have the operation." From that, that was in March I didn't find out about the pathology report until when I went and saw [the doctor] late into April and he said, "You've got problems." He said, "I apologise, I've got to tell you you've got cancer," and that's, that's where it had all stemmed from. But just those two trips in the night in Carnarvon to the toilet and I noticed that as the time went on I was progressing more and more to the toilet but not voiding properly. (Richard)

Otto, a 70-year-old participant, whose wife was also a retired nurse, went to see his GP simply because his wife had insisted that it was time for him to have a check-up. He went feeling well and experiencing no symptoms of any kind.

It was my wife, she said that I had not been to the doctor for some time and it's about time I had a check-up so ultimately I gave in and along I went. The first test that the GP ordered was the blood test and I think it was within a week after the blood test he rang me up advising that he possibly might like to see me, so I went down and saw him and he mentioned that the PSA showed some higher readings than normal and perhaps I ought to be referred to a urologist, which I did and of course that- after I saw the urologist he in turn advised me to have a needle biopsy carried out, which was done, I think it was on 23 October any way a week after on the 29th was when I had to see the urologist again and then he had the results and he said "yep here it is" and that's how it [a diagnosis of prostate cancer] came about. (Otto)

One more participant, Winston, a 61-year-old man, also visited his GP with no particular issues in mind. He sought advice from his GP because he believed he had reached an age where he should be more generally aware about his health.

Well I went to him because I thought it was time to go and visit a GP who was specifically engaged in matters of men's behaviour and health. When I went there I didn't see myself with any problems (...) I went there on the basis that I felt that men should be more alerted to this time in their age, as women are (...) (Winston)

Therefore, for all the men in this study, the point at which a diagnosis of prostate cancer was sought or obtained had little or nothing to do with responding to concerns about, or symptoms of, prostate cancer. That is, for the men in this study, seeking and receiving a diagnosis of prostate cancer was essentially unrelated to prostate cancer. Instead, the diagnosis of prostate cancer was insidious; that is, it came about by way of men responding to an alteration in an unrelated component of their lives; such as the need to attend to nocturia, disturbed sleep, general health concerns, maintaining relationships, or the need to prevent the exacerbation of PTSD. Prostate cancer remained silent; it made no direct contribution to the "if and when" of men seeking a diagnosis.

### ***Responding Emotionally to the Diagnosis***

Perhaps because of the insidious way in which the prostate cancer became a reality in the lives of these men, only one man in the study acknowledged feeling a high level of stress following the diagnosis. However, Herbert, the 77-year-old, had

postponed confirming the prostate cancer diagnosis for four years following his original PSA test. It was therefore difficult to know how much of his reported stress was due to the diagnosis, and how much was due to the stress added by his procrastination.

Nevertheless, Herbert's reported level of stress was not evidenced by his observed emotional state, or by his affect. I mention this, because none of the men in the study, when talking about feelings, demonstrated any noticeable change in affect or emotion.

David: And so when you got that diagnosis [of prostate cancer] what was happening was [that] you actually were feeling quite stressed and –

Herbert: Oh, very stressed ... I became very stressed the time between being told I had prostate cancer to ... when I had the bone scan, until after I had the bone scan (...) (Herbert)

All of the men in this study were hesitant about revealing their feelings towards the diagnosis of prostate cancer and the treatment discussed with the urologist, or else they disavowed any feelings of concern and uncertainty. That is, I was left with the impression that men were minimising their feelings about prostate cancer, by controlling both their affect and emotion.

It [the diagnosis of prostate cancer] wasn't anything startling because I had read previously, not that I had any personal involvement in it but previously I had uh heard people say and talk that once you reach a certain age level it's not uncommon to have this condition (...) (Otto)

When there was a response, it was most commonly reported as shock (although I did not see any behavioural evidence of this); men not understanding what prostate cancer meant or how it had come about. Herbert described the shock using the metaphor of being shot between the eyes.

(...) [Being told you have prostate cancer] ... it's like somebody in the war gets bloody shot right between the eyes and they think oh shit, it would never happen to me ... but it has ... (Herbert)

The shock was coupled with a kind of cognitive amazement; men reflecting upon their more recent, or sometimes chronic, health state and observing that there had been no indications, no warnings from their bodies, that something was amiss.

David: Going back to the very beginning when you were first diagnosed with prostate cancer, what was your reaction to the diagnosis?

Cecil: Well, **a little bit of shock**, you know, because I've been feeling fit and ... I know I've got diabetes and I've had it for five years now, but apart from that I didn't think there was anything wrong with me. (Cecil) [Emphasis added]

Cecil's response to the prostate cancer demonstrated a kind of minimising or attenuation of feelings when compared with his earlier response to his wife's diagnosis of bowel cancer.

[My] wife, she had bowel cancer, that comes **as a terrific shock** sort of thing. Fortunately they got it all out and there was no need for chemotherapy or radiotherapy or anything like that afterwards (...) (Cecil) [Emphasis added]

However, the feeling of shock did incorporate, as already observed, a reflection on men's previous health states and experience. Gerry also included a judgement about magnitude, prostate cancer classified as being of major importance. Interestingly, given this "major" classification, there was no demonstration of emotion.

I was pretty shocked [when I received the diagnosis]... we hadn't- well sorry tell a lie, I hadn't expected it um- I suppose I've had my normal run of the odd diseases during my life but I've never had anything major (...) (Gerry)

For the participant with PTSD there was no reported emotional response to the prostate cancer diagnosis, and I observed none in the retelling. However, what Robert described was acute hyper-vigilance, as he began a desperate search for questions and practical strategies that would keep his disavowed anxiety at bay.

(...) [It's] the strangest thing, I mean I'll never forget the urologist when he said to the wife that you know [I had cancer], because she mentioned that she had some growths or whatever herself in the womb or wherever and uh he just said to her this is cancer! that sort of stunned her (...) to me once he mentioned the word cancer my mind starts working, it just clicks on ... cancer right, now how am I going to deal with this. (...) No I'm not listening no I've, it's probably like I'm locking it into me (sic) brain to say that cancer, what do I know about it, what do I need to know about it, um all that runs through me in seconds. You know, am I going to die you know is it going to kill me is it, how bad's it going to be, the whole lot will go through me in three seconds, it will go that fast my brain, my brain would go whoosh, it would go whoosh. (Robert)

The opposite of this response was demonstrated by Winston who, although feeling inquisitive about the prostate cancer, as opposed to anxious, also identified a

dreamlike feeling, as if the cancer and the experience were not real. This experience may be interpreted as a reflection of the cancer's silence, providing this man with no tangible markers to which he could respond.

[Initially] I was quite relaxed I didn't feel as though there was an issue because I felt good in myself and I didn't have any symptoms that I could express as being umm ... my feelings were to go about my business, and to stay switched into a positive frame of mind, I didn't think for any of those times that, that umm I was anxious, I felt more like umm inquisitive about it; that was the first; inquisitive yup yup, (...) it was a little bit like a little bit of a dream in way, it was sort of like not quite fitting in. (Winston)

The early feelings expressed, or unexpressed, by men were important in the context of their attempts to begin revealing the prostate cancer, and in understanding the experience they now found themselves contained by. However, the generally muted nature of men's emotional responses provided little information about the feeling states generated by the diagnosis of prostate cancer. In this muted context, men were attempting to take their first tentative steps into an experience that was inscrutable, armed with very few affective templates with which to engage with this potentially life threatening disease.

### ***Revealing the Prostate Cancer***

Given the muted emotional response to the prostate cancer diagnosis, it is perhaps not surprising to observe that, at least initially, prostate cancer held no meaning for men, and could not do so for as long as it remained silent and camouflaged. As one man pointed out, prostate cancer is "(...) an insidious sort of thing that you can't see, [not] like [you can see] a boil, it's not there." (Herbert). Confronted with silence, the men in this study appeared to experience difficulties with accessing and expressing their feelings about prostate cancer; almost as if prostate cancer, in being silent, contrived to silence their feelings. Consequently, these men had no markers that would facilitate their understanding of the nature of prostate cancer, how they should respond to it, or how they should feel about it.

Men tacitly appreciated that prostate cancer was a disease to be considered when reaching late middle age but had no real understanding about, or well formed language to describe, the cancer or what it and its treatment would mean within the context of their daily lives. Furthermore, because the prostate cancer was, as one man described it, a "silent partner" (Dixon), there was no immediate evidence to substantiate its

corporeality. Therefore, each man was required to accept the word of the urologist for the cancer's existence.

[I've had a heart attack and] I've got a pacemaker I can show someone the bloody hole, there's nothing, I'm taking the word of the urologist that I've got (...) [prostate cancer]. (Herbert)

Although none of the men refuted the reality of the prostate cancer, there was a sense in which revealing the prostate cancer became a necessary task. That is, revealing the prostate cancer provided the necessary material, emotional, and social contexts for understanding and engaging with this potentially life threatening disease.

### *Concretising the Prostate Cancer*

In trying to understand the prostate cancer the men in this study first had to acknowledge its materiality, its concreteness; they had to establish the prostate cancer as a real and material presence in their lives and in their bodies.

I wasn't really quite convinced [about the prostate cancer], I'm still not convinced because I've got no, absolutely no symptoms or no actual feelings, nothing in particular." (Otto)

Some men looked for the presence of cancer symptoms in the kinds of physical cues they would generally have interpreted as being indicative of disease. However, they were largely ignorant about the signs and symptoms of prostate cancer, and consequently resorted to forming vague hypotheses about the causality of physical cues provided by their bodies. Forming hypotheses, however, was difficult as there was nothing to see.

[My friends say] "you've got cancer but you don't look [like] it. You don't, you can't see nothing wrong with you." "No", I said, "you can't see nothing wrong." (Richard)

Because there was nothing to see, it was almost impossible for this participant to differentiate between symptoms that could be due to prostate cancer, and those that belonged to other known disorders. Consequently, when he experienced symptoms that he would hitherto have identified as being due to arthritis, he felt confused and wondered if the symptoms were the result of the prostate cancer. He looked around for confirmatory experiences, and recalled a friend with back pain who had been diagnosed with a spinal cancer.



I can understand what you're saying because I did go through, probably three, four weeks ago, when we were in Geraldton. Yes four weeks ago. I was getting to – this day, come lunchtime and it was the mid day tablet and I thought, “Well I'm getting bloody tired.” And [my wife] said, “Well go and lie down, well what's wrong with you?” I said, “My backs aching.” It, it did go through my mind then, that, “Hey, maybe it's the prostate that's getting into the spine, it's cancer.” Because I had an old mate, an old workmate, he died of cancer of the spine and I can still see him sitting over there, and he said, the night he came round and he said, “God,” he said, “My back,” he said. “I can't get out in the garden,” he said. “If I can get down I can't get up.” And I said, “Well what's wrong with it?” And he said, “I don't know.” He said, “I've got a terrible pain in my back.” And I said, “You got anything else wrong?” “No, no, no, it must be arthritis.” Well it was only a matter of three weeks and they told him he had cancer of the spine. And that went through my mind that it, it sort of hit home then because I was having all the trouble with the cold weather. But the last week, I haven't been [so] bad. So I know it's not cancer, it's arthritis. (Richard)

Therefore, the silence of the prostate cancer, and the absence of symptoms, caused some men to misinterpret the familiar indicators of minor illnesses, aches, and pains. Indeed, those familiar indicators were converted into the symptoms of prostate cancer.

[E]verything I get wrong with me is something to do with my prostate ... get a sore finger, get a sore toe, my arthritis is a lot worse, must be prostate ... get a cold, must be prostate ... I'm exaggerating but that's the first thing you start thinking of. (Herbert)

A reasonable interpretation of these observations is that the prostate cancer's lack of material presence caused some men to lose confidence in their ability to interpret commonly experienced events. In time, as demonstrated by the case of the arthritic back pain, these men returned to a point of equilibrium, a point where they regained confidence in their interpretations. As a result, they were able to appreciate that the symptoms they experienced were not due to the prostate cancer. In falsely attributing symptoms to the prostate cancer these men had engaged with a material presence, albeit metaphorically. Therefore, and paradoxically, attributing commonly experienced symptoms to the prostate cancer helped to ground the cancer in each man's material world.

Other men did not experience the need to attribute common symptoms in this way; for them the cancer remained silent. However, one of these men, on hearing the suggestion from his GP that he may have cancer, said “Hey, it's caught me. It's the dirty word.” (Richard). The metaphor he used appears to refer to the cancer as one would another person. That is, the prostate cancer, as an entity, has caught me; “the dirty

word” (the big C) has got me. Similarly, another participant established a metaphorical relationship with the cancer, endowing it with human-like qualities of communication capable of reminding him of its presence. Contained within the metaphor is the idea of no-impact or no-effect; a sense in which materiality is conferred, in the first instance, on the basis of what the cancer is not doing, or the effect it is not having. Knowing what the cancer is not doing therefore speaks of what the prostate cancer could do, the way in which it could act, if and when it chooses to do so.

[The prostate cancer is] foreign but it doesn't remind me (...) whereas if it, if it was reminding me it was there I'd be doing something about it. Which probably comes back to the male thing again whereas a woman would have it dealt with but because it's not always there, not affecting my life, it's not affecting me, it's not having, it's not stopping me from doing things, not stopping me from going to work, it's not affecting my mode of thinking, I worry about, I suppose you could say it's a silent partner and until it speaks [until it communicates with me] then I will do something about it but I like to think I'm going to do something about it before it speaks. (Dixon)

Therefore, personifying the prostate cancer in this way allowed for the concretisation of the cancer. Moreover, ascribing an abstract sentience to the prostate cancer, as a way of understanding its presence and potential behaviour, provided the cancer with a sense of predictability; something like, when it is time to take action it will tell me.

A number of men in the study had experiences of chronic illness (Herbert, ischaemic heart disease (IHD); Cecil, diabetes mellitus; Robert, PTSD; Richard, Crohn's disease). These men had an intimate understanding of the nature of their disorder and the way in which it manifested; a practical understanding derived from living with the disorder for a prolonged period of time. However, for one man in particular, the silence of prostate cancer was particularly problematic as there were no familiar cues to help him track the behaviour and progress of the cancer. This silence resulted in a process of comparison; comparing the prostate cancer with his history of IHD. However, the process of comparison did not reveal any clues about the nature of the prostate cancer; comparison only told him it was not like heart disease.

Well, the heart disease that I have, I know I've had a heart attack, I know that my heart is damaged um and wasn't working well so they put a pacemaker in ... and I feel alright. But with the prostate it's more insidious than the heart disease, it's there but I don't know how bad it is. It gets back to that one word CANCER (chuckle) it gets back to that word. If you can change that word (...) coin a [different] word and stick it to prostate I wouldn't feel so bad, it's stupid I know

that's stupid (...) but you say cancer or even if you say lung cancer, I'll always think things are not good. But with your heart, you know you have a heart attack, they look at your heart they can monitor it, you get back to working reasonably well uh I've a pace-maker put in, none of those things fazed me like this did, nothing fazed me, I tell you what like this did. (Herbert)

This participant's use of comparison provided the prostate cancer with a metaphorical presence, which did allow him to engage with it; and therefore allowed him to concretise it. Also, in a similar manner to personifying the cancer, comparison contributed information about what the prostate cancer was not like. However, for this man, an understanding of what the prostate cancer was not like (not like a heart attack) acted as a constant reminder of its silent and ominous presence. Therefore, rather than providing this man with a way of engaging effectively with the prostate cancer, this form of concretisation served to immobilise him.

It is difficult to know the extent to which the men in this study were able to visualise the prostate cancer, if they did. When asked how he saw the cancer Winston replied, "To be honest with you I don't see it at all. To be honest with you I don't hardly ever think about it (...)" (Winston). Equally, when I asked Dixon how he pictured the cancer he replied, "I don't, I just see it as there I just have to deal with it." (Dixon).

Therefore, men tended not to visualise or describe the cancer as an entity and, where materialisation was possible, the image or form of the cancer held by the men remained unspoken. For some men, revealing the prostate cancer was difficult; its silence and the absence of materialising symptoms created a discontinuity in understanding as they tried in different ways to ground the cancer in their reality. Some of these men, either because it was the only way they could provide the cancer with a presence or because it represented their usual logical style, referred the prostate cancer to the ageing process.

[The prostate cancer] doesn't feel real. I mean I don't have any trouble with voiding, I don't have any trouble not being able to control the bladder and probably having that knowledge well there's nothing wrong down there, that whatever it was is, is, is a part and parcel of the – part and parcel of growing old (...) (Richard)

[Prostate cancer is part] of the aging process yes, certainly because I mean after all whether you like it or not, I mean one is in a certain age bracket which more-or-less dictates that well, you're most likely going to have this. (Otto)

Referring the prostate cancer to the ageing process rendered it graspable and to some extent “normal”, a way of acknowledging its presence without having to relate to it as an object. Referring the prostate cancer to the ageing process therefore established it as something that could be accepted as real.

### ***Providing the Prostate Cancer with a Social Presence***

Just as the silence of prostate cancer created the necessity to provide the cancer with a concrete presence, the same silence provided a context within which to provide the prostate cancer with a social presence. In attaching meaning to the cancer, the men in the study allowed the prostate cancer to evolve from a biological object, with no more than a material presence, to a relational object with a social presence. As a social and relational object the men in the study were able to engage with the prostate cancer in the same way they would an individual, albeit metaphorically.

[The prostate cancer is] a little bit like the guy that comes to stay for the weekend and a month and a half later he's still there (laughter) you know ... and by now he's living in your bedroom and you're out living in the sleep-out ... (laughter) well we get them, and this little fella called cancer the guest he he's like that too so the host has to be a little bit more locked in in a way; yeah I was apprehensive because I, it took me over for a little bit of time and then I thought no; it's not (...) (Winston)

However, there was a drawback to the real, though insensate object, acquiring a social presence; men could also experience the prostate cancer as a metaphorical individual capable of acting with malicious intent. Moreover, men could use language to think about and describe its social attributes: “cancer scares you” (Gerry); “it’s a killer” (Winston); “cancer is death” (Herbert). Therefore, not only was the prostate cancer able to generate fear as an insensate object, it was also able to generate fear as a metaphorical individual situated, as it now was, in the men’s social world.

I don't know anything about it [the prostate cancer] ... the education is just not there ... and I guess its just cancer, that word cancer ... think of something else to call it and it's not as hard (...) It's simple, I guess you can call it what you like, you can call it terminal but in the long run its just death, cancer is death. (Herbert)

Furthermore, some men identified the social nature of cancer and its attributes, one man describing cancer as a taboo subject, something not to be talked about, and therefore something to be feared.

Ahhh the big-C, yeah the words my mum and dad would never mention basically, because my mum died of breast cancer, and um; cancer was just not a word mentioned. (Gerry)

Winston linked his understanding of cancer to the socialisation of fear, cancer as “someone” to be feared and avoided.

The fear is there, I’m sure David in my reconciliation (sic) of it, because we’ve been taught what a nasty little creature this thing called cancer is. Now that fear has been well and truly engrained in us because it usually kills people or we feel as though it does because we hear about the killing number (...) (Winston)

Only one man in the study construed the cancer as something symbolised by its visual presence. In this sense the cancer was provided with a social presence on the basis of the way in which it, or its treatment, altered external human morphology and functionality. Therefore, while there was nothing to symbolise the prostate cancer, either morphologically or functionally, the cancer did not acquire a social presence.

[The word cancer throws up in my mind] (...) someone bedridden, someone who’s gone- there’s an officer at the station that had cancer and he had half his face, half his neck and face removed, (...) I suppose you could say it’s a visual thing, like you see the children in hospital their heads are shaved, well not shaved they’ve lost their hair through the treatment, you can’t see that with me. (...) I’m still working, I’m still running, still walking, still riding a bike, mowing lawns and all that sort of thing. (Dixon)

### **Re-Plotting the Reference Points of a Stable Lifeworld**

In describing how the men in this study responded to the prostate cancer diagnosis, I may have created the impression of a distinct boundary between the immediate experience of the diagnosis and the experience that followed. Such an impression is an artefact of description and bears no resemblance to the continuous nature of the men’s experiences.

I want to make it clear, however, that it was necessary for men to respond to the prostate cancer diagnosis in the way described, before further engagement was possible. This observation notwithstanding, even though all the experiences of responding to the prostate cancer during the peri-diagnostic period were contiguous, there was an implicit discontinuity between the life of each man before diagnosis and their life after diagnosis. This discontinuity, this stumble so-to-speak, contained a context of uncertainty, an uncertainty created by the jumbling of many of the markers of stability

previously provided by the lifeworld of each man. Therefore, the men in the study were faced with the task of demarcating the prostate cancer experience; that is of recognising, re-defining, and re-plotting many of their markers of stability; the reference points of their hitherto stable lifeworld.

### *Incorporating an Illness Experience Context*

In re-plotting the reference points of a stable lifeworld some men in the study first reflected on their prior experience with illness. I have already observed that a number of men had experiences with chronic illness. It was mainly these men that appeared to use these experiences, as a way of establishing a context within which to understand, or re-establish, other reference points.

Robert, the 57-year-old man with a history of PTSD, acquired after being assaulted by prison inmates when he worked as a prison governor, clearly identified his emotional and behavioural state prior to receiving the prostate cancer diagnosis. He also identified a support marker, and a marker that clarified the importance of planning ahead. Moreover, this participant provided a context for clarifying the “limits of safety”, discussed in the next section, and revealed the shaky nature of his emotional state. However, he also established what he was able to achieve, and how much he had improved; a context of balance.

Well while I went through the problem [the PTSD], when I first come over here [to Western Australia] I was [a] shaking bloody nervous wreck, I was very bad I couldn't go to shopping centres or I just didn't want to get out of the house uh, it was like that condition that that footballer had you know, I was always tired, and um and I didn't want to- [my wife would] go somewhere and I'd stay home, I couldn't stand kids screaming or the noises of yelling and that would tense me up, so she was so helpful, well she's always been all me (sic) life and I mean she's been so supportive um through this period even though (...) I have picked up a lot, I can snap and I can be back similar to today um a bit depressed after the incidence (sic) took place over the road, and I used to go to the shopping centres and I was so paranoid of running into a crim or someone like that that would recognise me and whatever. I've got over that I can go to shopping centres when I want to but even now I can only take- I believe me stress levels are very low, [but] they don't need much to put me back into a bit of depression, so I plan ahead all the time um and she helps me plan ahead (...) (Robert)

Herbert, aged 77 years, with a history of chronic IHD, had received a pacemaker following a number of myocardial infarctions (heart attacks). Herbert had experienced his heart attacks with equanimity and a definite view that all would be well; he felt ill but then he felt better. He even continued to feel confident when another patient died in

the bed next to him. However, Herbert's prior illness experience, albeit one with a good outcome, established a context for responding to the prostate cancer that was riven with uncertainty and a lack of confidence right from the moment of diagnosis.

Yeah, yeah, [having prostate cancer is] a lot different, I don't feel as confident, confident in tackling this one as confident I was tackling the heart one. (...) (Herbert)

On the other hand, Cecil used his wife's experience with bowel cancer, and his own experience of impotency to provide the illness experience context for his prostate cancer. The impotency had resulted from his type II diabetes having been left untreated for some time. Cecil had, therefore, been living with impotency prior to the diagnosis of prostate cancer, a fact that meant he could discount one of the potential effects of the prostate cancer treatment. With respect to his wife's bowel cancer, apart from having had a good outcome, the experience contained an idea that the successful treatment of one type of cancer provided a positive context for the treatment of a different type of cancer.

[My wife being an ex-nurse and having had bowel cancer helped] [i]n as much as they managed to get the cancer out completely without any extra treatments and that sort of thing, so that gives you confidence that it can be sort of treated. (...) [Further with respect to the impotency] [w]ell the diabetes effects me as far as that goes sort of thing, so I thought well that's no problem I've lived with that for years. (...) I'm already impotent so, what's the difference? (Cecil)

A further positive illness experience context was presented by Richard, a 70-year-old man with Crohn's disease. What stands out in the recounting of his experience with Crohn's disease is a distinct marker of support. Richard had experienced effective support from a support group, one that had provided him with appropriate information. Most importantly, however, his experience following the diagnosis of his Crohn's disease had not left him isolated; there were others in similar situations. There was a clear sense in which the earlier context of normalising support resonated with him when he received the diagnosis of prostate cancer; he acknowledged that he was not isolated.

Probably the Crohn's has [helped with the prostate cancer] because I was fortunate enough, Sister Smith was in the hospital up here, she was the nurse and she came up and saw me and I had probably spoken to her before in the hospital there but never to the degree of when she came up and said, Richard you've got Crohn's and this is what it's all about." And she said, "We have a support group, would you come along?" And I weighed it up in my mind and I thought, "Well I know nothing about Crohn's, there must be literature out there, where the hell do

I get it from or what process you've got to go through?" and I said, "Yes." And she said, "Well it will be two weeks time," which was two weeks after my first operation. She said, "You don't have to come," she said, "I know you're going to be sore." I said, "Yes I'll come," and from that time on, that's how things are sort of settled in my mind. Because there was old people, when I say old people, my age, there was female, male, and young ones. Hey we're all in the same boat, we want information and this is, that helped me in the moment when they said, "Well you've got cancer," I thought, "Well I'm not on my own." And that's how it's been. (Richard)

Not all the participants had a well established or clear illness experience context upon which to draw. The youngest man in the study, Gerry, a 48-year-old, could recall only minor injuries or minor surgery, certainly nothing that could compare with the magnitude of prostate cancer. Therefore, his illness experience context was essentially devoid of the kind of markers that would have helped to establish his response to the prostate cancer. Indeed, Gerry referred indirectly to an idea that the nature, quality, or magnitude of a prior illness experience may assist in preparing an individual for, or absorbing the impact of, a new diagnosis, at some point in the future.

[The] last time I was in hospital I was five getting my tonsils out so; I've had uh you know one broken arm and one broken wrist and that's about all the injuries I've in my life uh I suppose I just sort of, I was just surprised something was wrong, just very shocked and surprised (...) (Gerry)

Therefore, incorporating an illness experience context, for some men, provided an important early mechanism by which to begin identifying the necessary general markers of stability. I would suggest that reflecting on earlier illness contexts provided these men with important early stability; a triangulation-point, so-to-speak, from which to plot their own particular reference points. However, I would also observe, as evidenced in the experience of at least one of these men, that early illness contexts can act counter-intuitively. That is, illness context experiences may establish, or exacerbate, a context of uncertainty or misgiving, that becomes attached to extant experience.

### *Clarifying the Limits of Safety*

Using the illness experience context to establish a triangulation point, from which to plot individual markers of stability, necessarily brought into sharper relief points of potential instability and danger. That is, the men in the study needed to become aware of the boundaries in the terrain of the prostate cancer experience beyond which they considered it was unsafe to venture; they needed to clarify their limits of safety.



In describing the limits of safety I am aware that the men in the study did not talk about the concept of safety as a distinct entity. However, there was a quality about some statements made by these men that referred, for example, to moments beyond which action should not be postponed, or should not be taken, or recognition that certain limitations should be held in mind. Therefore, clarifying the limits of safety represented an undeclared reasoning process used by some men to determine or limit action, to protect their physical or emotional safety while responding to the prostate cancer.

Winston, who eventually decided to forego traditional treatment, and who had postponed having a biopsy to confirm the presence of prostate cancer, appeared to know when the moment had come to agree to have a biopsy.

After the postponement [of the biopsy] I then had another blood check done [a PSA assay] which was then blood check number three and it had moved from 17.8 to 18.6 or something like that, the figures are here um I had that done on a Friday he hadn't called on the Monday, he hadn't called on the Tuesday and I thought well maybe it has subsided and anyhow he rang and said 'well I am afraid it's still high, it's higher than before in actual fact um we need to act'; and he forgot that he'd booked me in and I said '**well I'm ready**', he said well I'll have to book you in and I said, no you won't you already booked me, I'm there at 7 o'clock in the morning, and he said OK I'll look after you (...) (Winston) [Emphasis added]

Dixon, who had opted to spend an extended period of time reflecting before accepting a urologist's advice to have a radical prostatectomy, also recognised that the point at which he would need to make a decision was approaching. Dixon used the PSA level as a yardstick for monitoring the progression of the cancer, but was also aware that his Gleason score was seven. There was also a sense in which he recognised the limit of safety, and then established a buffer zone, or further safety margin, so as to protect against error.

[I] talked it over with my wife [about when I should have surgery] and I have agreed, that might be a better way [to put it] because she thinks of me as a stubborn coot, but I must say that I was thinking next year that if the PSA levels weren't OK that I would have it next year but, I've come back towards Christmas now and if the PSA levels are not OK then I'm more inclined to have it done prior to Christmas, so I guess I have softened my view in relation to surgery. (Dixon)

Both these men acknowledged, on some intuitive level, that there was a point beyond which they should not go, even though nobody had provided them with that specific information directly. Moreover, being aware of the limits of safety was related

to taking action in stages. That is, recognising the limits of safety with respect to the sequence or timing of action; something analogous to understanding that emotional resources were finite and required wise handling. Gerry recognised, for example, that he needed to manage a main area of concern (the uncertainty of being in hospital) before he could move on to the management of other aspects of the prostate cancer experience.

(...) I can't deal with it [the whole experience], it's [not] that I'm not interested in it because these are the immediate concerns. (...) I'm quite happy to deal with it but you know as I say we've planned [our life] down the track [in] 12 or 15 years time so I intend to be here, but yeah the uncertainty is that hospital section and that recovery period afterwards so yeah let's get that over and done with and move on after that. (...) I need to deal with this part now, this is my uncertainty part here so let's deal with that part now. (...) [I]t's like going on a ship and going to the engine room it's not my familiar environment so I've got to be careful, I've got to look out you know. (Gerry)

There was a sense then, for some men, in which having an understanding of their individual contexts enabled them to take appropriate action so as to maintain their physical and emotional safety as they defined it. However, there were also moments when not taking action represented an imperative. Robert, the 57-year-old man with PTSD, for example, was only able to act on immediate events; to act in a future oriented manner generated a level of anxiety that was intolerable.

No I don't, I don't, I have no set future plan um I don't you know, I'm hoping I live another 30 years but I mean I haven't planned for that, I haven't um even considered that, I consider the problem now and how am I going to deal with it. (Robert)

For similar reasons this same man was unable to accept any other treatment than surgery, this being the most likely treatment to remove the cancer completely. This participant was unable to contemplate living through a prolonged treatment, such as external beam radiotherapy, because of the contemplative anxiety it would generate. Therefore, action had to be immediate and swift, to act otherwise would have pushed him beyond his limit of safety.

No no no I don't think I- I think if I had cancer I was going to have it operated on anyway for the reason being that because of my PTSD I didn't want to wait five years and worry about it, have that worry on me (sic) mind having to go for a test after test, I didn't want to go through radiotherapy not knowing that I was going to get it and I would still be worrying again so the best alternative even prior to him suggesting, for me was to have the oper- to have an operation. I wasn't aware how big a operation it was until he explained it but my initial

thoughts, I I thought when I went in there for the second reading after the biopsies I had a slight feeling it may be cancer. (Robert)

What these men demonstrated was an understanding of moments in time when taking or not taking action was right for them as individuals; that is, moments when taking or not taking action maximised their physical or emotional safety. None of these men reported being placed under duress to act or not act according to the priorities identified by health professionals. Equally, however, none of these men identified any discussion with a health professional that indicated that the health professional was aware of the limits of safety, as defined by each man's specific context.

### *Clarifying Intra-personal Reference Points*

Prior to a diagnosis of prostate cancer the men in the study perceived their lives to be relatively predictable, and were able to access self-defined intra-personal reference points as a way of evaluating the stability of their lifeworlds. Therefore, in general, these men knew how they would respond to daily events, knew what they were able to control in their personal environments, understood their emotional responses to events, and could describe the values that guided their actions.

However, on receiving a diagnosis of prostate cancer, the predictability of these men's lives and the erstwhile stability of their intra-personal reference points, were challenged and compromised. Therefore, clarifying intra-personal reference points had to do with the men in the study evaluating some of their points of reference as a way of regaining the predicability and stability of their lifeworlds. In the course of such an evaluation essential values were examined, personal expectations reassessed, and end points clarified.

### *Aspects of the Familiar Self*

Aspects of the familiar self refers to those relatively stable characteristics of oneself that assist in making sense of, functioning in, and adjusting to, an external world; that is, characteristics which assist in maintaining a cohesive, continuous, and harmonious self (Wolf, 1988).

There was a sense in which the prostate cancer challenged the ability of the men in this study to maintain a continuous and cohesive self. That is, the prostate cancer experience disrupted confidence in those stable characteristics that, hitherto, had helped

to maintain a cohesive and continuous self. This challenge caused some men to reflect; as if asking the question “how useful are these aspects of my self?”.

Herbert perceived himself as being habitually pessimistic, a fact that particularly coloured the way in which he viewed his early progress following the diagnosis of prostate cancer. He also saw himself as a worrier, but tried to hide this from those around him. There is no doubt that the prostate cancer raised concerns for him about the utility of such seemingly stable characteristics.

My family tell me that I'm a great pessimist, they are probably right; I look at things and try to take uh, a practical view of them, and I guess I've always thought; on the downside of things you know, I have been pessimistic. I'm a great worrier, I'm a worrier within myself, but people don't think I am, but I am, a born worrier. (Herbert)

On the other hand, Richard tended towards consistent optimism and resilience, regardless of the problems he encountered during the treatment of his prostate cancer. He reflected on the genesis of this resilience, and laid it squarely at the feet of his mother and her time in history.

Dad, dad, well when dad was working he was an inspector on the Railway and was away all week and they [my parents] came up, probably, well they did come up in the depression years. I guess a little bit of hard life which they did have, I mean they had nothing much that I can recall, I'm trying to think when we first had electricity? 1938\39 or something like that, and I, I can still see mum going out to the back verandah to the old Coolgardie safe to set the bloody jelly in there and I think a little of it's [my resilience] come from her to me. She's had to do it but then when, when, mum was a good blood donor and the last lot of blood she gave was when, or it might have been a couple of weeks after when they discovered that she had cancer. That affected me in that respect that I thought, “Well why the hell did she give blood, did that bring it on?” Those and then when she did go to Perth to the hospital, I can't think of the doctor's name and he came out and he said, “Well your mother's only got six months to live.” And that sort of, that got at me a little bit and I thought, “Well why, why is it happening to mum because she's only fifty-eight, fifty-nine, but having said that, all that, probably my resourcefulness has come from her. Not because dad didn't want to give it to me but he wasn't there. (Richard)

Such reflection on the past, and remembering the experience of his mother appeared to be instrumental in reminding this man about his own resilience. There was a kind of historical continuity that helped in supporting the stability of his resilience, especially when he recalled that she too had been diagnosed with cancer.

The same participant also referred to not being the centre-of-attention, of being kind and considerate, and of being predictable. These aspects of his self reflected his way of engaging with the world, and this was echoed by the way in which he engaged with the prostate cancer. More importantly, he held these characteristics up to the light and found them to be those of his choosing.

I often get told by the family, my kids, they say, "Pop, you're not bloody Hercules." But I still think that I'm as good as what they are whether it be that I've gained that experience from my working life, I don't know. My wife has often said, "Slow down. You don't have to do it like that," but that's me, that's me. I want to do it. I'd much rather do people a good turn than I would a bad turn. I want to help. When it comes to saying that I've, well I've seen people that I've worked with, they're retired, gone home and sat in the front verandah and in six months they're dead. Well that, that's not me. I'm, I like to play a practical joke. I let them play it onto me and I accept it and I guess that's the way I'll still go because they often say, "Bugger you, you're never down, you always come back with something," and I say, "Well you take me as you find me," and I said, "All my working life I was like that." I thought of my work mates probably more than I did myself. I used to say, "Oh Christ I feel crook today," but no I won't have a day off, I'll go to work because if I don't go to work, someone else has got to be called in so I'm inconveniencing them and that's the way I've been all my life. And that's what I think about this [prostate cancer] now. I don't want to inconvenience anybody (...) (Richard)

Robert, the participant with PTSD, described aspects of his self that he perceived as predating the cause of his disorder which, therefore, predated the prostate cancer diagnosis. This man viewed his approach to life and problems as methodical and definite; he identified an ability to be flexible, to talk with others about issues, and to think all aspects of an issue through before making choices.

[E]ven before I had the incidents in the prison probably went over 18 months; but even prior to that um I was still very methodical, and uh if I said I was going to do something I done something. It would have taken a lot, because I put so much thought into it, but I was never one that would, wasn't flexible; if someone come up with another idea I'd listen but nine out of ten I'd already covered all the bases; you know I was that type of bloke that I was, that I would put a lot of research into trying to implement something because I spoke to people, I went and spoke to other staff or the people involved and got their feedback before I formulated something, and that's the type of bloke I was, I was able to formulate routines of running a prison. (Robert)

In the context of a life without prostate cancer these reflections could appear as nothing more than stories about daily experiences or past lives. However, these discussions occurred in the context of an extant diagnosis of prostate cancer. I would therefore argue that the characteristics of self, described by these participants, provided

them with a reflective reference point; a process by which to assess the effectiveness of their engagement with, and adjustment to, the cancer. Indeed, in the process of reflecting on what had hitherto been viewed as stable characteristics one man, at least, reflected on characteristics that were implicitly evaluated as unhelpful (worry and pessimism). There is also an important sense, however, in which narratives such as these reinvested each man's lifeworld with an awareness of continuity and hope; what was stable before prostate cancer will be stable again.

### *Aspects of Valuing*

Aspects of valuing refers to those values held by the men in this study that helped to provide them with a central reference point around which to organise important, often existential, concerns. It would be reasonable to observe that those men who talked about what they held to be of value tended to be those in late adulthood (aged between 60 and 80 years) (Colarusso, 1992). Maybe because of the reflective nature of this developmental stage (Colarusso, 1992), the quality or longevity of life presented as a focus within the context of the prostate cancer diagnosis.

Herbert, the oldest participant, who was being treated with hormone ablation therapy, reflected on his decision to receive treatment and how this related to his age. He identified that he was still mentally active, still able to look forward, still able to engage with life, and therefore still able to value his life because of these attributes.

ahhh, the fact that something could be done [about the prostate cancer] (...) increased my certainty, uhh, when you believe you've got some living to do you take all the options, but if I was older and I was 82 or 83 I might, I might think the whole thing's different, If I was 80 I would say shit no don't worry about it (...) do nothing, but seeing I'm 76/77 I have this belief that whilst I'm, whilst my mind is reasonably active I should try. (...) [I should try for two reasons] because I want to and because I'm still active, so those two things go together, I want to do something, if I wasn't active and I was run down I would say shit no, just leave me alone, and I'll plod along until the time comes [when I die].  
(Herbert)

The same man also talked further about the nature of his dying, contrasting his perception of dying from prostate cancer with the quick death of a heart attack. However, the value he espoused was less to do with concern for him and more to do with concern about the affect a slow and lingering death, as he saw it, might have on his family.

David: (...) One of the things you said before was that you didn't want [a] slow decline into, into death, whereas with your heart attack if you were going to die it would be quick and –

Herbert: Yeah, yeah, I would have a heart attack and bang you're gone, I could die tomorrow. (...) Nobody wants to sit about and know that something's going to happen, if you suddenly die you haven't got to; I look at putting your family through all that [anguish], you know. (Herbert)

He further talked about the quality of his life; in particular, maintaining its quality. Incorporated within the narrative was the value he had come to place upon maintaining his usual activities, and how much he valued the enjoyment derived from such simple things. Most importantly, however, this participant referred to the value of reaching a point of acceptance; a recognition that the prostate cancer would play itself out in his life, regardless of how much he wished it to be otherwise.

I've settled down now [with the prostate cancer], I go day-to-day, and this is the way I'm going to put up with it (...) you know I'm going to, I'm going to, I feel reasonable, I'm not silly enough to think that uhh things are going to get better, they're only going to get worse, and that's in everything, I mean, I have a brother who has a pace-maker and his main worry is that he won't be able to play golf, you know, I've got past that I'm not worrying about not being able to play golf because I can't and I just want to keep things that I do, day to day things going, I go for a walk, I might go for a swim, I vacuum the house, I cook, I do all those things, if I couldn't do them then my quality of life is slipping, once if you told me I would vacuum the floor and do the cooking I would have said you've got rocks in your head, because I never had time, but I do it and I enjoy [it] and it's part of my life. (Herbert)

Richard, a 70-year-old, reiterated the value of not wishing his family to suffer in any way for him. He also reflected on his life, on the benefits he had accrued, and on his wish to enjoy his life until the end. I would also observe, embedded within this narrative, a subtle form of anticipatory guilt expressed in his hopes for how things will be; a sense in which his ability to laugh until the end would expose his family to the least anguish, and sustain them at the time of his passing.

[I'm not avoiding the prostate cancer]. I know it's there. I think that, let's face it, I've had a pretty good life. I've done a lot of things, I've travelled a lot. Down the track that, that worries, that would worry me most of all is to see the family suffer for me. Not me for them but them for me and I wouldn't, I wouldn't like them to say well, "Dad you've been pretty good but this is the time." I don't think I want that, I honestly don't want that. I would rather them think, "Well hey, lets enjoy it til the last minute." And I know with my wife I mean she's never been sick. Well when I say, never been sick, she's had a few things. But

quality of life, that for me is, that's the main thing. If, if you can enjoy life, you can laugh, that's the biggest bonus you can get and I, that's the way I want to go. (Richard)

On a more pragmatic level, Robert clearly identified the importance of truth and straight talking in his dealings with the urologist. This man organised all of his communicating around the concept of truth-telling as a way of preventing any surprises that would exacerbate the potential for anxiety associated with the PTSD. Therefore, as a reference point, truth-telling exemplified far more than an abstract value; for this man the value of truth-telling represented an integral component of a stable lifeworld. Without truth-telling his emotional survival was in jeopardy.

Well, you know the urologist and my treating doctor are so straight with me, this is what I like you know I'm very blunt and I don't buggerise around, I say to them don't fuck around with me you know, I want to know exactly what stage we have, where we are so as I can make a clear decision, I don't want a what if and maybes and whatever, if you can't answer me don't answer me, but I want the truth, I want to know what, and he was you know- the urologist as I said he was amazed that- people just withdraw, I don't I want to know. (Robert)

On yet another level Dixon referred to a change in values as a result of comparing one illness experience (the death of respective spouses) with that of the prostate cancer. Although this participant and his wife had hitherto subscribed to the value of saving to have a good life, the value had shifted to a new position of living to have a good life. That is, a good life was defined as occurring in the present, as opposed to being postponed until a time that was affordable. Contained within this narrative was a realisation about the impermanency of life and a reaction to this in the form of "making hay while the sun shines".

Yeah I just say well that's-well that's life and you've got to move on, and my wife's attitude now is that her first husband was to save and have a good time, whereas now let's live and have a good time don't worry about saving and... yeah that's how we look at things now, still work but maintain have a good time, if you want to do something you do it um yet don't skimp and save and not live at the same time. (Dixon)

As a central reference point, the idea of what is valued by individuals has been put forward as a way to organise important concerns during moments of existential change. There is a clear sense in which some of the men in this study came to reflect upon, and organise future action on the basis of identified values. It is difficult to know the extent to which prostate cancer catalysed an examination of what men held to be of



value. However, there is no doubt that the men identified here were able to gain clarity about their intentions, actions, wishes, and imperatives for survival, through the valuing process generated by the prostate cancer experience.

### ***Concerning End-Points***

End-points speak of moments in time that were taken by some of the men in this study to represent the denouement of actions, conscious wishes, or intentions. These future oriented moments, acted as reference points against which to monitor changing priorities, manage the use of time, make choices about treatment, and think about the end of life.

Herbert talked about what he considered to be “a reasonable life”, by which he meant the quality of the time he would like to experience before he died. For him, happiness could be achieved if was able to reach the age of 80 years. However, he also felt that once he had reached this age he would want to live longer if the quality of that time had been good. Therefore, what this man found himself facing was the difficulty inherent in contemplating the end of life. For him, the end point became elusive; a reference point that changed according to its proximity with the present.

I believe that if I can get to 80 and live a reasonable life, to 80, I will be happy, you know (...) [but] I guess when you get to 80 you'll think, oh shit, this is alright, I may as well go to 85. Those are sort of things that flash through your mind. (Herbert)

On the other hand, the same participant fantasised about the time he had left (before the cancer killed him) and used this to make a judgement about the utility of having a knee replacement. Herbert reasoned; since the treatment for prostate cancer could never be as effective as the treatment for IHD, and would kill him sooner than later, he would be wasting his time in having a knee replacement.

[The prostate cancer is] still there telling me, telling me don't waste your bloody time with your knee, you'll probably die before you get yourself walking again. (...) I'm not confident that the [prostate cancer] treatment's going to be as good [as it was for my heart attack]. (...) [I]f you said it was my heart I'd say oh shit I'll have my knee done, but because it's prostate cancer I'm saying, not worth it, haven't got enough time. (Herbert)

A plausible interpretation of this statement is that the degree of anxiety Herbert experienced had become invested in his perception of time and, more particularly, in the

point at which he believed time would end. That is, the more anxiety he experienced, the more he fantasised about diminishing time. As time diminished his perceived life became increasingly futile, and the futility became the reference point against which to evaluate the utility of acting in the present.

Richard, on the other hand, talked about end points in quite a different way. This participant postulated that the amount of time left was less important than the quality and actions contained by that time. Consequently, he chose to discount the amount of time (which in any case was an unknown) as a reference point for endings; and focused instead on his use of time as something he could monitor and control.

(...) [If I found out the prostate cancer was aggressive] I think that I would say to whoever's around me, family, wife, "Hey look, there's still time left, lets go and do something." I don't, I don't think I'd go, I'd feel as though I'd want to be shut up, I wouldn't want to be like, termed as a leper, I can't don't do this, can't do that. No I don't think so, I think... Friends of ours, their son died, he was only forty-two and I draw a little bit of strength from him because he said when the doctor went to him he said, "If you're going to come in here and tell me that I've only got x-amount of bloody days to go, or weeks," he said, "Don't bother." He said, "Because I know where I'm at." And he said, "What time I've got left, I'm going to prepare myself and I'm going to look after my family." And I draw a little bit of, a little bit of support from that and I think it's pretty damn good thinking. But having said that, I mean circumstances will change. (Richard)

### *Aspects of Personal Control*

In considering the nature of personal control, in the context of prostate cancer, the men in this study ranged along a continuum from those who felt that overt personal control of events was important to those who handed personal control over to some divine or spiritual power. In talking about personal control, I am referring to those intra-personal constructs (including attitudes) that provided men with information about the constituents of their life that were important, and which they might be able to influence or regulate. In this sense, knowledge about personal control represented another reference point against which to evaluate their engagement with the prostate cancer.

Dixon, a 54-year-old police detective, demonstrated the complexity of understanding personal control. This man framed his perceived control of the prostate cancer in the context of a number of recent losses and difficult situations he had experienced. My sense is that he talked about being able to differentiate between those events in life that were open to personal control, and those that were not. Moreover, he suggested that the confluence of events sometimes contrived to reduce personal control;

sometimes to the extent that one had to give up personal control and hand it over to a divine or spiritual power. Ultimately, he suggested a point of balance where an individual controls what s/he can but accepts, as opposed to simply differentiating between, that some events or consequences will always fall outside such a category.

(...) I must tell you that there has been a scene that I was at that I had to go and get counselling and it was only when I had counselling, I only had one session, it was with a clinical psychologist, but that particular scene involved four children and father, with those um, with the children, but unbeknown to me in that same six month period my wife had passed away and my dad had passed away as well but I didn't realise that until it was pointed out to me, once it was pointed out you just move on, so; how can I put it not a spiritual connection I'm not a religious person, but it has been said that to a certain degree I'm a spiritual person I don't know if you think I'm waffling, I'm a spiritual person because I have an affinity with the bush and what evolves in the bush, you know life in the bush and all that sort of stuff, ok how do you relate that back to this; but that's my belief it's not a religious belief it's a spiritual belief and I also believe that we're destined for a higher level as well, whether that's right or not I don't know, that's how I sort of feel that if my number's up my number's up and there's nothing I can do ab- there's nothing anyone can do about it, but with this [the prostate cancer] there is a certain part of it that I've got control over. (Dixon)

On the other hand, the same participant showed how difficult it was to reconcile his espoused belief in balancing and accepting the relative nature of personal control, with the experience of just being him in an everyday world.

The positions I usually get myself in, or the situations I usually get myself in is that I've got control of them and this is probably one [the prostate cancer] where I didn't have control, so I may have been struggling but to me; myself I don't think I was struggling but I was probably, well I was probably struggling to control it [the prostate cancer experience], whereas everything else that I do I have usually got control, or I'm able to control it, or offer advice so it's controlled. (Dixon)

Maintaining personal control also had something to do with being able to make solo decisions. Some men implied that it was acceptable to talk with their partner about the issues, but that the final decision about actions (eg. having treatment) would be the man's alone. Personal control remained personal.

(...) I made the decision [about treatment] myself even without the wife. I discussed with the wife but the wife knows me and she knows that I would have had a number of alternatives and she knows that in life I've been pretty pedantic about what, what I want to do and once I do something I'm very confident that I'll complete it, so. (Robert)

On the other hand, Dixon demonstrated that even though making solo decisions was important, maintaining personal control of events was anything but clear cut. Indeed, maintaining personal control was exposed to a number of conflicting feelings, and a number of different priorities.

It's my decision and um yeah that's my decision and; like I bounce it off her to see what her reaction is and yeah; but she's been very supportive by saying that hey [she] can do without it [vaginal intercourse]; but I'm saying I can't do without it. BUT if it comes to the crunch you have to. (Dixon)

Richard was able to illustrate two further areas of personal control; one connected with the mundane, the other with achievements, both impacted on by prostate cancer or its treatment. The first had to do with being able to go out into the everyday world unhindered by the side-effects of treatment, in this case urinary incontinence; the personal control of bodily functions. The second had to do with dreams, wishes, and intentions still waiting to be realised (eg. making a trip, building a shed, growing orchids) before the progression of the cancer made further achievement impossible; the personal control of self-fulfilment.

Probably you think and you wonder but as the doctor said to me, he said, "Has it stopped you going out anywhere from going out visiting or leaving the house because you want to be near a toilet or all that?" and I said, "No." I said, "The main thing that I do look for, I want to know where the toilets are though, if I do need them, that's the first thing in my mind. Oh yes, there's one there and there maybe one over there." I know where I am, I know the environment I'm in but to the extent of stopping me, no. It won't stop me. And a friend or a cousin of mine over in Victoria, he said a friend of theirs, he had prostate cancer and he said all he wanted to do was do the things that he hadn't completed in life and that was to travel which he did do and he died happy many years later and that to me is, that's all I want to do. I want to achieve something. I did have a lot to achieve yet that I haven't achieved and for this to be a death sentence or whatever, no it's not, it's just another little incident in the book and you've got to slow down a bit, that's all. (Richard)

This idea of maintaining personal control over daily events was reiterated by Dixon who summed up the sentiment perfectly when he suggested the prostate cancer would not prevent him and his wife from continuing with their lives. Moreover, alongside the importance placed on maintaining personal control over life events, was the idea of doing one's best and striving until the end; being all that it was possible to be.

I don't feel I've been dealt a hard blow [by the prostate cancer], some people would say why me why me I just think well, it happened you can't change it, why try to change it and why try to feel sorry for yourself why not just move on, do what you can to the best of your ability and also at the same time; also at the same time live don't, don't box yourself in, it's not going to stop me from doing the things I want to do. Or correction, doing the things that my wife and I want to do (...) (Dixon)

### *Aspects of Masculinity*

Masculinity might be considered as one of the cardinal intra-personal reference points for men as they engage with all experience, and not just the experience of prostate cancer. That is, it would be a truism to suggest that masculinity is embedded in all facets of men's engagement with prostate cancer. However, I have tried in this thesis to position masculinity as a contributing context, one of a number of contexts within which men respond to prostate cancer, as opposed to the dominant context. Nevertheless, in exploring the experiences of men with prostate cancer, a cancer that only affects men; it was inevitable that some men in the study would directly refer to the gender construct of masculinity.

Herbert believed that it was probably more difficult for men to cope with prostate cancer because, generally, men did not expect to be sick.

I would think it was more, probably more difficult [to cope with prostate cancer], because you're a man. (...) [Men] don't like to think they're going to be bloody sick with something like that, you know. (Herbert)

The same man contrasted the ability of men to cope with the uncertainty of prostate cancer, with the ability of women to cope generally with the uncertainty of illness *per se*. His view was that women, because of their socialisation into roles such as mother and child-bearer, were more practiced from an early age to manage the uncertainty associated with health issues.

No, women are much better at coping with uncertainty than men are. (...) [G]enerally it's accepted that women get more problems, so they learn at an early age to be able to handle that sort of thing [sickness and childbirth], whereas men, apart from getting a cold when you're young and running round the place, you don't normally get sick. (Herbert)

Reflected in Herbert's statements is the belief that men are stronger and healthier than women because men do not expect to become sick as often. Therefore, so Herbert's reasoning might continue, if men do not become sick as often as women, then men are

not as accomplished at dealing with the uncertainty of illness as women and, if this is so, then dealing with uncertainty is not men's work. A corollary might be, therefore, men do not admit to feeling or expressing uncertainty. As such, there is a sense in which masculinity, as an integral component of a man's lifeworld, might present as a skewed reference point acting against the interest of men as they respond to prostate cancer.

Richard, another of the "older" men, referred to the utility of the male penis, one of the purported bastions of masculinity (Potts, 2000), when suggesting that he was still a man because he did not have to sit down to pass water. He also referred to another bastion of masculinity, the male libido (Potts, 2000); mitigating its loss due to hormone ablation therapy by way of his advancing age.

[T]he doctor said, he said, "Well your sexual drive will be over," and I said, "Well, it should be." I said, "We're on three score and ten. So it should be going by the board now." He did say, "Well there's things we can give you," and I said, "No, I'm not interested." To the effect of not being a man I don't think that that deteriorates me because I reckon I can still keep up with the young buggers working and everything, keep up with them. (Richard)

This statement is impregnated with traditional assumptions about masculinity, acting to buffer against external perceptions that, because of the prostate cancer and its treatment, this participant was no longer a man. As a reference point, there is once again a sense in which this man was led away from a more balanced approach to adjustment.

Robert spoke disparagingly of other men who prevaricated about being treated for prostate cancer because they were afraid of being impotent. The symbolism of the erect penis, as an indicator of a man's masculine status, is used powerfully by this man to explain the avoidance of issues related to impotence.

So [information about impotence and prostate cancer] it's obviously it's not getting out to these people or they are withdrawing and not prepared to discuss it even with their wives or family or their own local doctor and how to get over that problem I don't know. I think it's an individual, I certainly believe it, it's an individual approach that men take and as I say I don't believe, I think they use the excuse that they want to keep their manlyhood (sic) and their erection, I think they use that as an excuse. I do, I don't believe it, deep down I don't believe that is the main problem. I don't think men are prepared to cope with it so they hide behind or mask behind their situation, "Well I'm going to still keep my erections and fuck the cancer." (Robert)

The same man described a similar issue with respect to men receiving a DRE, as part of the diagnostic process for prostate cancer. He suggested that men avoid the DRE

because of its association with homosexuality and anal intercourse. Furthermore, with respect to talking about such a practice, he suggests that it would be considered as taboo to admit to having received a DRE.

Well I think that's a fallacy too, I think that's another example of bullshit with men that they, you know, "No one's putting their finger up my arse." This is bullshit. This is absolute bullshit because it happens but they won't acknowledge it to another man. And you know, it happens, it happens quite regularly but they think it's lowering themselves to say, "Someone put their finger up their arse.". (Robert)

What these exemplars demonstrate is the powerful symbolism contained within the concept of masculinity, and the ways in which masculinity as an intra-personal reference point can manoeuvre men into taking actions that may not be in their best long-term interest.

### *Interpreting Information*

The men in this study diagnosed with prostate cancer found themselves exposed to an overwhelming amount of new information; information they were expected to interpret and make use of. However, the information received was not simply that transmitted by language. These men also found themselves experiencing new feelings, new thoughts, and new sensations as a result of their encounter with prostate cancer and its treatment; new information that needed to be interpreted accurately. It would be reasonable to observe, in the context of this study, that much of this new information was not contained in the mental lexicons of these men and, more significantly, the mode of interpretation was often absent or underdeveloped. It was the mode of interpretation that formed the reference point for the men in this study, and it was the absence or underdevelopment of this reference point that had the potential to cause difficulties in interpretation or outright misinterpretation. Therefore, the work of men in re-plotting this reference point entailed assimilating new information into their mental lexicons.

## *Interpreting the Evidence*

Interpreting the evidence concerns what men discerned from the information provided by health professionals or from the literature they read, which helped them to understand the prostate cancer or make choices about treatment.

Using the investigative process as a metaphor Dixon, the police officer in the study, painted a picture of how he viewed the process of gathering and reflecting on the evidence.

Oh ok, I've got the complaint the statement from the victim, I've got the report saying I've got prostate cancer ok, that's the offence, I'm going to investigate that offence so I learn what the elements are to that offence then I learn what the defence is to that offence, so you see the way, and then I look at all that gather the evidence so to speak uh, ok I'll take some additional statements, I'll go to the internet and read up, that's my taking information from other people, witnesses so to speak, so I've probably dealt with it in an investigative manner and probably to a certain degree it's been an investigation and the resolve at the end of the day is going to hospital. It's probably a logical process all the way I've gone through it and now I sit down and look at it and, at the same that I was going through that process I'm applying the 'KISS' [Keep It Simple Stupid] principle, this is what the offence is, oh yeah you've got prostate cancer, it's a serious offence so to speak if I can compare it to a wilful murder or something like that, do you follow what I mean that the highest offence you can have in a man (...) and that's probably what I've done all the way through, which would annoy the shit out of some people gathering all this information. But you're presenting your best case forward, the urologist is the Judge and you've been sentenced to a stay in hospital. (Dixon)

Gerry, the youngest man in the study, summed up the impact of seeking information and interpreting the evidence very clearly.

Oh I think it makes you feel more anxious personally just because it's another thing you've got to worry about, you've got to go and do the research for yourself and find out, and I suppose that forces you to look up the different things and say righto these are my options what are the different results of those how good are the results um what are the problems associated with it um so I suppose it gives you a better overall picture. (Gerry)

Robert best exemplified the idea of achieving a comprehensive view. However, for this man gathering the evidence, weighing it up, and making an appropriate decision represented not only control of the cancer, but also control of the PTSD. Therefore, seeking out the finest detail became an imperative.



I wanted the “fors” and “againsts” the uh- what treatments were available, what were the uh side effects, what were the permanent side effects what were the initial side effects, and as it would affect our life me and me (sic) wife, there was never a problem in relation to further children, so that didn’t worry uh I still have to follow through but I did mention to him in relation to saving the nerves on either side if possible uh naturally he couldn’t answer that until he’d done the operation. I went through with him with the radiotherapy I wasn’t [impressed] at all, and I probably spoke to five or six blokes at the bowling club, two of them had operations two hadn’t, another one sitting there with a big enlarged one so you know I sat for an hour, hour and a half with each of those and, and man to man hows- how you going how you dealing with it what symptoms you, and they were very very open with me. (Robert)

Herbert (77 years old) believed there probably was information about prostate cancer, but he was not aware of it. He contrasted this perceived information deficit with that of heart disease. Herbert was aware of the information about heart disease, because he had a long history of heart disease. He interpreted prostate cancer in a much more negative and anxious way than he did the heart disease.

[There is a real awareness out there about heart disease] [y]es, a real awareness and, you know, they seem to be able to do amazing things [about heart disease], but with prostate there isn't a whole heap of things, there probably are, but I don't know about them, or I've never known about them. (Herbert)

This participant also demonstrated the difficulties associated with understanding the use of statistics by health professionals, in explaining the outcomes or effectiveness of treatment. There is a sense in the following statement where this man described a mismatch between the modes of interpretation; the physician interpreted destroying 80% of the cancer as good, the patient interpreted keeping 20% of the cancer as bad.

Well [the radio-oncologist] said, one of the things the guy said to me was that it will kill 80% of the cancer but 20% will still be there. (...) [All I know is] that I've still got it, I just look at it, the 80/20 bit as being, what the hell the 20% is still there and will probably kill me anyway. (Herbert)

Herbert may, on the other hand, have been interpreting the information he received in a way that heightened his anxiety about the prostate cancer. Indeed, following his diagnosis of prostate cancer he decided not to read anything about prostate cancer because of the negative messages it gave him.

David: So researching prostate cancer and reading stuff about it, is that something that would help you?

Herbert: No, I guess, I've got this funny thing, I don't even want to read anything about it, does that seem silly?

David: In what way silly?

Herbert: Well, you know, all the stuff that's printed looks pretty negative to me, and I don't want to read about negative things, I only want to read about positive things. (Herbert)

On the other hand Otto, a participant receiving neo-adjuvant hormone ablation and radiotherapy, expressed a complete understanding of the literature he was provided with, and of the information provided by the radio-oncologist.

[H]aving read those books [about prostate cancer] and things and having had a few sessions with the Radio-Oncologist, and he said well the way things are at the moment he said that if we reduce the whole ball-game to a smaller scale [referring to reduction of tumour volume using hormone ablation] we'd have, we will have ever so much better chance of more or less hitting it straight on the head and getting rid of it. (Otto)

Other men referred to talking with the “right” people or hearing the “right” information. For Richard this meant sharing his understanding with his family, and checking out his understanding of what he had been told with them. He also emphasised talking with traditional practitioners because they knew what they were talking about. Therefore, this man was implicitly suggesting that it might be important to be selective about sources of information, so as to maximise the accuracy of interpretation.

[It's important] to talk about it and I don't believe that you should put it under the carpet because the more the family know, the more I know, the more people tell me, qualified people. I don't mean people down the track [who] will say, “Have you tried this remedy? Have you tried that?” Or something like that(...) (Richard)

Robert supported this idea, also identifying the importance of asking the “right” people. However, this man also emphasised the further importance of men actively seeking information, and doing so from a number of different reputable sources.

[Getting information out there is] very important, very important, I think men should um certainly enquire more you know and uh discuss more with people the right people you know, you know you can go and talk with an idiot you drink with or someone but you're wasting your time go to the people that, you can find them if you ask you know. (Robert)

With respect to using and interpreting the written word, in the form of literature provided by health professionals, Cecil identified how much it helped him in making a decision about treatment.

Well as I say that booklet that the urologist gave me was very good, it's an excellent book and that I thought was a real good guide, it explained everything and uh that really did help me to make my decision. As I say I mean none of us likes getting any disease but if the doctor had come up front and said look it's not going to be a bed of roses but these are the options, go home and think about them- I was, well I, you know as I say I feel I've made the right decision so as I say it's a bit of the pain in the butt sort of thing but you've got to live with it, you've got cancer and this is the treatment so (chuckle) so I'm quite comfortable with it. (Cecil)

While most of these men limited their discussion to interpreting the information gained from the doctor, or from the literature provided by the doctor, Richard extended the idea of interpretation a little further. Firstly, he referred to investing the information received with a degree of perspective; a reference to not using information to catastrophise or distort events. Secondly, he referred to understanding the source and nature of bodily symptoms, and therefore to not attributing symptoms incorrectly.

We, we, we do. We sort of, well I do anyway. I, I, I brush them away and say, "Ah, there's plenty worse than me. There's a lot that are not walking around. I think of the kids that have spina bifida and all this or spastic or something like that and I think, "Well what the hell am I grizzling about?" I've got nothing to grizzle about. And – but I, I can now, say, "Well yes, that pain, I know what it's from, I know what the symptoms are," I know from the Crohn's that if I get it up here that it's definitely Crohn's. If I get it down there, it's prostate. If I get it in the back and the hip, hey arthritis. Bugger this weather, let's go north." (Richard)

Therefore, for the men in the study, interpreting the information provided by health professionals and contained in the literature they read depended, in part, on the requirements established by their prior, co-existent, and ongoing experiences with illness. As such, interpretation of information also depended on the extant emotional state of these men, and consequently the degree to which they were able to contain the implications of the prostate cancer. Furthermore, and perhaps not surprisingly, the ways in which men interpreted information about prostate cancer depended on the ways in which they habitually interpreted information about difficult issues. Therefore, the ways in which the men in this study understood information about the prostate cancer and its treatment, and the ways in which they used this information, depended on the contexts produced and reproduced by their lifeworlds.

### *Other Messages Received*

The men in this study interpreted the information they received, from what ever source, as a way of making sense of the prostate cancer, and as a way through to making treatment choices. Apart from a regulated amount of information provided verbally by the urologists, and the literature that was also provided, all the men were left very much on their own to choose a treatment. Indeed, with the exception of one man who sought a second opinion and another who talked with six men about their “enlarged” prostates, none of the men discussed the options with anyone other than their respective partner. Some men, however, did seek information from the internet.

Consequently, there were very few “other” messages that were received by the men in this study during the peri-diagnostic period. “Other”, as used here, refers to additional human and media sources of information, or reactions to the cancer diagnosis received from those external to each man’s immediate family.

Herbert believed that the peri-diagnostic period had been a very negative experience for him and his family. He informed other people about his prostate cancer, but felt that the messages he received were pessimistic. Furthermore, there is an implicit suggestion that it changed the way these people communicated with him; people became guarded when talking with him. This left him with the feeling that he wanted to push the experience into a corner and leave it there.

Yeah, that's what I feel, and I know that I tell everyone that I've got it, I don't believe that, I tell everyone that I've got prostate cancer and you've only got to look at the horror on people' faces, but tell somebody you've got a bad heart, nobody worries, everyone says oh shit that's alright, makes some crack like go and get another one or something, you know. (...) I get that [response], oh I'm sorry, and I think shit, I tell them and I know how difficult it is, if somebody told me something, immediately you think shit what do I say? you know, and that applies to who ever I tell. (...) The look on people's faces you say well they think I'm going to die, and they will tread gently. (Herbert)

This reported change in the way in which other people responded to, or communicated with, the man with prostate cancer was further evidenced by another man in the study. It is interesting to note, once again, the non-verbal nature of the response.

The, the connotations [about dying] are there from different ones. You know, well I mean, you can, I have seen them, people we've been talking to and they say, “Oh what’s wrong with you?” or I’ve said I’ve had prostate trouble, as soon

as you say, “You’ve got prostate trouble,” I noticed a few people and this just maybe sound very weird but I’ve seen them take a step back as though you’re a leper. (Richard)

There were also messages received from what was not said or messages not received. Herbert, the participant with the history of IHD, again used what he perceived as the much more positive experience of his heart attack, to evaluate his experience of prostate cancer. Also, and of significance, was the manner in which this man referred to messages received from his body. The trajectory of the heart attack included a period when he felt unwell, and then a period when he felt better. In this sense, his body provided him with a message allowing him to monitor improvement. The prostate cancer provided no such message; its absence was therefore interpreted as bad news.

Never even occurred to me, No, with that illness [the heart attack] it didn't occur to me that it would be; I was told that, I guess the difference between the two things [heart disease and prostate cancer] was that the cardiologist said "You'll be fine, you'll get back to normal", but nobody has told me that where I am now, nobody tells me "you'll get along OK", but and I guess I believed that cardiologist because by the time you've had a heart attack you get to feeling better, you almost you don't have any worries, you think what's all the bloody fuss about. (Hebert)

Dixon received a message through the process of comparing two men he knew with prostate cancer. One man had progressed well following a radical prostatectomy; the other man had progressed poorly. There a sense in this narrative in which this man used the juxtaposition of “good progress” and “poor progress” to evaluate his own conflicted position about receiving treatment. There was also an implied question posed by this participant about his motives for delaying treatment; he considered the man who progressed poorly and wondered if, in the end, he would be acting selfishly by doing nothing.

[T]here’s a farmer I used to work for in my holidays, he’s got prostate cancer and he’s had the full-on operation; I didn’t manage to catch-up with him recently, but I saw him in the street for about two minutes and he looks really good and I think oh but- on the other hand there’s a guy here who used to be a senior person (...) and he retired two or three years ago, he’s worked hard in his retirement and now he’s got- he got a call probably in the last three weeks and he’s only got eight months and he’s got a prostate cancer. But he had an operation ten years ago and he hasn’t done anything since ten years ago, hasn’t followed it up; so that’s probably um; it’s probably made me think about it a little bit more and probably not take a selfish view and look at it overall. (Dixon)

The limits of treatment refers to surmised or provided information about the consequences or limitations of treatment, which acted as a reference point against which men were able to evaluate the impact of treatment (or no treatment) on their lifeworld. To the extent that some of this information was inferred, it demonstrates the way in which the interpretation of information may become skewed by other experiences and attitudes.

The importance of understanding the limits of treatment was clearly identified by Otto, using the analogy of buying a car, in which the salesperson provides the “gloss” but none of the important functional details. This participant suggested that salespersons consider their clients to be vacuous and, as such, easily misled. There is a sense then in which this man, in applying such an analogy, spoke of the need for transparency, the need to be involved, the need not to be patronised by health professionals, and the need to understand what the future held in store.

(...) [Treatment] is something dealing with you and I'd like to know what is happening and what the possible outcomes maybe as well. No it is important to know. It's like the modern day well that's a different thing again uh you buy a motor car today, first of all you walk into the shop where they give you this shiny pamphlet, it's got CDs in it and it's got some wood grained dashboard or something; not a mention of any of the mechanical details or specifications, and when you go and ask someone, those golden cuff-links lads and whatever brigade they are they don't know, so what does that, what does it really mean, how do they treat their prospective clients, as someone who hasn't got a clue so they can tell you whatever they want to. But no, I think it's important to include persons concerned about what sort of procedure, what sort of treatment and then what it does entail. (Otto)

Equally pragmatic, Cecil, who always erred on the side of optimism, wanted to know about the impact of treatment on his leisure activities. This was an important treatment limit for this man, as much of his perceived quality of life was invested in his sporting activities.

I mentioned to the doctor, I said I'm a mad keen golfer, and bowler, and he said don't worry about it, go for your life, enjoy it. (Cecil)

Inferences were made about the outcomes of treatment; inferences that signified hope and fear, and acted as potential precursors of adaptive and maladaptive responses to a lack of information about treatment. Herbert, who experienced the peri-diagnostic period as extremely stressful, found himself disbelieving and filling-in the gaps simply because the urologist had not taken time to reassure him he would not die.

[B]ecause nobody [said it wasn't the end], they said oh yes we can treat it even if it's in the bones, and I tell you bullshit, you know, you know, I've seen people die of prostate cancer before, when their time was up was when it got in their bones (...) (Herbert)

Another participant, Otto, who approached the prostate cancer diagnosis in a positive and matter-of-fact way, projected his hopes onto the future in describing the outcome of treatment as he was left to perceive it. It would be reasonable to observe that information about the outcome of treatment was presented by this man's radio-oncologist in the form of probabilities. This suggests that some men were left to extrapolate the data on the basis of nothing more than hope.

Well on, well I'd like to think that the treatment will reach the stage where, where the radiotherapy will actually be in the position to pin point and then eradicate, get rid of the- bombard the actual nucleus of the cause of the condition and ultimately uh I won't have it anymore. (Otto)

Cecil also highlighted the potential dangers of using myth in identifying the limits of treatment. This particular individual did not discuss his belief in the myth about surgery causing a cancer to disseminate with his urologist. Therefore, even though this participant's wife was a nurse, he was not disabused of the falsity of his inference and made the decision to have radiotherapy. However, the issue here is not the relative merits of surgery versus radiotherapy, but the dangers of basing inferences on spurious information.

Well I've got a theory it could be completely wrong, I think my wife has proved me wrong on this one, but as far as I'm concerned once they put a knife into your body, I feel it makes cancer in particular spread, you see it's um. As I say I can be completely wrong. (Cecil)

There were treatment effects that, although not of a life and death nature, did disrupt the participants' usual routines. Gerry contemplated the limits of treatment with respect to the length of time he would be incapacitated and bored following surgery.

I'm going to be incapacitated basically for five to seven weeks uh where I think and I don't know but the first three weeks I'm going to be sitting on my arse watching television which drives me nuts um but boredom I don't like sitting around. (Gerry)

Richard reflected on the greater disruption to his life as he described curtailing his life until the treatment had been completed.

I mean there's a lot - but probably looking at it and since I've been diagnosed, I mean we always used to go up north in winter because of my back. It's curtailed that a little bit but that is only for the moment until I get whatever treatments have got to be done or what phase I've got to go through and once that's settled then well, it's life as usual, up up and away. (Richard)

These men referred to putting their lives on hold, removing their daily expectations of the "normal" to another point in time so as to accommodate the treatment process. This, putting one's life on hold, is reminiscent of a rite of transition, the marking of an individual's journey towards a new social status (Beattie, 1964). If this is so, what these men did not talk about was a process that facilitated such a transition, nor was there mention of the social status that would follow. Therefore, it would appear that in the secular church of health care the relevance of such a rite was silenced.

Also silenced was an honest discussion about the meaning of the feminising effects of hormone ablation therapy. It is evident, in the following extract that neither Richard nor the doctor was able to talk directly about the meaning of hormone therapy, without making use of a gender laden comparison that challenged Richard's ability to cope.

Well it's rather strange. It'll mean that, they say it's a ladies or women's treatment [hormone ablation therapy] but they say, a lot of friends have said, "Oh you never know, you might come out with big boobs," and I say, "Well I might get some money out of this. I could go on the stage." They've, they've explained to me, or the doctor explained to me that, that what I could get could be hot flushes. He said, "You'll be like a woman then," he said, "They go through them. Sweats," He said, "You might get a night sweat." He said then, "Apart from that you might have diarrhoea and those sort of things." He said, "Do you think that will stop you?" and I said, "No." (Richard)

### ***Clarifying the Relationship with Medicine***

It would be reasonable to observe that none of the men in this study experienced any kind of conflictive relationship, with any of the doctors they encountered, during the peri-diagnostic period. I think it is important to recognise this lack of conflict as forming the context within which participants engaged with medicine. Of course, it is not possible to be sure that a lack of manifest conflict was a true indicator of the quality of the doctor-patient relationship, given the status of medicine in contemporary society. However, there were aspects of the doctor-patient relationship that raised some issues



for participants, even if they were not subsequently raised as such with the treating doctor.

### *Identifying the Urologist's Responsibility*

Generally, most of the participants believed that it was the responsibility of the urologist to provide clear and unequivocal guidelines about the most appropriate method by which to treat the prostate cancer of each individual. Indeed, this kind of guidance, if not prescription, had been the participants' usual experience with medicine in the past. However, all of the men in this study encountered a position taken by their respective urologist in which the man was provided with information and asked to choose their treatment.

This non-prescriptive position taken by the urologist created some confusion, and some anxiety, for the men in the study. Gerry, a 48-year-old custom's officer, summed up the nature of what amounted to role confusion by suggesting, "I'm a customs officer, that's what I do, you're a doctor, that's what you do, you make some decisions" (Gerry).

This same man experienced a similar non-directive response from his urologist at the time of the first consultation when he was asked to decide if he wanted to have a biopsy of his prostate to confirm the presence of cancer.

I went to the urologist and he did another digital rectal exam and he said it feels a little bit rough; we need to go and do a biopsy. Well he didn't actually say we need to do a biopsy we had a discussion about it and he didn't want to tell me to go and have a biopsy, so when I said to him well I don't really care, I'm not going to have a biopsy done if that's your attitude he said well you can't do that, I said well why not you're telling me it's not really important, the score's not high enough um he said well if something goes wrong and you die of prostate cancer you might sue me. I said well I won't give a fuck because I'll be dead, it won't worry me in the slightest. He goes oh that's not the attitude, I said well you tell me what to do if you think I should have a biopsy then I'll have a biopsy I don't mind, maybe I should have minded a bit more than I did but- he said I think you should have a biopsy, I said OK, that's all I want to hear, that's all I want to know, thank you very much, put me in for it, let's organise it, but he wasn't willing to say one way or the other at the start, so. (Gerry)

There is a clear indication, provided by the urologist in this exemplar about his legal concerns regarding the participant pursuing litigation in the event of an unfavourable outcome. This was the clearest indication given by any of the participants as to the urologists' reasons for not providing unequivocal guidance. It is interesting to

note that Gerry used a very clear metaphor to elucidate what he perceived to be the responsibility of the urologist.

You don't go to the guy that fixes your car and tell him what's wrong with it you tell him the symptoms but you don't tell him what's wrong with it, it's his job you know you don't tell a baker how to bake bread because that's his bloody job. A doctor is a doctor, you tell me what to do. (Gerry)

Herbert identified a further dimension to being provided with clear guidance about the best course of action to take in treating prostate cancer. This was the dimension of confidence. This participant refers implicitly here to the idea of anxiety, and being asked to make complex choices in the context of such anxiety. Therefore, he suggests that if the urologist had provided clear guidance and had been definite about the most appropriate treatment to offer, then this would have imparted confidence.

I just believe that he should have said, we'll do this, and I think this is important, it's important from the confidence point of view ... if he says to you these are the three things that could happen, and you've got the choice, and one of those things is do nothing, it doesn't give you much bloody confidence in the rest of the things that he said, so I would think that the doctor should say "OK Herbert, look you've got this and we're going to put you onto this ..." he knows which is the best thing to do, rather than give you a whole lot of options and ask "what do you want to do?", it's a confidence thing. (Herbert)

The notion of the urologist "knowing" and being the "expert" was reflected in the experience of another man in the study. Otto contrasted his complete lack of knowledge about prostate cancer, even following his reading about it, with that of the expert knowledge of the urologist.

It wasn't quite like this because he didn't talk about the treatment he said well read about it and then the choice is yours, and this is something that I didn't quite agree with because after all he is an expert in his field and still to leave the ultimate decision of which the client, in my case really hasn't got any idea or any detailed knowledge, that area is somewhat disturbing because OK I know it's my prostate, my decision, but I still, I'd be guided by his advice which uh wasn't forthcoming. I just looked at him and I smiled and said gee-wiz bit of a grey area, and he said yes extremely so (laughter). (Otto)

### ***Trust and Faith***

The concepts of trust and faith were referred to by some participants. There was a sense in which these concepts appeared central to the doctor-patient relationship, and to the confidence experienced by these participants. To some extent, the idea of trust

was contained within the knowledge of the urologist; the knowledge they had about treatment and what was best for the patient. Trust was also reflected in the way in which participants freely gave control to the urologist; control over treatment and therefore effective control over matters of life and death.

[I have to trust the doctor] I mean there's nothing more I can do, I mean all I can do I can just follow the instructions, take a pill in the morning, one in the evening and have a blood test and go and front up and- (...) there are certain areas where you can be in control but other areas where you can't. I mean this is one that I'm, I'm not an expert in this, I don't know what sort of tablets I'm [taking] now, what sort of injection I had, I mean I am relying on the expertise of other people. (Otto)

Moreover, there was a chain of trust that extended from one referring doctor to the next. Robert, the participant who also experienced PTSD, and for whom a trust in professional relationships was of paramount importance, trusted his GP to refer him to a urologist that would be appropriate, skilful, and knowledgeable.

Well yes [I trusted him] I saw him [the urologist] as that's his trade or that's his skill and even though you know, I'm the only one, I was referred from my own doctor to him without even asking, my doctor knows the way I am with him so I'm sure he wouldn't send me to someone I couldn't discuss with all my stuff because he knows I would. So I had that confidence. (Robert)

The idea of trust and faith was further reflected in the idea of always cooperating with the doctor. Cecil was asked if he believed that there would be any sanctions applied if he did not fully co-operate with the urologist. He was asked this question because he had demonstrated unquestioning loyalty and understanding towards all the doctors he had encountered. Also contained in this narrative is the idea that, in some way, having faith and being compliant represented an integral component of being cured. That is, those who do not cooperate do not get cured.

Oh no I don't think so [that things will go wrong if I don't do what I've been asked to do], it's a, as I say, the bottom line is that you've got to have faith in your doctor, so the doctor has said now this is the score, and as I said before, this is the score, what's the good of messing around, rocking the boat and bucking the system and acting like a yahoo is not going to fix nothing (laughing) so uh and I want to get cured so what is the point of messing these doctors around? That's the way I look at it. (Cecil)

### ***Relating to the Doctor***

It would be reasonable to observe that the majority of participants in this study acted with a degree of deference towards their respective doctors, a deference captured in the words of one man who stated, “the doctor surely knows what’s best for you (...)” (Herbert). However, some of the evidence for this observation was contained in what the men did not say about their relationships with their doctors, as opposed to those experiences that were told to me during my interviews with these men. The one man who did raise particular issues, with respect to relating to the doctor, was the only man in the study to decline the offer of traditional treatment in favour of a self-directed “alternative” approach.

However, it is important, with respect to context and equity, to identify that this individual was not in any way “anti” traditional medicine; the choice he made was not about proving traditional medicine to be defective. Indeed, this man always voiced great respect for the traditional practitioners he had encountered.

I’m very respectful of the urologist I think he’s been an interesting fellow, I’m respectful of the radio-oncologist and I’m, I’m an admirer of their endeavours for what they believe in, but I’m saddened because they, they are pre-occupied by that one searching track [of traditional medicine]. (Winston)

Nevertheless, Winston’s first difficulty occurred when the urologist made the assumption that Winston would agree to have a biopsy and, consequently, made the arrangements to do so without asking Winston beforehand. A couple of weeks later Winston called the urologist to tell him that he did not want a biopsy.

I rang him and said that I didn't want the biopsy, I'd spoken to my doctor [GP] and I wasn't looking for any encouragement for people to tell me to go for it or not go for it but I was a little apprehensive about [the fact] (...) that biopsies have their own little issue um so I thought what is it here so I discussed it with my doctor and he said well it's your call, naturally enough, and so I said well I'll go for a postponement came back here and phoned the Urologist, and he wasn't very happy you know I mean his tone was; [I] was inclined to think well um you know what is it, I said well look I'm going through a course of my own and I've just decided that I'll have another PSA done [before agreeing to a biopsy], and he said 'well look you can have as many PSAs done as you want', that was sort of like the closing comment, and I said OK then I will (...) [W]ell he was probably working on the basis that look I've seen these numbers up this high before, I've given people a fortnight off, a month off, and it doesn't come down I'm sure, you have as many as you like to make, to make me feel as though, appease me (Winston)

The urologist was keen for Winston to have the biopsy. However, Winston felt as if the urologist was not taking his position seriously, that he was being mollified, and therefore patronised. Indeed, Winston felt as though there was no real understanding between him and the urologist; that it was difficult, perhaps, to relate to a man that was so single minded.

He asked me in conversation how was I getting on how was I feeling, and I said good, which was not telling any fibies (sic) you know it was the truth um when I told him I was researching more deeply [about prostate cancer] and needed to postpone the biopsy procedure I felt that he was a little bit short about it although he said well look (...) I, I'm sure that we'll need to do it sooner or later and then (...) no, there was no specific, (...) how do I use this, no fondness between the two of us in terms of where you know I was at, and this and that; he (...) was gracious but he wasn't into it [alternative approaches] like I was perhaps and that's not being critical it was, he he's always remained (...) matter of fact, clear cut, dresses that way too (...) (Winston)

Winston felt uncomfortable about such an encounter, and was left feeling as if he had been subtly coerced, albeit that he maintained his resistance. There was also a sense in this interaction in which Winston's opinion, or position vis-à-vis treatment, was not valued by the doctor. Winston used the language of hierarchies as a way of explaining the interaction and, in this context, presented his behaviour as essentially aberrant; not conforming to his usual temperament.

Yeah, I felt uncomfortable, I felt as though I was um I was baiting him, I felt as though I was giving the indication that I wasn't so sure of what he said ought to be done, I felt uhh as though I needed to gather some forethought and some strength in myself to deliver the comment that I wanted the postponement uhh I remember thinking that I had to have the courage to do it because after all this man knows his business OK, so there was this higher versus lower um academia or you know so if I may be permitted to say I I think that I could have gone through the procedure but I needed to be sure I had the courage to deliberate and investigate myself for after all, it is me that we're dealing with. Normally my behaviour is to oblige the other person (...) (Winston)

In some respects Winston felt shut out, not listened to, not involved in the decision making that anticipated the treatment of his prostate cancer. He was presented with an obstinate silence about alternative approaches, both in the literature he read and in his relationships with the specialists. He therefore felt judged by the protagonists of traditional medicine in a way that did not speak of mutual respect.

[I didn't like the] little book I didn't like any of them, (...) but he [the urologist] was like the book and the book was like him, and the book and him and the other

guy [Radio-oncologist] were similar they all fitted into this schooling thing and um and not one of them not one of them not even the book had, there's a little chapter in here about other therapy [pointing to the book called Localised Prostate Cancer] just a little snippet um but none of them were encouraging me to investigate my own condition in terms of the time frame, and there was no encouragement to look outside the specific information that they had given according to the results they worked with. And there was no, I'll get this word in a minute, there was no (...), there was no therapeutic flavour in it at all there was no light brush stroking of you know, 'I don't know maybe you could', there was none of that there was a picture with a frame around it and that was it. (Winston)

When Winston finally informed the radio-oncologist of his decision not to accept the offered neo-adjuvant therapy and radiotherapy, he received a letter advising him that the radio-oncologist did not agree with his choice but would accept him back into a treatment programme if he changed his mind. I asked him how he interpreted the letter he had received.

Well I interpret that a little bit like that's what I expected, I expected that because I know that in a way I'm walking away from the collection of opinions that are now channelled to take all of us down this thing like a tube train in the direction of the radiation; having (...) become aware that I was now not so much the nigger in the wood pile but a person who was stepping aside from the conditioned and (...) scientific belief that this ought to be the way to go, and I'm respectful of that but (...) I knew that I was away a little bit from the [traditional] course of opinion that I would get somebody saying things to me - well why are you doing it are you sure of what you're doing and I have discussed this with you before and you know you could be poisoning yourself with the nutritional aids that you're using (...); but I also felt that they had to protect themselves and they had to prove in a funny sort of a way that they are righter than I am right (chuckle) if I can put it like that and, and they know what they're doing and like anyone like a father or any figure person um he likes you to believe in what he's saying and if you're not doing that it casts a little bit of a spell or an element of doubt on their opinion (...) and it's a lovely letter you know it's a matter of fact letter but he has [left] open - he's not saying well look-like they may have said five or 10 years ago don't come back (...); so even he is improving (...) [although not] in terms of becoming more able to adjust to a person's right of opinion. (Winston)

Although Winston did not state categorically that the ability to relate well with the doctor was an imperative, he did suggest that the quality of the relationship could be adversely affected for a number of different reasons. On the other hand, another man in the study suggested that the nature or quality of relating was not as relevant as getting on and doing something about the cancer.

(...) I can't say that the relationship between the doctor and myself is an unpleasant one, it's not at all, but uh perhaps it's his personality I mean each and

every person displays a different sort of reaction to certain issues. (...) I think it's like uh doing a job, I mean some people find it important that you have to be liked or you like someone, well I don't think that comes into it. If you've got a job to do then, you might not like it, or the other person might not like it but you're going to do this and that's what you're doing. (Otto)

This position was supported by Cecil who also believed that finding a solution to the problem was more important than relating with the doctor in a way that would cause problems.

I don't know if it's my nature or not David but [if] a problem comes up [with treatment] I don't give say an immediate response to it, the bottom line is always what's the solution, how can I get to that point and making waves and things like that, it's not going to help you. (Cecil)

Other men in the study were happy with the way that they were able to relate with the doctor. Dixon felt that the urologist he consulted presented him with the options, but did not try and coerce him into accepting immediate treatment when he indicated a need to think about his future options.

[The urologist] sort of indicated the earlier you have the surgery the better off that you are, but he wouldn't push it, these are your options and you do this you do that and without being pushy saying you must get it done you must get it done. (Dixon)

Robert reported that he felt he had developed an appropriately direct relationship with his doctors, one in which he believed himself to be part of the treatment team. He did his bit, and they did theirs.

I look at [this] as a team but I believe they've got their own skills; that's his job, that's his job, this is my job. My job was to get myself fit for the operation both physically and mentally accepting the operation. The surgeon, I'm satisfied that he's skilful enough to perform it, the anaesthetist, a very confident man who- and he was sitting beside me when I woke up in the recovery room showed that they are all professionals in their job and I think I was probably a professional patient. (Robert)

### **Responding Mind-Sets**

A mind-set describes the habitual or characteristic mental attitude that determines how an individual interprets and responds to situations (Knowledge News, 2004). Extending the definition, the responding mind-set would refer to the mental

attitudes demonstrated by the men in this study as they interpreted and responded to the prostate cancer.

With respect to this study, this description of the responding mind-set underestimates the complexity and plasticity of the process that was involved in the construction of each man's response to the prostate cancer experience. Such a description does not incorporate the social, emotional, and intra-personal contexts of each man; nor does it allow for changing contexts as each man constructed and reconstructed their own experience, and their response to that constructed experience, over time.

Therefore, the responding mind-set, as used here, is best understood as the progenitor of a dynamic mental process. Such a process integrated the intra-personal, the social, and the emotional, so as to enable individuals to construct and reconstruct their contextual response to prostate cancer from moment-to-moment. In this sense the responding mind-set represents the initiator of a reflexive process.

### ***Buying Time***

Buying time was a significant responding mind-set; one that allowed some men to slow the process down so as to support their present or future engagement with the prostate cancer.

However, Robert believed that some men viewed prostate cancer as a death sentence, and therefore avoided talking about (and taking action against) the cancer in the misguided hope that the cancer would go away.

You know, I think a lot of men accept it as death sentence and I refuse to. I just totally refuse to. I would never have accepted it as a death sentence. They think if they don't talk about it it will go away, well they're only kidding themselves and then they leave it too long and that's when you get all the complications.  
(Robert)

No evidence was provided for this participant's position by the other men in the study. Be that as it may, I would propose that what this participant alluded to was not an anticipation of death, but the potential impact of future loss symbolised by the prostate cancer diagnosis and its treatment. It was this future loss, I would suggest, that two men in the study sought to mitigate by adopting the responding mind-set of buying time.



The first man, Herbert, who had received a PSA assay four years prior to the first interview, had put off having a biopsy, partly because his GP had advised him to do so. There were no feelings reported at the time that he anticipated dying because of the raised PSA. However, it would be reasonable to conjecture that, for whatever conscious reason, he did not feel ready to have a biopsy performed.

Yeah well that was in 1990 [that I had my PSA tested], I reckon I first got it four years ago. (...) [My] PSA was fairly high, but they decided not to do anything about it. (...) The doctor I was going to at the time said it was better just to leave it. (Herbert)

So Herbert did nothing, and continued to do nothing, but over time, he did experience some dissonance about his choice. Eventually, Herbert found the dissonant feelings more difficult to sustain than the desire to postpone seeking a biopsy.

Yeah, well, it was [difficult to have that information about the PSA in mind] and every time I thought [of] it, every time I came back from the North, I thought I'd go and get a test [a biopsy], you know, eventually that's what I did. (Herbert)

However, at the point at which Herbert decided to seek a consultation, so as to have a biopsy performed, it is highly likely that he was prepared to do so. Therefore, it is equally likely that Herbert's responding mind-set had bought him some time by allowing him to engage incrementally with the possibility of future loss.

Dixon, the 54-year-old police detective, was the second man to use the responding mind-set of buying time. This man did not postpone the prostatic biopsy but did postpone, for almost exactly one year from the point of diagnosis, his decision to have a radical prostatectomy.

[I am not having the prostatectomy] not at this stage (...) we've made an appointment to see the urologist (...) so I'm going to take feedback and he can explain it to her [my wife], she wants to know what the options are even though they're in the book, what the options are if you don't have any treatment, but I think at this stage he was talking about option one which is a watching brief, that's one of the options or we can go and do the op. (...) [Regarding the options] I probably have a very selfish view and not looking at it overall, my reaction was; oh well maybe- I'm into motorbikes and I've done a couple of trips across Australia and one around Australia and I was thinking perhaps I should do one more trip before the operation so to speak; then take it from there and, and not jump in now, get the operation over and done with, get the sex side sorted out (...) I think at this stage I would probably like to monitor it for six months and see what happens from there. (Dixon)

When presented with the diagnosis of prostate cancer Dixon was not ready to accept that the time was right to have a radical prostatectomy. He found the idea of post-operative impotence difficult to accommodate, and needed time to work through the new experience of recognising the presence of others in his world who wanted to share, and support him, in the journey.

The responding mind-set of buying time, as just described, assisted in the mitigation of future loss associated with the diagnosis and treatment of prostate cancer. However, a second, and perhaps less obvious context, for the use of this responding mind-set had to do with mitigating the future loss of life itself.

Dixon had found the possibility of a loss of sexual potency difficult to accept; he bought time so as to reach a point of reconciliation with himself with respect to this future loss. Yet, in the final analysis, the desire to “buy” more time to live became the symbolic altar upon which he was prepared to sacrifice his potency.

But I can probably say this, “I don’t want my potency taken away, there’s going to be a stage when it does get taken away, but I want to be around. When, when it gets crucial, potency can be taken away as long as I’ve got a couple of years above that’. (Dixon)

Another participant, Gerry, the customs officer, also referred to the idea of buying more time, with respect to longevity, when he talked about the children living at home and of things still to do. There was a clear sense, contained in his words, in which he was expressing the future-oriented need to complete unfinished business.

I want to live past 65, I’m 49 in a month or so, I want to be alive, I’m going to retire at 60, I’ve got things I want to do, my wife and kids and stuff like that and travelling to do and stuff like that, so you know to me 75 is a pretty good option to kick the bucket, I don’t care, if I’m still reasonably fit and healthy and can walk around um, that was one distinction my mum always made was that I want to die with my marbles intact. So that’s the same for me, I want to be reasonably OK to get around, but I don’t want to die at 65 I’ve got too much to do. (Gerry)

### *Acting Sensibly*

Acting sensibly exemplified an important responding mind-set that facilitated men’s engagement with the peri-diagnostic experience, through the application of values associated with being logical, establishing priorities, acting in time, being disciplined, and acting with regard for self and others. The application of these long-held values provided men with an algorithmic device that acted to trigger their response

to the prostate cancer and its treatment. Acting sensibly also furnished a catch-all mechanism, albeit implied, for camouflaging difficult feelings associated with the prostate cancer and its treatment.

Cecil, for example, believed that counselling assistance for people in general was overdone. He implied that it was up to each individual just to get on with things.

I've come from the old school, I wasn't affected directly by the second world war but you know your parents were and friends of ours and (...) the thing is you used to say well look it's happened get on with it and, but these days "oh you poor dear you need counselling, you need this you need that"; I mean we all have these tragedies and this sort of thing but all right, well that's my theory anyway, I most probably would be different if it affected me more deeply sort of thing you know but um I think they do go overboard with counselling and this sort of thing these days. I'm not saying it's not necessary it is in some cases but I think they overdo it a little bit now. (Cecil)

Cecil was not criticising those people who required counselling, but he did use the apparent criticism as a way to dissemble his own concerns, and to steady his resolve to just get on with it.

(...) I do the best I can to get the best treatment I can [with] what's available now you see and that's the way- it's no good saying oh well just curl up in a ball and play dead sort of thing, so you just keep going on. (Cecil)

This position was supported by Otto who, when talking about his encounter with the urologist, and asked if he felt the relationship was an important one, also dissembled.

I hadn't really thought about the importance of it [the relationship with the urologist]; I mean what I found important was to get on with it and get something on the way and then resolve something. (Otto)

Furthermore, acting sensibly provided a safe way of engaging with doctors and medical treatment. Trust and faith was described previously as a means by which to circumvent the dangerous possibility of clashing with medicine; acting sensibly, as a responding mind-set, furnished another approach to the same end.

The way I look at it David is that, all right I've been diagnosed with it [prostate cancer] (...) I don't like it (...) and I want to get cured, and the only way I know of getting cured is is taking medical advice and going through the programme that's been set and (...) that's the only way I feel anyway that you know I can get a cure for it, so so it's straight down the middle (...) (Cecil)

For Dixon, acting sensibly meant being methodical, being direct; and reducing the factors associated with events to their simplest terms. Of course, it is reasonable to suggest that in the process of reducing events to their basic terms, Dixon was able to disassemble the feelings associated with those events.

I can have a direct way of dealing with things and it may offend some people um I use the KISS principle, keep it simple stupid, (...) if you've got a scenario I can usually carve it up into black and white or into something really simple. (Dixon)

Equally direct, Gerry was able to identify his clear objective in seeking treatment for the prostate cancer. For him, the only priority was to receive the most effective treatment that would provide him with the quickest positive outcome.

[Hormone] [a]blation therapy, OK, for three to six months before [curative treatment] well, shit, that defeats the purpose, you know I'm going there to do a fix up job to get it fixed and get out. (Gerry)

Acting sensibly, for Robert, was always defined as acting so as to prevent or attenuate the anxiety associated with his PTSD. He knew that unless he was able to control the anxiety, he would be unable to make reasonable decisions about the prostate cancer and its treatment. I have mentioned previously the idea of the PTSD acting as an amplifier of Robert's difficult feelings, and the ways in which he prevented them from exacerbating anxiety. Here, in the idea of acting sensibly, is another example of this amplification effect providing an insight into the way in which Robert used a responding mind-set to prevent anxiety.

Well the PTSD is probably me (sic) first priority; um if I can't control that your emotions go, your depression comes and so the other things become irrelevant, because when I get depressed I'm not interested in anything so for me to make a proper and precise decision on what to do the PTSD had to be rectified, had to be controlled first, and I wouldn't have made a decision if I had of been as I initially come over [to Western Australia], so I've now set my life, I don't- I'm home a lot but I do a lot of self meditation and breathing exercises and relaxing uh you know and uh the exercises and whatever. I've changed my lifestyle, (...) so in every aspect of my life I make a judgement in everything even driving a car or whatever, um I never get- I never try and put myself in the situation that may inflame; a car can go past me and drive like maniacs [I] let them go I just stay in my set lane and go at my speed, I don't let outside things influence me and upset me. (Robert)

However, acting sensibly was not always as clear-cut as the application of a mind-set might suggest; sometimes there were conflicting priorities involved. Dixon provides an example of the difficulties encountered when two responding mindsets interact and confuse prioritisation; in this case buying time and acting sensibly.

[A] [l]ittle bit of pressure from someone [his wife] but at this stage I'm tossing up whether to have the operation very early in the year or go for a bike ride four or five weeks then come back and have the op. I'd probably like a little bit of guidance from the urologist as to how long it takes one to get over the operation and to have the strength back to ride a bike and go on leave and recuperate at the same time. I don't know how long that takes. (Dixon)

Dixon asked the urologist at what point, post-operatively, he would be able to manage lifting his motorbike should it fall over. Dixon did not ask the urologist how long he could safely postpone surgery, in the context of the rate of growth and potential dissemination of the prostate cancer. Dixon postponed surgery, went on his journey, and when he came back he had the radical prostatectomy.

Dixon was aware that his wife and daughter were concerned about the progression of the cancer. He was also aware that his wife and daughter defined acting sensibly as having surgery as soon as possible. However, Dixon placed acting sensibly in the context of his lifeworld and, taking everything into consideration, made a decision. By making the decision to go on the journey Dixon bought some time to accommodate to the need for surgery, and to the future potential loss of his potency. He therefore mitigated the potential conflict between acting sensibly and buying time, by incorporating the two mind-sets.

Indeed, in the end, using a rich metaphor suggested by his motorbike journey, Dixon revealed his insightfulness, his wisdom, and his hopes for the future when his rite of passage, his journey was completed.

Dixon: (...) I do know at the end of the day I can't ride this one out. (...) Because it's [prostate cancer] in your face media wise and now you pick up more and more in the paper, oh I know what I wanted to talk about. In the West going back a couple of weeks ago, [my] daughter's ringing me up, "When are you doing something about it Dad?" because they had a series of articles on it and I was getting the phone calls and the reminders as well and that was in the West and they did a very comprehensive article on it. I didn't keep it, my wife may have kept some of them so I do know, plus with the reading in hand that I'm not going to ride this one out. It's just a matter of when I don't ride it out and decide to have the operation. Yes, I'm not, not that naïve, I'm not going to ride it out; I won't be able to ride it out.

David: Okay, so that suggests then, there are more important things to you than just potency.

Dixon: Health. I suppose, there's health. I'll be still able to run, do all those sort of things. I still want to be able to mow the lawn, still want to be fairly active. (Dixon)

### *Active Optimism*

Active optimism refers to a responding mind-set that contains the certain belief that the future will turn out well in the context of appropriate behaviour. Therefore, active optimism contains both an attitudinal and action component; a belief that difficult events will turn out well, and a propensity always to act in a future oriented manner so as to support favourable outcomes.

Dixon believed in fate, but also believed in his ability to control some life events, even in the context of prostate cancer. His ability to control events was connected to his belief that it was possible to influence the future favourably.

It's a paradox um; it's probably; it probably comes back to my job as well like you see some senseless things and you think; we had one here three weeks ago where a guy got knifed, got knifed by his best mate and you think his number's up; he had no control, he didn't even know what was coming, he expired on the spot. That's what I say if you're on a bike and somebody takes you out your number's up you've got no control over that but, with this [prostate cancer] I've got a certain amount of control, that's how I look at it; I know it doesn't equate but that's probably the best way to explain it. (Dixon)

Moreover, he was always able to reframe what initially appeared to be a difficult event as something more positive, more future oriented, and more hopeful.

There's still a future. Thing is you haven't been given a sentence have you, a death sentence? Not at all and, probably being selfish again as I reflect on the good years I've had and I'm certain that I've got a lot of good years in front of me; just I guess it's just being positive about it. (Dixon)

Another man, Gerry, was able to generate a positive outlook by using the statistics he had been given by his urologist. However, the responding mind-set provoked a response that enabled him to choose the more favourable perception.

Yeah it's a more positive outlook; when you say that in 10 years there's a 25% chance you'll be dead, well now with me [after treatment] there's a 75% chance

I won't have to worry about the 25% or the 75% you know there's a 70% chance that I will hear no more from this cancer. (Gerry)

Equally, Cecil demonstrated an ability to remain confident that he would be cured, and was able to hold this belief in mind as he engaged with treatment. His confidence had the further affect of controlling any anxiety he may otherwise have felt.

No, and I feel confident that I'll be cured, that's at the back of [my] mind all the time now, OK, we go through this hormone treatment and then we have radiology and hopefully that should fix it, so that's put my mind at rest, I'm not anxious about it at all. (Cecil)

Robert, the participant with PTSD, had deliberately developed a mind-set of active optimism as a way of controlling anxiety. Therefore, when presented with the prostate cancer diagnosis his first thoughts were directed to the future and to the certainty of cure.

Well I thought how am I going to cure it, that was my first thought, ok I've got cancer, now what are we going to do, what's the next step. (Robert)

### **Minimising the Emotional**

None of the men in this study demonstrated their feeling states emotionally in my presence. That is, none of the study participants were emotional about the prostate cancer or its treatment during the time I spent with them carrying out interviews. This does not mean that these men did not experience feelings about the cancer and its treatment, nor does it imply that they were not emotional at other times either publicly or privately. However, it would be legitimate to observe that for the majority of men in this study the demonstration of emotion was assiduously avoided, consciously or unconsciously.

Minimising the emotional might have represented one way by which the men were able to maintain control of a new and potentially life threatening experience. However, this is an easy inference to draw given the kinds of stereotypes associated with being male, and just as easy to conclude that the men were not demonstrative because they were being men. The reality, I suspect, was more individual, more complex, and more contextually driven than such simple cause-and-effect explanations might allow for. That is, the participants' constructed emotional responses to the prostate cancer experience appeared muted for a multitude of reasons.

### *Hiding Difficult Feelings*

Some men avoided the emotional content of the prostate cancer experience simply by not talking to others about their feelings, or by avoiding situations where they might have to do so. Dixon identified himself as a private person and isolated his feelings by adopting a position of staunch independence; presenting his position as a character trait, something solid and dependable.

[My wife] she's an outward person who likes to talk about things; I'm a very private person always have been and she's probably having difficulty in dealing with me because I'm so private, I don't want people to know my business um basically I can face it on my own; maybe; and um; because she's saying you have to tell your family; no I don't have to tell my family- I may have to tell them down the track, but not at this stage, I would never ever tell them until after the operation (...) (Dixon)

The same man, whose wife's former husband had died of lung cancer, also protected himself from potentially having to experience his feelings about the cancer by keeping the news about it from his step-sons. His motivation for doing so was sincere and complex, but the net effect assisted him in achieving his goal to remain emotionally "private" and separate.

[My wife's] (...) got two boys and they're 16 and 15 and she says what about the boys they should know, I said no (...) they've been through enough and particularly one of them the youngest one if you tell him I don't know how it's going to affect him because he was close to his dad and all that sort of stuff, and how come there's- you know you've got someone else mum and he's got cancer as well what's going on and- so probably being, for the right reasons or the wrong reasons we've been protective of the boys and when it comes to the crunch when I've been in hospital that's when we'll tell them not before. (Dixon)

Herbert linked the reasons why men do not tell, to the gender attributes associated with being male. In particular he contrasted men with women, suggesting that women talk about their problems but men do not. It is interesting to note that this man did not talk specifically about his emotional response to the cancer, although an emotional presence might be detected in the pathos contained within the following narrative.

I think, (...) women are more gregarious and so they tend to talk about their problems more whereas men uh- I go to a Club and there's, and I find out, I tell everyone I've got prostate cancer, you know, tell everyone and there's a dozen men there said to me oh don't worry about it I've got the same you know; but



they never told me before. They told me because I said look I've got prostate cancer, I don't know what's going to happen or how it affects me- half a dozen of them said oh don't worry about it, so that tends to bring it all out, but men don't talk about it (...) (Herbert)

The ex-prison governor, Robert, talked about the male work culture, and the way in which men who were seen as not being in control of their feelings were deemed not to be coping. Therefore, such a culture inhibited the telling of emotionally laden stories, by presenting men with the imperative to play out the “macho” image.

(...) I was debriefed probably eight to ten times in the seventeen, eighteen years I was in there [the prison service], you know, some major incidents I was involved in but [a] total fucking waste of time. But there was so much I would have liked to have let out but [I was] afraid to because of [the] repercussions. (...) They'd hold you, they'd hold you back on promotions and stuff like this because they'd say, “He can't cope with it,” so you'd have to play the macho fucking image. Not a problem, doesn't worry me and take it home. (Robert)

Men hiding feelings, is really no different from women hiding feelings, and is not, I would argue, a useful gender marker. However, there does appear to be a cultural expectation that women will be emotional but men will not (Lutz, 1996). Therefore, the difference between men hiding feelings and women hiding feelings is more about cultural expectations than it is about what women or men actually feel. However, there is a sense in which men might experience a “loss of face” unless they hide their feelings about events; something that does not happen to women.

(...) I don't know if it's a male thing or what, women show their emotion but men don't and I think women get emotional about their health whereas men don't they sort of, oh yeah, not a blasé attitude but, it'll sort itself out (...) (Dixon)

Dixon's observation is almost certainly true, in some contexts within which men operate; and is absolutely true in the context of his construction of hiding feelings. However, as a universal explanation it oversimplifies the complex nature of human behaviour by separating the explanation of behaviour from its context; social, cultural, and intra-personal.

For example, Herbert talked about the period between having a bone scan and receiving the results. He clearly connected his silence about his feelings to the expectations of people during his working life. So, he kept his feelings about the

prostate cancer to himself, even though he did not want to, because that was what he was used to.

Oh I experienced it and I worried about it, (...) I'm not a, most of those things I look after within myself. I'm not, which is not good, I tend not to talk about it, all those things people used to say to me in business; but you never worry, you're good, you're going to handle those things, and I used to say nahh if only they knew, if only they knew, because I do worry about it, or I did worry about it; but I wasn't demonstrative about it, so I didn't get up and shout that something had gone wrong, they used to say oh well I've got to fix [it] (...) Yeah, well that's the way I dealt with this I kept it in myself, which is not good. (Herbert)

Another man, Dixon, in talking about his experience with his family of origin, was able to explicate the context in which he learned how to manage the expression of his feelings. He further associated the period of his formative years with an historical moment when, and a geographical region where, men were “manly” and did not demonstrate emotion. Yet, it is interesting to note the shift between the context of his early years and the way in which he was able to admit to the demonstration of affection towards his children.

I believe I've got a manly approach to things. (...) It's that male attitude thing, and I think it probably comes back to my vintage as well as in my day, in my home town, my father never displayed any feelings to me, my mother displayed that type of feelings to me as well. (...) Yeah my family wasn't a touchy-feely family whereas my wife's family, they're, they greet each other with a hug and that, my family never ever did that if you know what I mean, my family never did that her family very much display that type of thing, I'm not used to it (laughter) and yet I do it to my kids. (Dixon)

Hiding feelings was also viewed as being practical; expressing feelings being perceived as a waste of time, something that represented a distraction from the real work of mending, making things right, or finding solutions.

[W]ell as I say we um I don't like to be overly emotional sort of thing I'm a little bit, not hard, but a little bit sort of practical you know, problems have arisen how do we deal with, it's no good balling your eyes out and um saying well you know um I don't know what to do or anything like that, and you just encourage each other and say ok this is, this is what's happened you know and we can do the best we can to get you right? (Cecil)

Showing emotion was viewed by Richard as something he did not do, had never really done, regardless of being reminded by his wife of the sometimes cathartic nature of his emotions when he did express his feelings. However, there was a sense in which

he was able to hide his feelings because it appeared that both his wife and his daughter worried about the prostate cancer on his behalf, that is, feeling by proxy. This idea of feeling by proxy might be an indicator of the way in which roles were taken up within Richard's family of marriage; and established a context within which the hiding of feelings was legitimised.

Yes well she's often said I don't, I don't show my emotions. I like to keep a hell of a lot of them to myself but when I do show it, I show it. She says, "You can get horrible nasty sometimes." "Well," I said, "That's everybody." I said, "You do the same to me." And no I do bottle things up but she understands it and it's been rough on her. She, she worries more about it [the prostate cancer] than me and the daughter in (...) [the country] is the same." But, no I, I just go along with it now. (Richard)

A further context within which to hide feelings had to do with what another man, Dixon, referred to as life compartments. Life compartments were a way of containing experience, a way of keeping components of his lifeworld separate, and a way of making sure that feelings remained hidden. The health compartment was a private compartment, and the feelings associated with it remained closely guarded; access to these feelings was vigilantly monitored.

I live my life in compartments which I do, um I have very few friends in the police force, but outside the police force I used to be an army reservist, they are my best friends, even though I ceased being a member ten years ago they're still my best friends, still see them still stay with them you know that sort of stuff and so therefore I do live my life in compartments, my army friends, the family on my side, the family on my wife's side, my work, I suppose you could say my recreation revolves around my motor bike and four wheel driving and that sort of stuff, and probably my health which is one as well; and no particular person except myself has got access to all those compartments. My wife might have access to a couple [of compartments] but overall not. (Dixon)

Maintaining life compartments in this way enabled Dixon to manage the affective component of his lifeworld, protect against interlopers, contain uncertainty, and achieve clarity with respect to his feelings about the prostate cancer.

No, [I don't feel confused at all about the prostate cancer] not at all not at all, probably because I see things in black and white like my daughter said (chuckle), localised prostate cancer. [It's black and white] (...) there's not a question mark hanging over it. (Dixon)

Feelings were also hidden, by maintaining a staunch bastion against the possibility of uncertainty. Cecil doggedly maintained that he experienced no uncertainty

associated with either the diagnosis of, or treatment for, prostate cancer. When presented with a question about uncertainty, or when encountering a potentially uncertain experience, Cecil immediately generated a positive re-frame that negated the uncertainty. That is, any issue that presented as potentially uncertain was converted into an action or a plan for action. Therefore, converting or preventing uncertainty in this way removed any intra-personal pressure to examine feelings of uncertainty.

No, [there was no uncertainty about the future] I think having gone through what my wife went through [with the bowel cancer], it was OK you've got it, so let's confront it and see what the- and the story you hear, people don't like statistics sometimes, but when they give you the statistics that 85% of men over 70 could have prostate cancer and then they come round to you and say a lot of people don't die of prostate cancer, they die with it, they go on you know. (...) I don't think there's anything uncertain, it's a question of making a choice. (...) [Uncertainty never entered my mind], no, no, I mean certainly you've got prostate cancer, how are you going to deal with it, there's no uncertainty about it. (Cecil)

I have previously described the role of trust in the context of the doctor-patient relationship. However, Cecil identified a further aspect of this relationship in the context of hiding feelings. He recognised the fallibility of the doctors but invested absolute certainty in their knowledge and expertise. Therefore, he pre-forgave any mistakes that might occur and trusted them absolutely always to guide him in the most appropriate direction. In so doing, Cecil was able to neutralise feelings of uncertainty. However, there was a sense in which this strategy acted as a double-edged-sword. By hiding his feelings, or potential feelings, in this way he made it difficult to do anything other than continue to deny, or hide, his feelings.

David: So the uncertainty, for example, of not knowing the best approach to treatment, the uncertainty of not knowing how that treatment will turn out, did those sort of things- [cause you any concerns?]

Cecil: I don't think so, you've got to have faith in your doctors, they give you the options, you've got to have faith in the doctor that they know their business. (...) Yeah, I must say I've always had faith in my doctor, he's an expert sort of thing, I mean doctors make mistakes I appreciate that, but basically I've had no sort of bad experiences from them at all (...)

### *Attenuating Difficult Feelings*

Though hiding feelings prevented men in the study from attending to doubts, uncertainties, or uncomfortable situations, buffering feelings suggests something

qualitatively different. Hiding feelings involved a process of removal or conversion so as to render the noxious, or potentially noxious, emotionally mute. Attenuating feelings, on the other hand, speaks of reducing the intensity of feelings so as to render them tolerable, therefore increasing the threshold above which feelings are demonstrated as emotion.

### *Being Stoic*

Being stoic speaks of a type of acceptance, a belief system, a way of viewing an event that renders it less traumatic. However, being stoic requires an understanding that an event possesses the potential to generate emotion.

Well you can't [control prostate cancer] I mean, I'm doing the best I can now to sort of combat it and rectify it, but it's, I mean (laugh) you've got something, you can't say well I don't want it, put it back, so as I say it's no good going hysterical about it and thinking the end of the world has come (...) (Cecil)

Just as Cecil suggested that it was of no use to think that the world had come to an end, Dixon identified the poor utility value of complaining. However, Dixon also points to a further idea contained by being stoic, which is the notion of storing up credit. That is, there is a sense in which longevity, or prior “good luck” during difficult moments, or good things that have happened during an individual’s life, somehow acts to ameliorate the impact of bad events (like prostate cancer) occurring in the present.

I've had fifty good years and um I can't complain um ten years ago I had a bit of a hiccough and um actually at that particular time if I'd been a smoker I wouldn't be here today so I feel that life's been pretty good to me and I've had good years, my kids are grown up from the first marriage and uh yeah. (Dixon)

Richard also spoke of the idea of storing up credit, but went further to suggest that prostate cancer was really an event that occurred in the scheme of things. That is, he viewed the prostate cancer as something that was part of life, a phase that he had to go through, no different from going to school or retiring from work. However, for Richard, there was further credit involved; there were family and people around him who were interested in him and his welfare. Therefore, he buffered his feelings through being stoic in two ways. Firstly, to “make a fuss” about the prostate cancer at his stage in life would have run counter to what he viewed as a stage in life. Secondly, making a fuss would have made him feel ungrateful, given the concern expressed by those individuals around

him. Therefore, for Richard, it felt more authentic for him just to accept the status quo. Accepting the status quo buffered feelings that had the potential to be disruptive.

(...) [A] friend who was here this morning as a matter of fact, she had her breast off when I had one bowel resection done with Crohn's and I grew up with her from school days, I knew her, I've known her for a long time and she was a person that I thought, "Well if she got breast cancer, she's going to go through the roof," but she dismissed it and so it's been a, "It's there, it's gone, get on with your life," and that, and that's how I feel, I mean, it's just another phase in your life. You, you come through, you go to school, you leave school, you go to work, you work, you retire and then you say, "Hey bugger it. Why do I get all these things at this stage in life?" But that's just, just how it's got to be. It's progress. Whether we've done something in our younger days, I don't know whether we should have done it but no, it doesn't really bother me when people say, "You've got cancer, how does it affect you, how do you feel?" It doesn't bother me. I can answer it and say, "Well I'm lucky. I've got people interested in my health and that's most important." friends, family, all that around you. (Richard)

Cecil talked about the way in which the prostate cancer treatment (radiotherapy) might prevent him from continuing, at least in the short term, to play golf, a game he was passionate about. However, the feelings such a possibility engendered were buffered by the idea of a trade-off; golf was traded off against the desire for a cure.

[If the radiotherapy impinged on my golf] I wouldn't like it but the bottom line is this is treatment for a cure; and that's what I want, I want a cure, so I forego my golf that's the end of the story, that's it. You can't have your cake and eat it (laughing). (Cecil)

### ***Magical Thinking***

Maybe not too far removed from being stoic, two men in this study used magical thinking as a way of buffering their feelings about the prostate cancer. Magical thinking is about providing explanations for events or experiences (like prostate cancer) that contravene the accepted laws of nature (Beitel, Ferrer, & Cecero, 2004). Moreover, explanations for such events or experiences usually refer to powers, phenomena, or principles for which there is little or no empirical evidence (Keinan, 1994).

Cecil talked about his life being directed by fate and of having a guardian angel. He believed that important events in his life had been directed in this way; coming to Australia from Rhodesia (now Zimbabwe), being diagnosed with (and cured of) schistosomiasis (Bilharzia), having the prostate cancer diagnosed while it was still localised.

[M]y whole life has been fate really, how we came to Australia was complete fate, and I thought there must somebody up there, or some thing, looking after me. (...) Well, the thing with fate is you can't foresee it, it happens at the time, and what ever it says, you're told about it and you've got to deal with it; you think you can see problems coming, you try to deal with it and suddenly just something happens and points you in a different direction, and you seem to follow that, and this has happened all my life. (...) I must have a guardian angel or something, it's just fate, something happens that points you in that direction, this is the way I see it yeah. (...) [Y]ou've got to be optimistic, as far as I'm concerned fate does play a big part in it, I don't know what it is, as far as I am concerned, that's the way it is. (Cecil)

For Cecil, fate had always been kind to him, had intervened at important moments in his life to ensure that he, or other people, made good choices about his future wellbeing. Magical thinking therefore warded off unmanageable feelings, as well as the anxiety associated with making decisions at difficult moments; if he followed his own injunctions, trusted in fate or his guardian angel, then all would be well. Therefore, he was able to remain optimistic about the prostate cancer and its treatment, and to focus all his efforts on mending the cancer.

Dixon also referred, albeit indirectly, to the use of magical thinking when talking about the prostate cancer diagnosis. However, Dixon was more practical in his approach, using erstwhile experience as the basis for comparison. Nevertheless, he identified that some events in life were left to the discretion of fate, were beyond the control of the individual. Therefore, although utilising a less intense level of magical thinking, Dixon was able to offset some of the more difficult feelings associated with contemplating the end of life.

I've been on my bike or motorcycle over east on five and six week trips, I've been on two of those, been around the top of Australia and the bottom and all that sort of stuff and I think well you know, at any particular time you could be taken out by a motorist or kangaroo or whatever but, here I think there is a bit of a control over it (the prostate cancer), I've got a certain amount of control over it whereas on a bike or in a car or at work or what's round the corner you haven't got control; but I also believe when your number's up your number's up as well. (Dixon)

### ***Using Personal Aphorisms***

Some men in the study used personal aphorisms as a way of accessing common, or cultural, knowledge dealing with the minimisation of emotion. These men used their personal repertoire of aphorisms as a way of displacing their difficult feelings onto the historical mass of all those who had encountered difficult feelings before them.

Moreover, personal aphorisms were a reflection of the “common sense” wisdom used within the family of origin to manage emotion. Therefore, the use of personal aphorisms allowed men to convert the emotional into the practical, and to reduce the gravity of perceived events (like prostate cancer) through the use of historical sharing.

[Y]ou try to live as long as you can and as healthy as you can, and if you can help it along the way then fine, but then if something happens that is life threatening what are you going to do about it, one thing is you can go and see a doctor, consult a doctor, see what their opinions are, if they can't do anything what are you going to do, at the end of the day we're all going to die so, no good worrying about it, that's the way I look at it, whether you die at 70 or 90, I mean you look at this poor chap in the Bee Gees, he got a twisted bowel or something like that, goes in for an operation, has a heart attack and he's gone, 53 years old, so [you] know it can happen to anyone, so as I say it's no good worrying about it, that's my philosophy in life anyway. (Cecil)

There was a sense in which aphorisms could be used as a way of postponing difficult feelings, such as worry; Cecil stated “I don't worry about things until they happen, or sometimes you can see something is going to happen [and then] you try and do something about it.”. Furthermore, worry could be avoided by being vigilant and then acting quickly when an event occurred.

Richard suggested, from a wider perspective, that the ability to laugh also prevented others from worrying, therefore adding an external motivation for attenuating difficult feelings. He also suggested a link between difficult feelings (worry) and a sense of personal gain; that is, what will be will be, there is nothing to be gained from worrying about it.

If you can't laugh, it's a sad world. I, I know. I've, I've often been told, they've said, “You joke about some bloody horrible things.” And I said, “Well, no good crying about it.” I said, “Why, why, why do we all want to be miserable?” I said, “There's enough of that in the world now.” And I was talking to another chap, he'd gone to Darwin. And I was telling him what I'd had trouble with and he said, he said, “Does it worry you?” And I said, “No.” And he said, “Well you never used to worry.” He said, “You never used to worry when you were working.” And I said, “Well, what's the point? If you're going to be late, you're going to be late. If you can't, if it's not there, it's not there, that's it.” I said, “That's my outlook on life.” He said, “Christ,” he says, “I wish I was like you.” (Richard)

Dixon, on the other hand, used an aphorism that talked about not dwelling on uncontrollable events. The situation he referred to was that of impotence, and he cast off the unnamed feelings onto the idea of the ego, while reaffirming to himself that he was



not dwelling on it. Therefore, by not dwelling on the difficult feelings associated with an event (like impotence), the uncontrollable was rendered somewhat controllable and the difficult feelings were attenuated. Furthermore, the time not spent dwelling on difficult feelings was liberated, to be used in other more practical ways.

If I can't control it I'm not thinking about it ... to a certain degree I'm thinking about it, but not, to a certain degree is probably uhhh, thinking about it ... probably the part I think about it is not the prostate cancer it's the fact that I have to go without- there's a possibility I might not be able to have sex, that's the male ego thing, cut your willy off what have you got? um; but I don't see myself dwelling on it at all uhh it's there don't get me wrong it's there in that I have to deal with it but I'm not dwelling on it. I have to go to the appointment on the fifth of July, but meantime I've got a lot of things to do between now and the fifth of July, I've got other things to do I'm still running and that sort of stuff. (Dixon)

Gerry's aphorism contained the message that life was always worth living, and that it was always more effective to look towards the "positive" than towards the "negative". Gerry also pointed towards maintaining activity; having things to do, keeping active, and having objectives. However, for Gerry, the aphorism's message also contained an imperative; it was unacceptable to view life in anything other than a "positive" way. Therefore, difficult feelings were attenuated by heavily diluting them with "happy" feelings, contented feelings, and events to look forward to.

[No I don't think about dying] [o]h shit no; what as in dead because of the cancer, nah, no I can't can't think like that, I have always had a positive outlook on life um I try and look at the better side of life you know, the glass is half full or half empty sort of scenario, but I suppose I've got things I want to do, you need to wake up and have some objectives to aim for to say right this is what I want to do. I like my work and I enjoy getting out of bed each day and going to work, because I work so that on my days off I can do what I want to do, but my whole attitude to life is reasonably positive and if you get yourself boxed and buried why are you bothering having an operation, why not just go and die, I think. (Gerry)

The idea of moving on was further explicated in another of Dixon's aphorisms in which he talked about the transient nature of difficult events, and therefore of difficult feelings. In being temporary, difficult feelings became graspable and controllable; with the motivation for action being similar to the "glass half full" idea expressed by Gerry.

[Prostate cancer is unfortunate] [y]ou live with it, just accept it, one of life's hiccoughs um ... I've got my mobility I've got my memory, you know the five

senses and that I think ... you know might- may not have a sex life but you've got all the other sense that you require and I sort of think if I was blind what would I do, yeah so that's how I feel that you just, it's a hiccup, hiccup grab it and move on, deal with it and move on. (Dixon)

I have mentioned previously the idea about displacing feelings onto an historical mass; the idea of a sharing of cultural knowledge held by those in the past. Cecil, however, was able to attenuate difficult feelings associated with prostate cancer through a sharing of another man's experiences of prostate cancer in the present; the tacit use of the aphorism "a problem shared is a problem halved".

[I]t's just a reassurance that I know somebody personally who's going through the same thing. (...) It does sort of reassure you that it can be treated. (Cecil)

### *Containing Worry*

While aphorisms frequently contained an indirect call to action, containing worry was an immediate and direct response to difficult feelings so as to attenuate any harmful effects. This strategy was predominantly demonstrated by Robert, the participant with PTSD; and was therefore a learned response aimed at achieving an immediate attenuation of difficult feelings by way of taking direct action.

I wouldn't muck around, I don't put anything in my mind that is garbage you know it only creates further worry so, I've had to retrain me (sic) brain and that is the way I can get sleep, and if I can't get sleep I get depressed. (Robert)

It is worth noting, however, that the PTSD acted as an amplifier; by which I mean that the PTSD provided many of Robert's responses to the prostate cancer with a presence. That is, without the imperative to contain the anxiety driven by the PTSD many of Robert's response to the prostate cancer might have gone unnoticed.

Therefore, for Robert, immediate action, often in the form of journaling his thoughts, feeling, concerns, or actions, became a way of attenuating anxiety provoking thoughts and their attendant feelings. With respect to the prostate cancer, he documented everything that he did and all the choices he made; and wrote to the doctors asking for answers to specific questions, or informing them of decisions he had made.

[As] I stated everything I done I documented, and I got it out of my brain; if I'd not documented everything I'd done it might seem funny, it obviously was funny to the urologist that I was able to, he's never had letters sent to him asking questions he's never had letters like this; and you know being so blunt in [my]

approach and [having] a positive approach and whatever, he's never had that from anyone but, I probably haven't gone in as [much] depth as I have with you that [is] (...) because of the PTSD, and that's the way I've dealt with everything um, you know I collate everything and uh everything is exactly where I have it, I know where I am [and] what I'm doing so I don't put any stress on meself (sic). (Robert)

Furthermore, Robert needed to manage his time in a routine manner, always being aware of the signals being provided by his body, slowing down, and eradicating difficult thoughts and feelings from his mind.

Yeah, your whole daily routine um even getting up in the morning I know how my body reacts so when I get up in the morning, there's no rushing for me whereas before in the jail it was fucking rush rush I had to get there it's like clockin (sic) on like you know it was crap you know, and uh you know I had to be properly dressed and what ever, it's regimental, [that] shit is out of me (sic) life and I've, it's no longer in me (sic) brain. Initially I was still fighting prisoners and crims and occasionally it comes back an incident might trigger something like that but no, I've had to retrain myself and I don't sleep well but I know that I've got to go through a routine in the morning prior to getting up I'll do the breathing exercises, they've done everything to me everything but blow me (sic) arse up that's about all you know, I've tried everything. (Robert)

Being able to put things out of his mind in this way allowed Robert to contain the worry associated with the prostate cancer; it became an extension of the way in which he managed his PTSD. The idea of putting things out of mind was also used by Richard, as a way of attenuating difficult feelings associated with the prostate cancer. Therefore, even when presented with a potentially difficult treatment regimen and a borderline-high Gleason score, he was able to contain the worry.

I know it's [the prostate cancer] there. I've put it in the background until such time it wants to say, "Well you better think a bit more about it," but as it is at this point in time I was a bit disturbed when they said, "You're going to have to go onto tablets and the implant and then maybe Radium down the track," and I thought well, thinking back and they said I'm point eight or eight, eight, score of eight out of ten on the scale, I thought, "Well maybe it's a little bit worse than I thought." But no, I, I honestly can't say that it worried me. (Richard)

### ***Mitigating the Perceived Severity of Prostate Cancer***

Mitigating the perceived severity of the prostate cancer had to do with achieving a diminished perception of danger, either real or imagined, through a process of comparing self with others. Individuals diagnosed with prostate cancer, or other diseases, whose cases were judged to be "worse than mine", generated a feeling of relief

for not being in a similar category. Other men, diagnosed with prostate cancer and successfully treated, generated a feeling of confidence. The net effect of either scenario was to attenuate the perceived severity of the prostate cancer or its treatment outcome, which subsequently provided for an attenuation of difficult feelings that might otherwise have been experienced.

Dixon, in comparing himself against children, was able to identify a position in which he felt unable to complain about the prostate cancer. In the process of this comparison Dixon tacitly diminished the status of the prostate cancer (a case of “worse than mine”). Hence, any difficult feelings he experienced declined when compared with those associated with dying children.

Well I've got nothing to bleat about, you look at little kiddies [with terminal diseases] they're the ones I feel for, why children get dealt such a harsh blow um why do they and I just don't know why and, that's sad I sort of feel um I reckon every child should have reached the age of 21 or whatever and they've had a happy childhood and, except that's not the way it goes and they get dealt a heavy blow. (Dixon)

Richard also felt compassion for sick or disabled children, identifying himself as the favoured one by comparison. He contrasted his feelings of compassion for the children with the feelings he felt for those who falsely attracted sympathy. My sense is that Richard was implying that, even though his experience was nothing like that of the children, he was genuine. However, his perceived luck in not being like the children, tacitly mitigated the dangers of the prostate cancer, and attenuated any difficult feelings he may have had because of it.

[W]ell we go back to the spina bifida kids sitting in the chair or whatever and they can't move, they're reliant upon somebody feeding them, dressing them, wheeling them around, toileting them and everything like that and I think, “Well hey, that's something that you can see. With me I can't [see the prostate cancer] but hey, I'm walking.” So I, I sort of, say, “Well I'm the lucky fellow, I'm the lucky one around here. And I've had, I've had my life, they're just starting, why?” That's what I say. Why? Why should it be like that? Why should, should some be worse than others? Where does it come from? There's no justice and then you go the other side of the scale, people, well one of them I saw the other day. He was, he worked out where I was but not with me and he walked by and a friend of mine he said, “Giddy Fred” And Fred is on a walking stick and I said to my friend, I said, “How long has he had a bad back?” And he said, “When it suits.” And I said, “Yes that's bloody right. They want to get on the band wagon. Sympathy.” Well I'm not, I, I don't want no sympathy. No. And I'm afraid I can't, I can't tolerate that because I think they're putting something over that shouldn't be there. If they're sick, they're sick, boom, done. (Richard)

Otto, using the comparator of cancer severity, set the prostate cancer against that of lung cancer and found the lung cancer to be more life threatening. Otto was not an overly excitable or demonstrative man, and it was not usual or easy to observe the expression of unpleasant feelings. However, he did imply a process whereby he reduced unpleasant feelings, therefore indirectly establishing the presence of these feelings, through the parallel process of mitigating the perceived severity of the prostate cancer.

Well I think the type of cancer what I've actually read about it till now is that it, well it's not as bad as it would be if I say [had] lung cancer for instance, that would be curtains for certain. Well it's not a pleasant thought to think oh yeah you've got the "big C" but at the same time I think there are different grades [of cancer]. (Otto)

### *Talking About Difficult Feelings*

The evidence presented speaks of ways in which the men in this study utilised a range of mechanisms, from hiding feelings to the use of personal aphorisms, to manage their affective world. Therefore, there is a clear sense in which the men in this study presented as emotional beings that, for reasons left unsaid, chose to engage with the emotional experience of prostate cancer in tacit, indirect, and understated ways. Nevertheless, the fact that they did engage with the emotional experience of prostate cancer, and that they did experience concerns, worries, and uncertainties in the process of doing so, is incontrovertible.

This conclusion is important because, in the gender literature, there is a tendency to see men as stoic and undemonstrative and, by extension, not emotionally engaged (Cheng, 1999; Frank, 1991; Kiss & Meryn, 2001). My sense is, however, that this spurious judgement is based partly on the observation that men do not talk about their emotional engagement.

With these ideas in mind, and having already observed that the men in this study were undemonstrative with respect to the prostate cancer, I now observe that they did not generally talk openly or directly about difficult feelings associated with the prostate cancer. However, when men did talk about worries and concerns, even in the context of non-therapeutically driven interviews, it did represent one way of providing an external narrative that, in the telling, assisted in the attenuation of associated feeling states.

Gerry, for example indirectly referred to a fear of the unknown, amongst other fears, when discussing his pending admission to hospital for a radical prostatectomy. He had not been an inpatient in a hospital since having his tonsils removed as a small boy.

Maybe it's losing control when you're unconscious if you know what I mean um I think it's just a fear of hospitals and operations and pain and stuff like that for me um that worries me; I haven't been there since I was five for tonsils so you know I just don't know anything about it at all. I really don't know what my fear is. (Gerry)

Although Gerry did not directly suggest the therapeutic value of talking about his concerns in this exemplar, he did refer indirectly to the attenuation of difficult feelings when he talked about sharing information, about his pending surgery, with work colleagues. It is interesting to note how, in the first instance, his implied motivation for communicating information was associated with helping other men to become better informed through their wives. His reference to the benefit to himself is stated as an afterthought.

I'm quite happy to explain as much as I know. It's like the girls in the office they all have husbands around my age and so I just explained what I know, they were very interested actually, maybe morbid curiosity I don't know, I doubt it actually they are nice people. Um, but yeah, so I'm trying to make it as open with anybody who asks or anybody who wants to know, to sort of uh I suppose take the load of me. (Gerry)

However, later on in the same interview Gerry became more open about the benefits to himself of talking about his feelings. He also presented an important reason for his being more open to the idea of discussing his concerns; his mother died not talking about her feelings.

I know if you keep it all [your feelings] bottled up inside yourself it's not going to be any better either, I know my mum did, she died bottling it up inside her. (Gerry)

Herbert, on the other hand, remained quite reticent about talking about his feelings, even though he experienced a great deal of anxiety during the early peri-diagnostic experience.

[When] you start talking about the unknowns of cancer and; you think oh shit, you know, when you've seen people die, I had my sister die of cancer in the hospice, (...) and you know, that's a harrowing thing. (Herbert)

However, Herbert did recognise the importance of talking about difficult feelings, as a way of attenuating their affect. On one occasion he said “most of those things [difficult feelings] I look after within myself. I’m not, which is not good, I tend not to talk about it.” (Herbert).

Just as Herbert was reticent, Richard was happy to talk about how he felt. Of course Richard also had a long experience with Crohn’s disease and had been introduced to the value of attending a support group early on in that experience. He did not attend a prostate cancer support group because there were none available in his area.

I’ve always said, all the [Crohn’s disease] support [group] meetings we went to, it didn’t matter where I went, I would say, “Don’t put it [difficult feelings] under the carpet,” whether it be a woman, a man or who. Don’t put it under the carpet. Talk about it, make it easier for everybody.” I said, “The more they know about it, the better it is for you, they can understand your mood swings”. (Richard)

### **Emotional Support**

Emotional support occurs within a relationship between at least two individuals, where at least one individual is living through or with a potentially traumatic, and possibly life threatening, experience. In such a relationship, at least one individual provides a measure of reassurance, encouragement, love, presence, concern, empathy, affection, and understanding (Helgeson & Cohen, 1996) to the individual experiencing the difficulty.

This description is reasonable as far as it goes. However, it begs the question as to how, and under what individual conditions, emotional support is sought. Moreover, the description does not take into account the ways in which emotional support might otherwise be provided. Within the context of this study, there are reasonable grounds for suggesting that most, if not all, of the categories of action discussed to this point played a role in the comprehensive provision of emotional support. As such, and with gender stereotypes notwithstanding, this idea about the comprehensiveness of action in the provision of emotional support, goes some way to explaining men’s camouflaged approach when seeking, or appearing not to seek, emotional support. That is, there was a sense in which emotional support was camouflaged, and contained, by all other categories of action.

### ***Stating Emotional Support Needs***

It is important to observe that the men in this study did not refer directly to their emotional support needs. Indeed only one man, Herbert, referred to the way in which emotional support might have been provided. Herbert, as previously identified, experienced a great deal of anxiety while waiting for a bone scan result. The bone scan was carried out to establish the presence or absence of bone metastases. Herbert believed that counselling should have been made available to him at that time.

To leave somebody between diagnosis and then bone scans without some, counselling is not good, is not good, that was a bad thing to get through, so a week of, or fortnight of not sleeping; well I slept, but I didn't sleep well. (...) Yes, the initial path is bad and this is why I believe; I'm not a bloody doctor, just a human being, but (...) I just believe that there should be counselling right at that point, not a week, two weeks, but right at that point. (Herbert)

Herbert believed that, had he received early emotional support through counselling, he would not have had such a poor early experience.

Oh I wouldn't have had all that anxiety and hypertension and; that build up of thinking, shit, you know, this is it, I felt all sorts of; in that period you feel everything that happens to you is to do with your prostate cancer, it's probably nothing to do with it at all. (Herbert)

However, with respect to the types of emotional support mentioned by Helgeson and Cohen (1996), Herbert was only specific about what he believed he needed on one occasion. When talking about the early relationship with the urologist, Herbert referred to the relevance of reassurance; “[The urologist said] it's not the end of the earth, he said you can be treated, and I thought yeah. But I think you need more assurance (sic).” (Herbert).

### ***Inclusive Synchronicity***

Inclusive synchronicity has to do with the way in which some men and their partners were able to communicate with each other about their feelings, needs, and concerns, without necessarily expressing them in words. That is, there was a sense of inclusiveness in the relationship that allowed each person to feel as though their understanding of each others emotional support needs were synchronous.

Cecil informed his family and some close friends about the prostate cancer diagnosis, but did not seek emotional support in any overt manner. However, contained within the phrase about his family having a close relationship, there existed a context in



which the provision of emotional support would have represented a *sine qua non*. Yet, and importantly, this kind of mutual support was qualitatively different from inclusive synchronicity.

Well I told my wife of course, yeah, and a couple of close friends sort of thing, you know (...), [and] I told all my daughters, the three daughters, once I had confirmation of it, so we've got it, how are we going to deal with it sort of thing you see. (...) [I would automatically have told my family] yes, yeah, as I say, we're quite a close knit family (...) (Cecil)

Cecil never talked directly about his emotional experience of having prostate cancer or receiving treatment, and yet he demonstrated no signs of decompensation (eg. anxiety, insomnia, agitation, relationship difficulties etc.) because of this. This suggests, that he was either an extremely “stable” individual or that he felt contained by the emotional support automatically provided by his wife (and family). My sense was that both applied. More importantly, Cecil talked about a type of automatic, or intuitive communication that existed between him and his wife; a level of inter-personal awareness that spoke of a long lived and inclusive intimacy.

[We've] got this sort of mental telepathy [between us] sort of thing yeah; well it happens quite frequently you know, I said to my wife um what about this then, you're reading my mind, almost as though she had been thinking about it before I said it sort of thing, as I say it's happened quite a few times now and it's it's a bit weird actually (laughing) you're both on the same wave length. (...) [W]ell she's thinking the same as I am you know, ok this is, we've got to get through this together sort of thing, help each other and this sort of thing, and that's the way it works; we're very close really it's as I say we had this sort of mental telepathy it's a very funny; and this is the other thing I mean I'll be quite honest with you, when you're younger you're emotional and in love and all this sort of thing, but when you get older your partner knows that you love, you don't have to demonstrate it all the time and this sort of thing, so this is the way we sort of go on. (Cecil)

In this exemplar Cecil also referred to an important idea about the maturity of a relationship. That is, the maturation of a relationship brought with it a sense of predictability; an understanding of how each person would respond and relate one-to-the-other, and an understanding of the emotional needs of the other. As such, there would have been no need to express difficult feelings, or ask specifically for emotional support, as they would be pre-empted, understood in the context of the family, and by the other person within the relationship.

Gerry demonstrated this process of inclusive synchronicity when I asked him to predict what his wife would say to me if I asked her to describe the way in which he would approach the prostate cancer.

David: If I said to your wife how would you describe Gerry and his approach to the prostate cancer what do you think she would say to me?

Gerry: That he's pretty positive, that he's you know not looking forward to it, that he's scared of hospital and he's scared of this and that but you know in general we are going to get through it and carry on (...), that's probably the real answer, we're going to get through it, both of us are going to get through it.  
(Gerry)

Therefore, it would be reasonable to conclude that what was being demonstrated was a knowing and intuitive process that underpinned the provision of emotional support within some long-standing relationships, and within some family groups.

Dixon, on the other hand, was in a reasonably new relationship. Dixon presented as an independent man who, although warm and engaging, had always managed his affairs and his emotional needs. Indeed, at the start of the study he presented as a very private man; a man disinclined to accept emotional support from anyone. Dixon's first wife had died a few years previously, and he had re-married only a relatively short time before the prostate cancer diagnosis. However, after his first wife died, and as his new relationship became increasingly familiar and settled, he showed signs of becoming increasingly more inclusive, if not synchronously so.

I have a responsibility to her [my wife] to not be self-centred and deal with it myself because I ... when, I look back to an incident when my [first] wife died, my sister rang up from over east and said we're coming over I said- she said mum's coming as well and your brother can't make it but we're coming; I said no need for your help I'll handle it, it's ok I can do it, they got really offended by that and they told me so, so I sort of, since then I think hang on maybe sometimes I have to put my hand out for them to come and help, and they came over and it was great it was good to have that support but I was prepared, don't worry about it we'll sort this out- I can sort it out, no we are coming and you've offended us by telling us not to come. So with my wife I try to be very careful of that, and I think it's good that she reminds me, that we're in this together but she is, she is very concerned that I will push her away and deal with it myself.  
(Dixon)

What Dixon described was the genesis and early development of inclusive synchronicity. There is a sense in which the adversity he experienced, through the death

of his first wife and the onset of the prostate cancer, acted as a catalyst for the reformulation of boundaries that had previously maintained a degree of emotional isolation.

### *Emotional Support within Relationships*

All of the men in this study were married with families, and all but one of the men lived with their respective partners throughout the period during which interviews were carried out. Winston, the one man not living with his partner, occupied the family house on his own, although his wife and adult children visited from time-to-time. Therefore, it would be accurate to observe that all the men in the study experienced emotional support within the context of one or more relationship; relationships with partners, with children, and with friends.

Men received some support messages, verbal and written, from family and others around them. What was interesting about these messages was the way in which they sometimes advocated for some kind of action on the part of the man with prostate cancer, or gave a clear indication of something the message sender expected. Messages also were important for what they did not state or advocate, and for attitudes they did not demonstrate towards the man with prostate cancer.

It's been good in as much as nobody, nobody felt sorry for me or didn't give any indication you know that they felt, and I think um pity is not good um because they only make you feel sorry for yourself and that doesn't help you know, but their attitude was um you'll be right you know, don't worry, whether that's their real thought or not I don't know but (chuckle). (...) Well I think they do the right thing to make you feel better yes, I think I think you need that, I think you need that sort of support, I really do, because if they'd all come around and said oh Jeez this is no good; uh be positive I suppose is the word, they're all positive people. (Herbert)

Dixon was impressed by a message received from his daughter, outlining the reason why she believed he should make a decision about receiving treatment. Part of the message sent was “between the lines”; a sense of mutual understanding about something contained within the family culture, in this case pride at being able to play Dixon at his own game; an ability to be black-and-white. The message sent, followed a business like explanation by Dixon about the prostate cancer and its treatment.

Yes, yes, I did describe it to her in that format [black-and-white terms] and um, broke it to her and just said this and this, I suggest you read the book, these are my options um I fully understand what my wife has been through, I fully

understand that I'm the only one surviving parent uh in relation to you at this stage and, but she has also responded to that um by, as I say I'm a black and white person, and she has also responded to me in a letter, and when you read the letter that's also in black and white but it's got a fair amount of emotion attached to it and, it has she has listed ten options which I thought was rather amazing that she was able to sit down and write these ten options, and this is what I think you should do because of these options bang bang bang; so basically said to [me] get it done soon. (Dixon)

Gerry received a written message of encouragement from someone he didn't know, the message having been sent through a mutual friend. The message was valued because it gave voice to some concerns or issues that Gerry had been processing but had not, up to the point of receiving the letter, expressed clearly.

Yeah, well yeah I think it does I think that's encour- I've got this letter from a- a friend of ours she is a nurse she's got some other friends who we don't know, obviously the same age roughly as my wife and myself and this lady wrote me a two page letter; who I don't know from a bar of soap, which was magnificent, it's just encouragement plus um things about sex things about life uh stuff you might not necessarily discuss with people you know she put it in a letter. (Gerry)

There were also moments when men may have been feeling uncertain about the future. Richard received a message from his daughter at one of these moments; he felt reassured, warmed, and supported by his daughter's words.

I feel I suppose pretty honoured to think that the kids think of me like that, that she [my daughter] said, "Hey, Pop, you're not going yet, you've got a lot of living to do." And I said, "Yes I know that," I said, "I'm not going anywhere." But no I do, I look up to them and say, "Well it's nice to know that they think Dad's around to help and guide or whatever, or whatever assistance we can give." That she doesn't want to see me go, that she's only thinking probably of the best treatment for me or whatever. (Richard)

A similar verbal message, negating the idea of imminent death, was received by Herbert from his wife. The message was important for two reasons. Firstly, because it represented a kind of "standing in the way of" by his wife; that is, Herbert's wife symbolically stood in the way of his fear, and proclaimed to him that he would not die. Secondly, the message was important because Herbert's wife's proclamation also stood in the way of her fear of losing him. Therefore, there was a form of mutuality contained within messages of support that acted to provide reassurance to both the sender and the receiver.

Well, everyone knows that I've got this thing [prostate cancer]um my wife always says you're not going to die or anything like that right now, so just enjoy yourself which we do. (Herbert)

The same mutually protective process was exemplified by Robert, this time in reverse. Here Robert was providing reassurance to his wife that he was not going to die of prostate cancer. He symbolically inoculated himself against the need to express his own fears, through his attention to what he described as her dependence upon him.

Well I just said to her you know, I'm not going to die of prostate cancer, I told her that for a start, I said we're very lucky we got it early it's a low grade so even if I did nothing I said it could be five or 10 years left, but I said I'm going to find the best possible way of treating this, and I'm going to be around a lot longer than you think, so don't have fears of you know, because she's very reliant upon me and I said don't worry I said I'll be- she said I never thought you'd die before me; I said don't worry I probably won't and uh because I'm a lot fitter and whatever I said no it is you know, don't let sort of you know, and she she believes in me a lot and that sort of settled her down (...) (Robert)

Robert, of course, suffered from PTSD and needed to maintain mechanisms that would forestall any anxiety. Therefore, he again used a mutually protective support approach when visiting the urologist.

(...) [S]he helps me plan ahead, and that was a reason why uh you know she cried and got upset about it [the prostate cancer] but, I said to her well we'll both go together [to see the urologist] because we've done everything together in the last 10 years and I said uh and I'll show you that this [the prostate cancer] can be resolved, I was very confident and um that's why I took her. (Robert)

There was also a sense, in which the partner in the relationship symbolised all of Helgeson and Cohen's (1996) descriptors of emotional support, just by their presence in the relationship.

Oh well she's [my wife's] been my rock sort of thing you know. As I say if you've got a problem how do you deal with it, and she's supportive of what we're doing, so that's, you've got to have a right hand woman you know (chuckle). (Cecil)

Herbert indirectly referred to the idea of emotional support being contained by the whole family; buoyancy being provided through the ability of the family to sustain an optimistic outlook when the man with prostate cancer could not.

It has helped me [having the family around], yeah if I had been on my own and thinking about, and thinking the way I am [pessimistically] I would have said uhh this is no good I've had it cause it's easier for me- that's the way I go but but having all these other optimists round (sic) the place makes it a lot easier. But if I had a heap of pessimists round (sic) me we'd all be down the bloody drain (laughter) (Herbert)

On the other hand, there was also a sense in which the ability of the family to maintain the buoyancy acted against the open expression of feelings. That is, consistent optimism potentially allowed family members to repress their own fears, and therefore denied the man with prostate cancer an opportunity for discussion.

[The kids have not mentioned the prostate cancer again] [z]ero, we sat down we had, at teatime, we discussed it um and that's almost the last I've heard of it. I spoke to my daughter down south and my son who lives down the road; and they were uh shocked but we don't talk about it, we don't need to talk about it, the kids are obviously quite happy that something is going to be done it's all going to be fixed up and they'll be having me back. (Gerry)

However, although partner mutuality, suggested previously, manifested in a mutually protective emotional support process, the idea that the family collectively carried, or enacted, components of support, and therefore carried components of the man's experience, had a counter-productive side to it. This was exemplified by Dixon's family who appeared to be carrying some of his concern, thereby allowing him to postpone action for longer. Hence, emotional support presented as a double edged sword; something akin to the idea of feeling-by-proxy described previously.

[My family are] carrying the burden and I'm not. Oh I guess I am to a certain degree if they're carrying the burden round (sic), why doesn't he get something done? And my daughter will say that. "Have you thought about the operation Dad?" You know, "About time you had a think about it, it's time to do something." (...) And yet, I think, "Oh yes, PSA levels are okay, I'll just cruise along for another couple of months and see where the PSA level is whereas they're the ones that are worrying, I'm probably not doing any worry about it. (Dixon)

## **CHAPTER FIVE**

### **RESPONDING TO THE POST-DIAGNOSTIC EXPERIENCE**

#### **Introduction**

The peri-diagnostic experience presented as a period during which the men in this study attempted to accommodate the prostate cancer within their lifeworlds. The major milestones involved during this period of accommodation included seeking a diagnosis, receiving a diagnosis, making a decision about treatment, and commencing treatment, if treatment was accepted. The work involved in this process was dominated by accommodating activities. These men sought to recognise the cancer as real, sought to hide or attenuate difficult feelings engendered by the prostate cancer and sought, in all of these activities, to disguise the need for emotional support. However, by far the most comprehensive and intricate accommodating activity demonstrated by the men in this study, during the peri-diagnostic period, involved locating, and replotting, the reference points that guided their daily lives.

I make mention of these activities for two reasons; firstly, because it is important to recognise their inter-connectedness and, secondly, because they continued into, and beyond, the post-diagnostic period. The post-diagnostic experience contained all the life events of the men in the study from three months following the diagnosis of prostate cancer. Of course, to some extent, this was an arbitrary point, as there was no absolute point of demarcation between the peri- and post-diagnostic experiences; no point beyond, or before, which some activities occurred and some did not. Responding to prostate cancer was, and is, an iterative process; a process represented on a continuum, with some activities achieving a greater qualitative presence during the peri-diagnostic period, and others during the post-diagnostic period.

Therefore, the process of lifeworld reconstruction continued as a central component of the post-diagnostic experience. However, the mood during this time was more reflective. That is, some of the men in the study were more able to reflect on the impact of the prostate cancer, and on the heightened existential anxiety the prostate cancer caused. Moreover, for most of the men, the post-diagnostic period was exemplified by the forward looking activity of perpetuating a stable lifeworld, while concurrently responding to treatment and to the impotency generated by treatment.

I would observe that the prostate cancer experience became more contained, and progressively less uncertain, during the post-diagnostic period. It was a time during which the men in this study were able to begin relocating the prostate cancer to a future context. As such, the post-diagnostic period became a normalising period; one in which these men began to assimilate the changes and move back towards the familiar and the stable.

### **Responding to Treatment**

Responding to treatment refers to the ways in which the men in this study responded, emotionally and descriptively, to the process, outcomes, and side effects of treatment. I have previously described the ways in which the men in the study revealed the prostate cancer as a material object; a necessary response to the silence of the cancer. In responding to treatment, however, these men were responding to tangible events in real time.

#### ***The Affective Response to Treatment***

The men in the study were generally reticent about discussing their feelings about the process and outcomes of the prostate cancer treatment. Such reticence was perhaps not surprising, given their earlier pertinacious attempts at minimising the emotional content of the peri-diagnostic experience. It is also interesting to observe that those few men, who talked about their responses to treatment, used the same emotional minimising strategies observed previously in this study.

[M]y PSA at the start was 13, it's 1.7 now, so that's an encouragement so ok it's, something's working um the doctor did say that um he wanted me to carry on with the hormone treatment because he wants to try and shrink the old prostate gland itself a little bit more, because my wife said to him you know your sweating is a little bit uncomfortable, ask him if you can stop it sort of thing, but I didn't ask him because he told me what the results were and I thought "well it's working" so, and it's a minor inconvenience as far as I'm concerned, a bit embarrassing but it's a minor inconvenience, and it's part of the treatment, and they tell you at the beginning of the treatment what's, what the likely consequences are sort of thing. It does prepare you, which is half the battle. (Cecil)

Not only did Cecil avoid complaining, but he worked hard to mitigate the impact of the neo-adjuvant hormone ablation therapy. Furthermore, he maintained his earlier belief in “not rocking the boat”, just in case something went wrong.



Gerry, on the other hand, did admit to feeling grumpy following a radical prostatectomy, but offset the response using the idea that it was not acceptable to be grumpy. Furthermore, in talking about his feelings of frustration he implied blameworthiness, suggesting there were no reasons for what he appeared to be interpreting as his tardy behaviour.

Gerry: I've been bloody grumpy [since returning home from hospital] I know that, I have been grumpy when I shouldn't have been grumpy. Grumpy the other day, grumpy yesterday. And I don't like being grumpy because it gets everybody offside.

David: And what do you put that grumpiness down to?

Gerry: Oh frustration I think it's part of it. Part of it's frustration on my part, frustration lack of sex. Frustration at not being able to do things I want to do (...). Where we are now, there's no reason why I can't do anything that I want to do. (Gerry)

There was a sense in which Gerry was surprised to feel as he did, surprised to feel enervated, and surprised to feel frustrated. However, nobody had talked to him prior to surgery about how he may feel post-operatively. He had been told about the possibility of urinary incontinence and impotence, but nobody had engaged him in a discussion about feelings.

Equally, Herbert experienced some confusion as he attempted to work out why he was feeling enervated. Perhaps, as a response to the confusion, he constructed a number of hypotheses about the cause or causes of his feelings. However, nobody had involved Herbert in an exploration of his future feelings, as a prelude to the hormone ablation therapy.

Yes, yes I do I feel that it's slowed me down um I, I'm still active, I still swim and I still do the garden but I can't, I'm certainly not as active as I was and sometimes I wonder whether it's the hormonal injections (...) that are causing it or whether um it's aging it's an interesting one to work out, but from the point of view of how do I feel, I feel I feel reasonably well I couldn't say I felt sick, I mean that's what I'd have to say straight away I don't I don't feel sick uh I get tired easily, in myself in my body I don't really feel sick, I have a high resistance to pain, I always have had I can stand a lot of, some people can't stand pain at all I can I feel I can stand a lot of pain so maybe that's in my favour, but uh (cough) the only thing that might have happened is I might have got some further arthritis which is, I don't know whether that's part of the act or not (Herbert)

It is difficult to know the precise impact, on Herbert, of the lack of emotional preparation before commencing the hormone ablation therapy. However, it would be reasonable to suggest that the unexplained enervation caused this elderly man to question his ongoing motivation for pursuing health care objectives.

(...) I get to the stage in life where I wonder uh you know how much you can improve yourself, I'm happy to go along with a lot of the things I've got rather than try and fix em (sic), I just think you know I'm getting older, things are going to fall apart (chuckle) (...) (Herbert)

Not complaining epitomised Cecil's enduring stoic response to the adversity of treatment. Cecil, however, acknowledged some surprise when he discovered that he had not been prepared for the length of time it would take before he knew the outcome of the radiotherapy.

[T]hey tell you there's a 95% success rate but they can't tell you, you know, until about a year or eighteen months [if the treatment has been successful] or whatever it is afterwards, he didn't say. I was surprised when I heard that because I thought well, once you'd been through the hormone treatment and the radiation, take a PSA and you should be right you know, but it doesn't work that way. (Cecil)

Similarly, Otto, another man who maintained a calm and reasoned approach to the prostate cancer and its treatment, felt some confusion when attempting to understand, in concrete terms, what he was experiencing.

Because if I'm dealing with some sort of, let's say building a house, I'm dealing with something concrete. I know I can get the facts, I can work things out. If I'm, well those beams, if I put them in, well what size do I need to have? The span is so much, the loading is going to be so much and we may have some wind forces happening once every twenty years at certain force, I can work it out I know. But with prostate cancer, it's still up and down. It's rather hazy. (Otto)

### ***The Response to Impotency***

By the end of the data collection phase of the study, six men were impotent, induced either chemically or surgically. With respect to the two men who were not impotent; one had decided not to have treatment at all, and the other man decided to accept a radical prostatectomy following the final interview; his response was therefore unknown. Of the six men who were impotent, the subject of impotency had been "written off" by one of them (Herbert) as a product of advancing age. Another of the impotent men (Cecil) had been impotent for some considerable time prior to the

treatment for prostate cancer, as a result of chronic type II diabetes mellitus, and believed he had nothing to contribute.

Of the four men in the study, who referred to their impotence, two did so minimally (Richard and Otto), either by providing no information about the feelings that impotency induced, or by suggesting the impotence was not an issue of importance. Therefore, so as to explore the response to impotency in a more detailed way, I intend to use the experiences of the two men who provided the most information.

Gerry, the youngest man in the study (49 years old), had made some reference to impotency prior to surgery. At that early point he had thought about the potential impact of impotency on his marital relationship. Indeed, Gerry's feelings about the potential consequences of impotency represented an important pre-treatment context.

[I]mpotency was one of my fears my reason for putting things off, um and whether that was a personal thing or not or whether I thought you know, silly me, that my wife would love me (...) less if I couldn't do it [I don't know] (Gerry)

For Gerry, the fear was that if he became impotent his wife would look elsewhere for a physical relationship. He knew his wife did not believe such a thing would happen, and he knew his relationship was founded on more than the sexual. However, given such a misperception it is worth observing that he was not provided with a formal opportunity to voice his fears, prior to surgery, nor was he helped to regain his lost perspective (other than by chance, and informally, during my interview with him).

[The fear] was for me, I don't think it was for my wife, for me personally it was something there yeah, I mean I hear stories of a guy I know who is having a relationship with a woman because her husband can't keep her happy, I think well I don't want that, I don't need that, not that I think my wife would go anywhere else uh but you know it's still a thought in your mind, it's still a deciding factor, it's still something that makes your decision making process not easy um I don't whether impotency is a; I suppose I don't have to worry about it anymore, I've worried about it and the decision's made and it's not just my decision it's my wife's decision as well in a sense. (Gerry)

Following his return home, after the radical prostatectomy, Gerry discovered that his fear of impotence had been realised. At that point, however, he mentioned some sense of hope for a future recovery.

Well it was one of my fears of the operation that I would not be able to have sex again and so far it hasn't happened [sex hasn't happened]. But I'm not concerned any way. Yes, so. Yes, so I suppose we'll try again soon. (Gerry)

I suggested to Gerry that he must have found not being able to achieve vaginal intercourse with his wife emotionally difficult. He agreed, but then reminded me that he was still a man, had fathered four children, and loved his wife. There was an important sense in which he needed to remind himself of his antecedent masculinity, just as he needed to remind himself that the foundation for his procreative acts had been love. Gerry was evaluating, he was also grieving a loss, albeit an unexpressed loss; he mitigated the feeling of loss by reminding himself that he was still, for the most part, a man.

Yes okay, I didn't look at it like that, but yes you're right. Very definitely. Yes, I think so. I think it does annoy me a bit not having it. But other than that I'm a man, I've sort of, a big part of my life, I've got four kids, they're a product of that emotion and that particular act and you know and the fact that I love my wife as well but you know. (Gerry)

Gerry tried again to have sexual intercourse with his wife six weeks post-surgery and was again unsuccessful; he was also incontinent of urine during his attempt. He found the experience to be distressing, although he did not describe it in this way, and also felt embarrassed and demotivated.

Oh we had one attempt at six weeks and all I did was piss all over her. (...) And yes, it was embarrassing from my point of view because my incontinence went "Phewww" and my muscle control went "Phewww" and as my wife said we had sex of a different sort after we'd cleaned ourselves as **I'd made a mess of everything**. I think that might be better now, that was three or four weeks ago. I think it might be better now but I've lost interest. I hate to say this but I seem to have lost a bit of interest. It's just, it's just not there. (Gerry) [Emphasis added]

It is worth noting the phrase Gerry used, "I'd made a mess of everything." (Gerry), when describing the aftermath of his attempt at sexual intercourse. There was a sense in which his response to that difficult moment, and to the prognosis that difficult moment implied, was muted. He believed he had made a mess of everything, literally and metaphorically; he was angry with himself, angry with the experience, and angry with the impotence, and yet he said nothing about his feelings, other than that he felt embarrassed. Perhaps, as I have suggested previously, to have spoken openly about such difficult feelings would have caused him to "lose face" and, in the context of incontinence, perhaps he felt he had been humiliated enough.

Gerry had originally made the point that he did not want to use drugs or devices that would possibly help with the erectile dysfunction. Approximately nine months after surgery Gerry capitulated and sought some advice from the sexuality clinic about the erectile dysfunction. There was no further talk about his affective response to the impotence, at least not directly. However, there was a sense in which Gerry's concerns, fears, and anger merged as he linked the news about attending the sexuality clinic with his continuing fear that his wife might seek physical comfort elsewhere.

Gerry: Yes I'm going to try the pump and if that doesn't work, well then we'll try the Caverject [Alprostadil] I suppose. I'm not looking forward to that part of it very much. And if none of them work, well that's just bad luck I'm afraid. Sort of battling with that one. That one I'm not particularly pleased about. From a; my wife (...) I don't particularly wish to give her permission to go and find satisfaction elsewhere. I know it does happen. I know there's a, one of the guys I know is fixing up a lady because the husband can't do it. Well I don't particularly want my wife in that situation.

David: Have you discussed all of this with her?

Gerry: No I have not discussed all of this with my wife because I think she would probably guess what my attitude would be because it's been my attitude all my life. If you're going to go fool around, you go and fool around but don't bother coming back in the door because I'm not interested, sorry, that's life. That was from day one of being married. "You fool around, that's great, but don't come back." (Gerry)

It would be reasonable to suggest that Gerry's feelings, attached to the loss of his potency, were displaced onto the fantasy (and phantasy) about his wife seeking physical comfort in the arms of another man. He did not discuss these self-torturing thoughts with his wife, claiming that she would know his attitude towards the fantasised adultery; essentially a double bind. Instead, he chose to punish himself for his self-imposed loss; after all, he had made a mess of everything.

Regardless of the perceived validity or precision of this psychodynamic interpretation, the important inference to draw is that Gerry's feelings about his impotency were rendered equally impotent. The approach to treatment did not automatically seek to help men express and manage difficult feelings in general, and impotency in particular, and the men in this study assiduously attempted to hide or mitigate their difficult feelings; a collusion of means. Therefore, at least one man in this study was rendered at once doubly impotent, physically and emotionally.

On the other hand, Robert, the participant with PTSD, responded to the impotency caused by a radical prostatectomy with equanimity and resolve. He did not express any feelings of loss, directly or indirectly, and firmly believed that the impotency had not impacted on his relationship.

I mean [loss of sexual intercourse] it's not a major contribution for a person my age, fifty-seven, fifty-eight, but probably a younger person would be a bit, I mean, I'm not overly sex orientated, but you know, it's something I can cope with at this stage and so can the wife, so. It's not, it's not affecting our relationship. (Robert)

Even though Robert provided no insights into his affective response to impotency, it is relevant to observe his reference to the ageing process as a way of mitigating the loss. It is also relevant to observe that a radical prostatectomy does not affect libido, or sensation, just erectile function. Robert was aware of this fact, and was prepared to alter his sexual technique so as to accommodate the erectile dysfunction.

I'm quite capable now to have oral sex and I get a sensation better than before. So yes, it's just the wife's probably not receiving any satisfaction but at her age and what is, she's not too concerned either so. You know, our relationship is still, still good. (Robert)

Notwithstanding the identified decline in the quality of sexual exchange for Robert's wife, there was a clear sense in which Robert maintained conformity with his earlier adaptive behaviours in his response to impotency. Indeed, he was able to establish a trade-off between potency and longevity, a choice that almost certainly resulted in his ability to accept the new status quo of impotency.

Oh yes, yes. Well, I mean prostate cancer to me is obviously a slow growing one but I don't know, the only way you can, whether they can totally advise you whether it's got out is to have the operation. I mean it's a gamble if you want to go on and on. I mean once it gets out I still believe that you know, you're setting yourself for a death sentence. It might take ten years but I had no intentions of going down that line to say, for the next ten years, yes I can still have an erection but that's it. I want to live thirty years. (Robert)

Furthermore, there was a sense in which his wife carried the hope of recovery for both of them. That is, given the possibility of some spontaneous neural regeneration over a twelve to eighteen month period post-operatively, Robert knew, because of his PTSD, that he was unable to manage the anxiety associated with waiting for a result. However, Robert could accept the immediate status quo of impotency because it was the

most effective way of managing the PTSD. Therefore, by supporting, and investing in, his wife's role of "patient hoper", Robert provided them both with an effective mechanism for managing the emotional component of their sexual future.

I've been told there will, there is a period of twelve to eighteen months it may take the nerves to bed in and work so, I accept that fact. I mean we can still have relationships me and the wife, you know, once a month or something like that but it's not, it's not the major part of life to me and life goes on. It's a part of togetherness for me and her but you know, we do so much else and she's never ever expressed it other than in a humorous way. You know, "I suppose I'm going to wake up one night and I've got a great erection poking me in the middle of my back or something," and you know, "It'll be on." And she's, she's always been very confident too that way. She buoys my confidence in life, she feels that I'll, I'll beat it. She's quite confident, yes she said, "Give it time, give it time," she's confident it'll work. (Robert)

### **Reflective Engagement**

Engaging with prostate cancer represented, for the men in this study, an encounter with a unique and potentially life threatening experience. As such, prostate cancer created a special kind of experience, one that challenged some of these men existentially, emotionally, and practically. That is, the prostate cancer experience caused some of the men in the study to reflect on their life experiences, on the meaning of their lives, and on what they believed to be of value. I am not suggesting that the insights gained were axiomatically apocalyptic, although such an outcome was possible. However, there was a sense in which reflective engagement, either simple or complex, represented an integral component in the process of lifeworld reconstruction.

### ***Becoming Reflective***

Becoming reflective refers to the ways in which some of the men in this study began to talk about the experience of prostate cancer in a less urgent way, in a way that suggested a degree of acceptance; an acknowledgement that the prostate cancer was part of their lives. Being reflective did not appear, in any significant way, during the peri-diagnostic period, an observation that supports the idea that other components of each man's lifeworld needed to be stable, or accessible, before reflection was possible.

Herbert used avoidance tactics prior to the final diagnosis of prostate cancer; he also experienced extreme anxiety during the early part of the peri-diagnostic experience. However, as Herbert started to accept the reality of the prostate cancer diagnosis, and

found his experience of anxiety was diminishing, he became more reflective about the cancer and his world.

Compared to six months ago, I'm more relaxed about it than I was six months ago And prior to that which was nine months ago when you first came I was pretty worried about it, so I've gone from that to being relaxed, and being a bit the same way now. (Herbert)

I am more reflective, yeah I am. I do reflect on it [the prostate cancer], even having known that I've had it for about three years, I'm more reflective on it now than I was you know I kept- when I first got it I kept going on thinking this is all bullshit because it doesn't affect me in any way I feel ok um, and I probably still feel reasonably ok. (Herbert)

Therefore, the freedom to become reflective, at least for Hebert, was contingent upon the stabilisation of the early experience and the acceptance of the cancer as a reality; both tasks associated with the work of the peri-diagnostic period.

Furthermore, Hebert's early anxiety with respect to what he perceived as his imminent death because of the prostate cancer gave way, over time, to a more reflective attitude towards his perception of longevity. Herbert reflected on the juxtaposition of the prostate cancer with his time in the world; with the insight gained he achieved a sense of balance.

I guess I have to think that it's later, it's later than you think all the time; if you start getting to the thought that you're 80 in a couple of years um, when I used to look at people when I was young um if they were 80 they were old, you know 80! and now 90 or a 100 is looking old, I guess I just think I've enjoyed myself as much as I can. (Hebert)

Richard, on the other hand, did not experience any acute anxiety during the peri-diagnostic period, even though he often mitigated the severity of the prostate cancer by referencing himself against those he perceived as "worse off". Be that as it may, during the neo-adjuvant therapy, and prior to commencing radiotherapy, Richard developed a deep vein thrombosis (DVT) and a subsequent pulmonary embolism (PE). The PE was almost fatal. As a result of this experience Richard became noticeably more reflective and, he believed, more tolerant.

I've learned, I suppose it's a silly thing to say but I've learned to accept things a bit more. Understand it and see people that are worse off than me. For instance this last time in hospital I had a chap come in, into the two bed (sic) where I was and we had seen him around here for years and years and years and years. He



had one leg shorter than the other. I knew him, hadn't seen him for a long time and when he came in he's got one leg above the knee cut off and the other one just below. (...) And you know, when I look back on those sorts of things though this is what, why it doesn't really upset me [the DVT and PE] because there is somebody worse than me and I'm walking around, he's not. He's been (sic) taken to the toilet and all this business, he's, those sort of things, he's in a bad way. And to me I've got nothing. (Richard)

It is reasonable to suggest that the prostate cancer experience and the gravitas attached to the PE, heightened Richard's reflectiveness. These same experiences also prompted Richard to connect with the depth of his enormous compassion for the suffering of others. There is a further sense, however, in which Richard's heightened reflectiveness, and manifest ability to feel compassion for others, converted potentially self-invested feelings of trepidation into other-invested feelings of concern, therefore contributing to the re-stabilisation, and reconstruction, of his lifeworld.

Cecil, throughout the peri-diagnostic period, and well into the post-diagnostic period, had maintained a position of stoic compliance. He believed that provided he complied with the treatment regimen, and did not contravene the implicit rules about strict cooperation with health professionals, all would be well, and the cancer would be cured. Given this prior context, it is relevant to observe, sometime after the completion of radiotherapy, that Cecil suddenly talked about chemotherapy and challenged its use.

You take it now, you're got to have chemotherapy because you've got cancer wherever it might be and you go through all this treatment and you feel absolute (sic) down in the dumps and you're sick and you lose your hair and all this and that, at the end of the line, you might have extended your life by six months or something. Why do it? I mean why put yourself through all that and I mean we're all going to die David whether we like it or not. (Cecil)

As a reflective moment Cecil's statement may not appear to be consequential. It is also difficult to know if the prostate cancer experience caused Cecil to become reflective, or if he had used reflective silence strategically to safeguard the stability of treatment. However, my sense is that the end of treatment marked a moment in time after which it became permissible to reflect on what might have been, or on what could be in the future. That is, the completion of treatment marked the end of a rite of transition and, with its ending, came a new set of rules.

## *Existential Reflection*

In referring to existential reflection I am, in part, referring to the idea of reflexive awareness, a process through which the mind becomes aware of its own operations (Ayers, 1998). I am also referring, in part, to the existential givens of embodiedness, death, freedom, meaninglessness, isolation, and beingness (Bugental & Kleiner, 1993). As such, the activity of existential reflection refers to a process, triggered by the prostate cancer experience, in which some men became reflexively aware of their “beingness”, and therefore of the existential anxiety such a state created. That is, some men attended to the impact of the prostate cancer experience on the existential givens, and to their heightened awareness of not being, albeit that they did not describe the activity in such a way.

Winston had engaged reflectively with the prostate cancer from the time of diagnosis. He had not accepted the neo-adjuvant and radiotherapy offered to him, deciding instead to treat the prostate cancer in his own way. It is difficult to know the precise reasons for Winston’s decision to self-treat. However, there was a sense in which his choice to self-treat the prostate cancer positioned him well for an act of self-redemption. That is, the choice became a way in which Winston could prove, personally and otherwise, that he was capable of engaging with his life and succeeding.

[F]or the first time in my life this is clearly now a position that I find myself in that I can’t blame anybody for and I can’t ask anybody any more than I’ve asked them other than for their advice and they’ve graciously given it, so now I have to determine how I deal with the issue [of the prostate cancer myself]. (Winston)

Of course this interpretation grossly under represents the complexity of Winston’s decision and his motives. However, his experience of bankruptcy some years previously and his long, but unsuccessful, efforts in the appeals court had left him feeling disempowered, separated from his wife, and seeking new ways to regain control of his life. As such, and regardless of the accuracy of my interpretation, the important insight acquired by Winston was that the prostate cancer represented a means to more than one end. It also became an opportunity to re-examine one of the existential questions, that of the purpose of life?

I’m not quite sure what my real purpose is, whether to have the the cancer to prove a point, um or to have the cancer and um and have it prove a point; and um why has my course in life gone the way it is when I brush my teeth three

times a day after meals and I've done the you-beaut exercises, I've got it anyway, what's it all about Alfie?, that's the thing. (Winston)

In the context of the prostate cancer, Winston had acquired insights into his motives for taking on the cancer in a non-traditional way. However, his rich and allegorical use of language had the capacity to clarify and, concomitantly, to obfuscate. He saw himself as a delinquent, and as someone with the potential for impulsivity, and he aspired to magnificent heights.

I feel as though I'm being delinquent and a bit juvenile and a little bit sort of like a misbehaving bad Teddy, but I've got to be careful because that's my natural tendency I walked into the supreme court with three or four books under my arm and they wheeled trolleys and I took them on, so I know what I'm likely to do and sometimes I don't think about it enough to not do it I shouldn't have done that, but if I didn't do that I wouldn't have got to Federal Court would I, and that's a higher court so there's the magnificence of it. You kill the person on the crosswalk and you become a different driver after that, I mean it's just so many things I mean is that good killing the person no it's terrible, but becoming a better driver not to go on killing is wonderful, you know it's hard to make these decisions against the wind. (Winston)

Winston asked himself two important and existential questions; "do I need to die to become the person I think I am?" and "do my means justify my ends?". The answers to these questions were still pending, and Winston was still self-treating, at the end of the data collection period. Therefore, in a very real way, the prostate cancer experience merged with the rest of Winston's life, as he attempted to reduce his existential anxiety by reconstructing his lifeworld.

Herbert, aged 77 years, was the oldest participant in the study. He talked about "old age", and believed that the world saw him differently, just as he saw himself as different, not as meaningful; nobody really took notice of him anymore.

Oh I always laughed about getting older you know, I know a lot of people or I used to know a lot of people and I used to be accused of knowing every farmer in Western Australia, or if I didn't know them they knew me, because that had been my life; but now my only claim to fame is if I stand on the corner out there uh I'm that little fat geriatric guy that stands on the corner and talks to everyone. In other words I still talk to everyone but people are not interested; they humour me and- that's what I feel, and I can understand that, I accept it. (Herbert)

There is a distinct sense in which this statement represented a metaphor for Herbert's engagement with the prostate cancer, and the way in which the prostate cancer had isolated him, perhaps even diminished him. That is, the prostate cancer, like

growing older, wrought a change in his lifeworld, a change that begged the questions about who Herbert had become, and what was his value. Moreover, in the wake of this existential reflection, Herbert identified that he felt less important, less relevant, and less in control of his life.

What's different is that I no longer have any bearing on anything that I do, I don't have any uh; I've got no reason to be looked at and said- whatever I say is uh irrelevant because I carry no substance. (...) I'm not productive, I'm not- whereas in my earlier days people uh people used to hang on what I said (...) But now um nobody worries about you anymore, you know I'm just that guy that lives on the corner that um has been here for 45 years (chuckle) um and people wave or, and you know as you get older a lot of your friends drop off um and yes like I said you're less important around the place. (Herbert)

### **Perpetuating a Stable and Dynamic Lifeworld**

I have observed previously that the peri-diagnostic experience was dominated by activities directed towards stabilising the lifeworld of each man in the study. I have also observed that the response to prostate cancer was, and is, an iterative process. In the context of the post-diagnostic experience, the important inference to draw from these observations is that the peri-diagnostic response to the prostate cancer experience was not, principally, future-directed. That is, the men in the study did not refer to, or talk about, their experience in a future-directed manner.

However, as the lifeworld of each man became increasingly stable the emphasis on time moved from one of exclusively managing the present today and again tomorrow, towards one of recognising the past so as to manage the present and the future, today and tomorrow. That is, some men became increasingly future-directed by perpetuating a lifeworld that remained stable while responding to, and assimilating, change.

### ***Monitoring Progress***

Monitoring progress had to do with tracking the success of treatment, or tracking the potential for recurrence, usually by reference to the PSA level. In general, the men in the study did not become overly attentive towards their post-treatment PSA levels, although they did use the PSA as a way of imagining their progress.

Winston, the participant who was self-treating, had felt somewhat vindicated when the first PSA level, following his decision not to accept traditional treatment,

demonstrated a reduction. However, the next PSA assay demonstrated an increase; Winston felt disappointed.

He [the GP] felt that that um ... that with the way it had gone the first time which was quite dramatic, coming from 18.7 back to 8.1; was sort of a little bit like going off to the golf course the first time and coming back with a good score, going out to Ascot a little bit and having your first bet and it always wins doesn't it and gets you into betting after that. Our expectations were high, and I have to say that I was a little bit disappointed in the fact that it had gone up a bit (Winston)

In response, Winston went to see his GP, a man who practiced both traditional and complementary medicine, who normalised the increase in the PSA level for Winston. As such, and regardless of the sensibleness of the GP's judgement, Winston felt placated and more able to continue along the non-treatment path he had chosen.

I went to the doctor and um and when I got there I was looking for him to give me some of his opinion as well in terms of why it had moved up, and he just reckoned that the emotions and the uh chemical behaviour of the body and where I was the day before and what I'd been doing and all those things and he wasn't perplexed at all. (Winston)

Monitoring the progress of the prostate cancer using the PSA level as a yardstick represented the only empirical means by which Winston could judge the continuing credibility of his no treatment choice. That is, a favourable PSA level provided him with the evidence he needed to remain future-directed, and not have to stop so as to manage the cancer in a more immediate way. However, Winston had remained optimistic and certain that he was on the right future path; he was certain that his way would see the prostate cancer cured. On the basis of his certainty, I asked him what stopped him from never having another PSA level assayed.

What stops me from never having one again? Um, just that self belief. I will have other PSA's done um because I think it's important to have some sort of yard-stick and (sic) where it's at, but, like the opinions at the moment there's some people that are for PSA's and there are some people not for them, and I'm aware of those arguments um I'm for them a little bit at the moment because **it's not making me afraid**, it's given me a, a signal or a bit of definition of where things are at. But give me that question [again], why would I not have one? (Winston) [Emphasis added]

Winston suggested that having the PSA assay prevented him from experiencing fear, fear caused by not knowing about the progress of the prostate cancer. Therefore,

there was a sense in which his ability to remain future-directed depended on his ability to monitor the progress of the cancer. That is, without the empirical evidence provided by the PSA assay he would have been forced to revert to exclusively managing the present today, and again tomorrow, so as to re-stabilise his lifeworld.

Gerry also experienced a small rise in his PSA level following his radical prostatectomy, at a time when he was just becoming more future-directed. Rather than receiving unequivocal reassurance from the urologist, Gerry was told the increase might have been a fault in the test or it might have signified an actual rise in the PSA level.

I went and had, to see the urologist about a month ago and my PSA count was actually point one. So it's gone up slightly. So he says I don't know whether it's a glitch in the test or it actually has gone up in which case we need to be [certain]. So I've got another test scheduled for the end of January. If that is point one or greater than then obviously the cancer's back and I have to go back to him in February. If it's less than point one then I'll just have another three monthly check up to make sure the glitch doesn't happen again. (...) I don't care. I do care, but I can't care if you know what I mean, I, I, I do care but there's nothing I can do about it. All I can do is wait til the end of January, have my test and if I go that way I have to and if I go that way I have to have radiotherapy. I've got enough sick leave at work that it's covered. (Gerry)

Gerry therefore had to wait. He tried to convince himself that he did not care, but qualified that response by suggesting that he could not care because there was no action he could take. Essentially, Gerry found himself being forced back into a position where he was unable to act in a future-directed way, he was forced to re-stabilise his lifeworld so as to manage the moment, and to continue doing so until the next PSA assay. Moreover, instead of being able to talk about his future life, Gerry referred again to putting his life on hold, having further treatment, arranging for further sick leave. Happily, the next PSA assay demonstrated a reduced level.

On the other hand, Herbert, who had experienced extreme anxiety, existentially and otherwise, following the diagnosis of the prostate cancer, had reached a point in his experience best described as tranquil. He had become future-directed and had accepted that the cancer would inevitably grow. However, he was moving on, and was not allowing the cancer to dominate his thoughts or his time.

[The prostate cancer] (...) doesn't fit into it [my life], really, I've tried to cross it out, so in answer to your question I reckon that it doesn't fit in there anywhere now, but I'm trying to just forget, I don't, I don't sit down in the evening and think that bloody prostate cancer's just getting bigger and bigger, which it

slowly does, but I don't think about it, I've got other things to think about. (Herbert)

Indeed, by the end of the first year following the prostate cancer diagnosis, Herbert was still feeling tranquil, and still monitoring the progress of the cancer in quite an informal manner.

I don't look at myself and think, I've got pain or something I don't have any feeling; you know, I don't really have pain that would say; when you have a heart attack you have a lot of pain but when you have this it's slowly sneaking on you that's all. But I haven't had anything that would make me think that my prostate [is] getting worse. (Herbert)

Monitoring the prostate cancer, either formally or informally, was attributed with varying levels of priority by participants. Although there is evidence to suggest that some men used the PSA level as an important indicator of progress (or decline), none of the men in the study approached serial measurements with undue anxiety.

### ***Knowing the Cancer***

I made the point in Chapter Four, when talking about revealing the prostate cancer, that the men in the study did not generally describe the cancer as an entity, even though they provided it with a metaphorical presence. The idea of providing the prostate cancer with a metaphorical presence was important, because it allowed the men in the study to relate to the cancer as they would any other social object. What was interesting, however, was that these men all carried a sense of the existential and physical threats, implied by the word "cancer", well in advance of diagnosis, and reacted to these threats at the time of diagnosis. As such, the work of the peri-diagnostic period (and beyond) was directed towards reducing these threats.

I reiterate these ideas because the metaphorical presence of the cancer did not diminish as a result of treatment, albeit that the physical and existential threat did, at least for some men. That is, the nature of the relationship with the metaphorical object changed over time, just as most social relationships change over time. Therefore, it would be reasonable to suggest that as each man came to know the prostate cancer, as an object over time, they became more tolerant of it, more familiar with it, and less concerned about it. Moreover, part of knowing the cancer, of travelling with the cancer over time, included becoming increasingly separated from the cancer; in some case both

physically and emotionally, in other cases just emotionally. I would suggest that such a process represented part of the work of the post-diagnostic period.

Yes I do uh I still think of it but but it's not as important as it was I find it's not; I think about it but it's not important or something that's going to grab hold of me and um lay me low I don't think in that way. I tend to think of it a bit in the long term, now. (Herbert)

Herbert no longer perceived the cancer as holding the same importance, nor did he continue to preserve the image of the cancer as the imminent killer. Moreover, the other representation of the insidious killer, the cancer gradually killing its victim by stealth, became an image that more engendered humour than fear.

Well you know uh how's this goin- (sic) what's the progression my cardiologist has just said you know, something else will kill you before that does but (chuckle) how much does it creep up on you, how long does it take to creep up, how long's a piece of string, you know, you tend to think of it that way. (Herbert)

Therefore, as the cancer became known, some of these men were able to contrast the prostate cancer with other historical experiences in their lives; a way of measuring their contemporary response. Most importantly, however, I would suggest that some of these men were able to separate and individuate from the cancer, to more clearly define their respective boundaries, and so became future-directed individuals once again.

Yeah, there is there is a change in my mental attitude to it, I guess you would have to say mental attitude and anxiety things that you would get, I'm not as anxious over it you know, I just look at it all and think uh huh I know what the problem is now and uh it's there and it's not going to go away. (Herbert)

On the other hand, being able to describe the cancer's signs and symptoms, its morphology, the risk factors associated with treatment, or the pattern of dissemination, represented another, albeit a less self-referenced, way of knowing the cancer. Cecil was able to describe, and know, the prostate cancer in this practical way.

I know prostate cancer can be serious, it depends what stage you discover it at, I mean I know that, and I think I was right on the borderline because when they did the biopsies I had four out of six of my biopsies were positive and then on the Gleason scale I was number eight which is right on the borderline again you see so I think, well I just hope that you know, got it in the nick of time. But if it had gone you know, further you know, it can spread outside the prostate and get into the liver or kidneys or that sort of thing well I know from reading books and all the rest of the stuff and once it gets into those vital organs, no matter what



you do, it's not going to stop it. So that's why I say, you know, come to the choice of chemotherapy or not, I would knock them back. (Cecil)

For Cecil, knowing the cancer in this distanced way was just as future-directed as, for example, Herbert stating that the cancer was not going to waste any more of his time. Furthermore, it perhaps represented the only way he could know the cancer, the only way he could contemplate the possibility of metastatic disease, and the only way he could voice his view about rejecting chemotherapy. The important point to make is that Cecil had always tried to remain separate from the prostate cancer, and he had never personalised it. That is, he had never perceived the cancer as anything other than a clinical entity; something to be known, something to be cured, but not something to be adopted.

In contrast to the individuated stance adopted by Cecil, as way of keeping the prostate cancer at a distance, Winston merged with the prostate cancer in such a way that it sometimes became difficult to know when he was referring to the cancer and when he was referring to himself.

I do believe that cancer comes upon us whoever we may be because we are not taking enough care [with] what it is that we need to nurture our self (...) and we keep on putting it [nurture] to one side and we deny ourselves the holiday or the sexual encounter or the red meat or whatever it is that we [are] passing over and giving it to someone else; (...) I have shut down on a lot of things personally for myself because I have been out there vigorously trying to prove to everybody that's got the element of doubt about me, that I'm ok and I'll get the thing [the cancer] fixed (...) [The cancer] it's like a bit of a bad smell it's just; getting smellier all the time and it's and the more it doesn't get fresh air and release and companionship and all the other things it harbours its heat or its potency for destruction and that's- that's about how it is. So for the first time I'm saying no I don't need to prove this anymore to anybody I have got cancer look I have got it there's the score sheet let's get on with it, let's try and find out why I've got it and I think all those things that I've just discussed are the things that help- that have helped me get it (...) And then I'm saying to the cancer well look you're not ruling me now I'm taking charge of my life and see how that suits you (...) I've decided that I don't need you to help me realise what you're doing for me anymore because I can do better without you and I value what you've done, go away. (Winston)

I have mentioned before that Winston's allegorical style held the potential to clarify and obfuscate, and such is evident in this narrative. However, it would be incorrect to conclude that he was deluded. Indeed, I would suggest that Winston's attempt to know the cancer was an attempt to know his self. That is, the relationship with the cancer had come to represent his relationship with the world. His relationship

with the cancer had become a way of proving to the world, and his self, that he could take charge and win, that he could once again be a useful, future-directed person.

However, in the process of developing such a “close” relationship with the cancer, and on the basis of his decision to self-treat, Winston found himself on the outside of the traditional health care system. The traditional system was unable to support his complementary approach to treatment, and it was unable to support him emotionally until such time as the cancer regressed, or disseminated, or he decided to accept traditional treatment.

### ***Legitimate Feelings***

I have previously observed that the peri-diagnostic experience was epitomised by the men in this study minimising emotion. I have also observed that the demonstration of emotion was conscientiously avoided, as was any direct talk about the difficult feelings associated with the prostate cancer. There was no evidence, with the passing of time and the progression of treatment, that the men in this study became any more demonstrative or any more likely to talk about difficult feelings.

However, for some men, as they came to know the cancer better, and came to place its presence in the context of recovery, there was a sense in which they were able to reveal aspects of their affective world more directly.

Robert had been confident from the outset that the prostate cancer would be cured, but had never expressed his confidence as clearly as he did in the following narrative. He identified experiencing a feeling of release, as once again he was able to look forward to the future.

No once I knew it was gone, even then it was never a, I was always confident and even if it wasn't I would, I would then jump another hurdle when it come (sic). Confidence, cocky whatever, but I'd researched enough and felt enough that believed that he got it all and he felt it but I know they're restricted in what they say but you can also blind freaking read between the lines (...) No I feel that, that, it's back to the old individual again, it's up to the individual and I think, I haven't any regret. I haven't any concerns for the future. (Robert)

Cecil had also waited for the first PSA test following the completion of his radiotherapy treatment. He, like Robert, had always remained quietly confident that all would be well, provided of course that he stuck to the rules. Cecil had remarked sometime previously that he was not generally an emotional man, tending more towards

the pragmatic than the emotional. It was therefore interesting to observe his response to waiting for the result of the first PSA assay. I had asked him if there had been any time when he had felt uncertain and apprehensive.

No, not at all, no not at all. No I just felt, you know, as I say just waiting for that, the first test, that was the crucial time but until then, I didn't know, you know. It's, well you just don't know what's going on sort of thing and when it came through I was actually elated. (Cecil)

Much like the idea of becoming future-directed, Cecil demonstrated a kind of opening-up. He became free to express his feeling of elation, and his sense of the uncertainty he believed he had never experienced. Therefore, it would be reasonable to suggest that the kind of feelings identified during the post-diagnostic period were legitimate feelings. That is, they were feelings directed outwards in a way suggestive of a different set of rules. Herbert provided some insight into what might be described as the illegitimate feelings, perhaps more associated with the peri-diagnostic experience.

Herbert: I've got to hang onto it [my experience] I've got to grin and bear it; this is what I'm trying to do, to grin and bear it because; but that becomes you know sometimes becomes difficult.

David: In what way?

Herbert: It becomes difficult in as much that it's, you get down you feel despondent and then the first thing you start; it's something I have to be careful not to become despondent I think that's important, in fact it's very important for anyone that has these sorts of things is not to feel despondent or sorry for yourself. (Herbert)

Herbert talked about "hanging on" and not becoming despondent, he also started to mention the consequences of becoming despondent, but stopped short of the word or phrase that would have illuminated this feeling. Moreover, he made an admonishment to the effect that it was imperative to guard against becoming despondent. Logically, and contextually, my sense is that he was emphasising the importance of not giving up, not giving in, not being weak, not being beaten by the cancer. That is, failure was associated with the acknowledgement and expression of difficult feelings, illegitimate feelings, and had to be avoided.

If this was so, then the emotional minimisation observed during the peri-diagnostic period was about preventing the expression of illegitimate feelings. Indeed,

expressing illegitimate feelings would have potentially threatened the success of treatment (perhaps magically) or the perceived ability of the mind to aid in the “fight” against the cancer.

As such, the legitimate feelings associated with the post-diagnostic period came about as a consequence of success, as a consequence of sticking with the peri-diagnostic rules, and as a consequence of serving time. I asked Herbert if he believed that a reduction in worry (a legitimate feeling) came about as a result of reflection or as a consequence of time.

I think it is probably time you know, I don't feel too bad, I feel alright, I get up in the morning and do what I have to do and I feel; reasonably fit. Not fit but I enjoy getting up in the morning, I still enjoy doing things. (...) [I]n other words I haven't got out of bed in the morning and thought bugger this I'd rather be dead, no that hasn't entered my mind. (Hebert)

Therefore, I would make the observation that the rules associated with the expression of feelings during the peri-diagnostic period had to do with minimising the difficult feelings (e.g. despondency, depression, sadness etc.) so as to prevent their emotional expression, and allowing the legitimate feelings (e.g. faith, confidence, resolve etc.) so as to maximise success. During the post-diagnostic period, and in the context of perpetuating a stable and dynamic lifeworld, the rules allowed for the expression of legitimate and illegitimate feelings so as to maximise the restoration of balance.

### ***Reflecting on the Difficult***

This thesis has identified a number of difficult experiences or feelings identified by the participants in this study, and placed these in categories driven by the data. I make this point, at this point in this analysis, because it parallels some of the ways in which the men in the study constructed their responses to the prostate cancer experience as it unfolded before them in real time, and then again in subsequent reflection. The difference, of course, between these two processes, my analysis and their experience, is that I am attempting to “experience”, and analyse, aspects of their experience twice removed. Once removed from the experience itself and the time it occurred, and once removed again from the person who experienced it.

As such, and in similar fashion, the men in the study experienced difficult moments in real time, and then re-experienced the same difficult moments in reflection,

but in a different context. Therefore, recognising the difficult in the context of the peri-diagnostic experience was different from re-experiencing (reflecting on) the difficult in the context of the post-diagnostic experience.

I did, I found it [the early experience] very difficult to cope with and I think that, that if they had somebody saying this isn't the end of the world, like you did, to me uh you were the first person that gave me hope, that may sound stupid, nobody left me, with the Urologist he said sorry I've got to tell you that you've got cancer and that was; nobody told me that uh well he did tell me but I didn't believe him, that it was not going to be the end of the world. (Herbert)

Herbert reflected on the experience and identified it as having been difficult, which was different from having the experience in real time and feeling it as being difficult. The difference lies, for example, in the observation that Herbert did not name, in the moment, the difficulty caused to him by not being provided with hope; it was only subsequent to the event that he was able to identify this as having caused him difficulty. Therefore, in the same way that analysis operates, it was not until after the event that he was able to say, for example, "so that is why I felt like that". This is important, because it suggests that a central function of the post-diagnostic period was about enabling these men to locate their ongoing experiences in a future context, by removing it from its original emotive context and reflecting on what it was.

Equally, Richard was able to look back at a difficult experience associated with deciding what type of radiotherapy he should have; external beam radiotherapy or Brachytherapy. This exemplar demonstrates very clearly the types of difficulties men are confronted with as they try to understand new information, maintain some sense of a cohesive self, and keep the health professionals on-side. He did not want the Brachytherapy, but agreed to it, but did not know why he agreed to it until he found himself removed from the moment and its emotion.

So I thought, "Well if I've got to have it, I've got to have it," but I didn't want it and I didn't want to say to them – it made, made me feel as though I was a "woose" to say, "I don't want that, I'll have the external." But they did initially say to me, "You don't have to have it." Didn't they? But I agreed to it because I thought, "Well this is the in thing." (Richard)

Furthermore, reflecting on the difficult also provided men with an opportunity to acquire insight, in advance, about those experiences that would cause difficulties unless avoided or modified.

I don't want to know the bad things, I want to know the good things, if there's any such thing, I only want to know good things because those bad things will depress me, I don't know if that makes sense? You hear, for instance um to coin something, like somebody on the radio saying it'll get worse and it will get terrible, and you'll be in great agony and pssh I don't want to know about that, I want to know about my progress but I don't want to know the gory details about where I'm going to finish up because that causes depression. (Herbert)

Had Herbert been confronted with what he described as “bad things” in real time, it is unlikely that he would have been able to name them, or have been able to differentiate between the moment that was safe (knowing about progress) and the possible next moment containing the “gory details”. However, in the context of the post-diagnostic period, and removed from the immediacy of action, Herbert was able to extend time so as to make future-directed choices that would facilitate his safety.

Therefore, reflecting on the difficult provided some men with a sense of clarity unachievable during the peri-diagnostic period. I have suggested that one of the reasons clarity was achieved, was because the experience could be reflected on in the absence of the original emotions associated with the event. However, it would perhaps be more accurate to suggest that reflecting on the difficult did not occur in the absence of the original emotion, but in the presence of an attenuated form of the emotion carried over from the original experience.

Winston had decided to reject traditional treatment for his prostate cancer. Having informed the radio-oncologist, he subsequently received a formal letter advising him that this specialist did not agree with his choice, but that Winston was welcome to re-see treatment should he change his mind. At no time did Winston openly suggest that he had felt disappointment or rejection. However, there was a sense in which, albeit allegorically, Winston revisited the difficult feelings he had experienced when he originally received the letter.

Yes they have washed their hands of me, like the Judge did. Yes. Well they're in the fast lane I feel David. They haven't, they may have been slightly offended. They've been slightly put out of their neat tidy little desk calendars and their diary pages and stuff for this bloke who won't fit into an appointment slot which I've measured as his surgeon to last three and a half hours and then he goes into that other room there and then after that he stays in for seven to ten days or some other time to practice. Now, you know, like have the hormone for three months and then have seven weeks of five days a week, bang, bang, bang at precisely quarter past four in the afternoon. But it's precisely that isn't it because it fits into that line of that page and also they've got such a queue up, **they've got to turn the page and Winston is left behind there.** Well, I wonder how he is

getting on probably when I'm driving home I might think of that guy that came in, you know, like a couple of guys that have come in , or women for that matter that have chosen differently, I wonder how they're getting on. But **the sad thing is they probably don't really know and don't probably ask** and if they did know or ask and know, because it was at least creating a new type of harmony for Winston, how useful could that be, for him as a surgeon or a radiologist. (Winston) [Emphasis added]

I would suggest that Winston felt both disappointment and rejection, and also sadness in the absence of an authentic expression of concern for him as a human being, or respect and support for his choice. My sense is that Winston felt discarded again by the intuitions representing mainstream culture, punished because yet again he had chosen to act independently of the accepted way. Being allegorical was Winston's style, his way of telling the story. I would suggest, however, that had he been confronted with the original feelings, as opposed to those that had been time displaced and attenuated; he would have found the telling of the story difficult.

Reflecting on the difficult, especially in the context of an attenuated emotional presence, was also a safe and useful way to revisit actions or decisions that contained the potential for self-recrimination. Herbert had postponed having a prostatic biopsy for three years after the identification of a raised PSA level. During the early part of the peri-diagnostic period Herbert had experienced difficult feelings associated with his non-action. Later on, during the post-diagnostic period, he was able to revisit his postponed action, but without the emotional overtones, and pose questions which, hitherto, he would have been unable ask.

(...) people like me who if I'd done something about it earlier I might have been better off. That's hypothetical, you know, but I, because I didn't do anything about it I'm inclined to think now I should have done, I would have been better off, that's my case, it's not everyone's case a lot of people uh would be, I must say that I've had a good life and I haven't worried about it; would I have worried about it more if I had known earlier, would I have had uh treatment for it, would I have had it out? (Herbert)

For the men in this study reflecting on difficult feelings, as a process that occurred during the post-diagnostic period, provided a mechanism for remembering potentially traumatic experiences or difficult feelings in an attenuated form. As such the process enabled these men to examine and evaluate feelings and experiences in an emotionally safe manner.

## ***Consolidating Support Relationships***

A further dimension of perpetuating a stable and dynamic lifeworld had to do with consolidating support relationships in the context of the post-diagnostic experience. I have observed previously that the men in the study had not referred directly to their emotional support needs. However, I further observed that some relationships demonstrated inclusive synchronicity, which provided for emotional support intuitively and automatically. All the men in the study received emotional support from family and friends.

I reiterate these earlier observations because there was an additional sense in which the men in the study did not discuss, in any detail, their support relationships. That is, there was a sense of expectation or, perhaps more accurately, advanced acceptance by the men in the study, that the important individuals in their lives would, *ipso facto*, provide the necessary support. However, the men in the study made little mention of other support relationships during the peri-diagnostic period.

In the context of the post-diagnostic period, and of lifeworld reconstruction, there was a contemplative quality about the way in which some men described their support relationships. In addition to this contemplative quality there was, once again, a sense of time displacement that provided for reflection as these men worked towards consolidating, and sometimes redefining, their support relationships.

Gerry had a radical prostatectomy, which left him impotent. Prior to surgery he had remarked that he and his wife would traverse the prostate cancer experience together. However, when he subsequently spoke about his wife he described a relationship in transition.

I suppose I have been surprised in that she's coped better than I thought she would cope. I suppose I'm probably seeing a slightly different side of my wife these days in the sense that she used to be a, a non independent person shall we say and no doubt that was only my perception, I think I think it was probably she was letting me doing (sic) it that way because it satisfied my needs and she got the job done that she wanted done whereas I know that she's quite capable of doing a lot of things. She surprises me sometimes in what she does (...). So yes, she doesn't depend on me for a lot. That's fine. Sometimes I wish she did a bit more occasionally. It would be nice if you just hung around a bit more instead of just shooting off with your mates and doing this and that, I could do with some trouble myself. But that's life. Or out to lunch all the time. [And no I haven't discussed this with her.] (Gerry)



I would suggest that what Gerry described was a sense of loss, a feeling of impotence, and an unconscious push to locate the relationship with his wife in a different, a more comfortable, place. It is important to note, however, that some of the implied disappointment Gerry referred to was a demonstration of projection; a disowning of aspects of his self (Grant & Crawley, 2002) as a defence against the anxiety associated with the transition he was experiencing. Indeed, Gerry went on to openly state that he thought his relationship had changed.

I think it's [our relationship has] changed slightly. Let see, I'm not sure how to put this. I think it has changed not necessarily for the better, just sometimes I get very agitated, bite her head off pretty quick sometimes sort of thing and I think that's part of my frustration and I suppose the fact that you don't have sex anymore realistically you don't have sex takes something away from you as well. Yes, hopefully we'll manage. Hopefully we'll manage. I mean it's twenty-seven or eight years now. I should get it right, it's about twenty-seven. Okay, twenty-six and a half. That takes a little bit, I think that takes a little bit away from - you know, the fact that we don't or can't have sex. I mean she doesn't seem as interested these days for want of better term if you know what I mean. (Gerry)

It was sobering, and moving, to observe the way in which Gerry tried to understand his relationship of twenty six and a half years, a relationship that prior to the radical prostatectomy had been safe, comfortable, and predictable. However, as the reality of Gerry's impotence consolidated he began to feel emasculated, uncomfortable, short-tempered, and unsure about whether the relationship would survive. Moreover, he began to feel that his wife was not interested; whether in him or in sex he did not make clear. However, I would suggest that it was himself he viewed as uninteresting, and different, because of the impotence. Therefore, in the same way that Gerry's sense of self was in transition because of the impotence, so too was the main support relationship he experienced with his wife.

Furthermore, as Gerry struggled to locate his relationship in a more comfortable place, as he tried to work out what the new set of rules should be, and as he waited for the first post-operative PSA assay, he reflected on the possibility of premature death. More importantly, however, he decided not to share his thoughts with his wife.

Gerry: I certainly wouldn't discuss the fact, you know, that I might be dead, that I'll probably be dead before I'm seventy. That's just a no conversation piece I'm afraid. (...)

David: Because you want to protect her in a way?

Gerry: I suppose that's it in a way; Yes, well yes. Not that I want to be mean to her at all but yes, but that I want to protect her. She was obviously as you saw, quite upset about the cancer deal. I was less upset. I can't say that I enjoyed it but I was less upset. But I don't see any point in her getting upset over it. If I'm going to die, I'm going to die. (...) I'm just not going to bother to discuss [it] with her because I don't want us to walk around with a ball and chain. (Gerry)

There was a lot of information contained in this short narrative, information about Gerry's feelings towards himself, his wife, and his relationship. However, the most important inference to draw from this narrative is that Gerry had lost his sense of the inclusive synchronicity he had hitherto shared with his wife; it could no longer be trusted. That is, maybe there was a chance she would not understand his feelings, she appeared more independent than before surgery, she spent less time with him, and she no longer seemed interested. If these observations were valid, then perhaps the relationship was no longer safe. Therefore, some of the work of lifeworld reconstruction, associated with the post-diagnostic period, at least for Gerry, had to do with re-defining and consolidating a support relationship in transition.

On the other hand, for Herbert, there was no evidence of a relationship in transition. There was no loss of the inclusive synchronicity he and his wife had always experienced, and her ability to buffer his pessimistic stance remained intact.

I'm a pessimist myself, she's an optimist um she never thinks anything is as bad, one of her daughters rings up and says something she doesn't immediately go into shock or anything, she says oh you know it's probably not as bad as that; that's what she does with me, you know, don't worry about it, you're all right, **I'd know if you were sick.** (Herbert) [Emphasis added]

Herbert's wife said that she would know if he was sick. This was an important statement to make, because it spoke of the way in which Herbert and his wife distributed the support roles in their relationship. Indeed, it was similar to the role described during the peri-diagnostic period as "standing in the way", where Herbert's wife told him that he was not going to die. Therefore, there was a clear sense in which, perhaps because of Herbert's pessimism, his wife had taken on the role of arbiter for what constituted real danger within the relationship. As such, not only was Herbert able to depend on inclusive synchronicity, he was also able to trust the messages provided by his wife about sickness.

This interpretation, driven as it is from the data, appears reasonable and, I would suggest, fairly represents the established dynamic between Herbert and his wife. However, there was a further level of interaction within Herbert's family group, which leads me to suggest that Herbert was not as emotionally "needy" as this, and earlier analysis implies, regardless of his self-proclaimed pessimism.

During the Second World War Herbert served in the Royal Australian Navy, coming under fire during a number of engagements; he was 17 years old. He recounted an incident to me that suggested a far greater level of hardiness and resilience than the contemporary evidence suggested. Herbert had been talking about the need for counselling.

[Y]ou know, um I think back to being a seventeen-year-old boy in the Navy um and seeing my friend's head cut off uh and I put it in a bag and it still had a smile on its face, you know (chuckle) that's when you, maybe you need counselling but we never knew what a Counsellor was, you had to grin and get over it, you know. (Herbert)

Herbert did "grin and did get over it", and did go on to live a full and productive life, and to raise a family of two girls and a boy. Indeed, his children appeared to play their part in preventing him from becoming pessimistically preoccupied with the prostate cancer. Herbert's children also normalised the prostate cancer for him, by referring the cancer to the ageing process.

Herbert: They don't think there's anything wrong with me, that's their attitude you're fine what are you worried about?

David: And do you feel that that's because there is nothing to see or because-

Herbert: Because nobody sees anything very much different in me except I'm getting older, maybe something in the prostate is doing something but to everyone else, family, everyone looks at me and says well, that's part of getting old you know. (Herbert)

However, I would suggest that some of the motivation for Herbert's family, in using such a normalising approach, had to do with their need to avoid difficult thoughts and feelings. Herbert was aware of the difficulty they experienced and felt compelled to collude. Importantly, the collusion caused Herbert to become isolated from what he saw as the truth, and therefore prevented him from sharing his difficult thoughts and feelings with his family.

To talk to someone you know is a member of your family about all this um, it's more difficult, a lot more difficult, and you have a lot more people not telling the truth; your family are saying "ah that's bullshit you'll be alright" you know. (Herbert)

As such, a façade of support was erected at the expense of truth telling and authentic sharing. More importantly, it was a façade erected as a trade-off, and in contradiction of Herbert's historical ability to engage with difficult experiences, thoughts, and feelings. Therefore, as an unconscious family strategy, such a façade of support was successful and did function to alleviate group anxiety, albeit at the expense of Herbert being able to share his innermost concerns. Later on, Herbert suggested that he believed it was easier, and more effective, to talk about the prostate cancer with someone not connected with the family, he said "Yeah, you're not having to be melodramatic." (Herbert).

For Robert, the support he received from his wife was a given; and inclusive synchronicity a well embedded component of their long standing relationship. However, Robert did not talk about difficult feelings with his wife; in fact he did not acknowledge difficult feelings associated with the prostate cancer at all. Much of this approach was the result of his PTSD, which required him to prevent anxiety from occurring. I asked him, on one occasion, if the prostate cancer had ever increased his level of experienced stress.

No, I, no, I, it was funny. I, it never worried me. (...) I suppose the initial shock certainly you know, but I, it never upset me you know that, I was more concerned with the wife than me because she was certainly shocked. (Robert)

Robert's wife was shocked at the diagnosis of prostate cancer, and there was absolutely no question about the genuineness of her response, or of Robert's subsequent concern for her well being. In this sense, it was clear that their support for each other was mutual and effective. Indeed, following the diagnosis Robert and his wife went on holiday to Bali.

Well once we got over the initial you know, crying and settling her down, I said oh well, you know, he's explained it and the biopsies gave these readings or whatever and I had this book and he went through it roughly with me, and I went through it with her and I said to her, I said, "Well it's, very low, Gleason's four and whatever and he's very confident and you know, I've spoken to my psychiatrist and my doctor as well as him," and I said, "The three doctors are all pretty confident that it's confined." (...) then I went to Bali, took her away for a week. (Robert)

However, on another level of engagement, and in the context of what Robert did not, or was not able, to express, there was a sense in which he was empowered to experience his feelings of angst vicariously through his wife. That is, his wife's shock and continuing concern for his welfare was, on one level a genuine expression of her deep felt concern. However, on another, unconscious, level she acted as a surrogate for Robert who was unable to allow his self to demonstrate such emotion because of its potential to exacerbate his PTSD. As such, and in the same unconscious way, Robert was able to manage his difficult feelings in the process of supporting his wife; a little like the aphorism "I believe what I hear myself say". Later, with both projective and non-projective intent, Robert said, "So I suppose it's by my positive approach with this prostate (sic) [that] has made her more confident." (Robert). Therefore, and importantly, Robert and his wife had constructed, and consolidated, a mutual support relationship that functioned effectively on a number of different levels.

### **Staying in Control**

I have tried, in this analysis, to keep away from phrases or ideas that are connotative of the gender stereotypes associated with masculinity. I have not done this for hegemonic reasons, or to try and hide what most certainly exists in the social world. I have done so because of the potential for such value laden terms to distract attention away from an authentic attempt to examine underlying motives and mechanisms, many of which have little or nothing to do with gender *per se*. Therefore, in referring here to the phrase staying in control, I am not referring to the common sense notion of men being dominant or controlling, but to the general activity of managing or controlling potentially difficult, damaging, or traumatic events.

Many aspects of the prostate cancer experience were too complex, technically and emotionally, for the men in the study to control in a direct way. Furthermore, the historical, physical, and social contexts of the men in the study sometimes militated against direct action, or were themselves complex. Therefore, for these men, staying in control could only be achieved indirectly (including unconsciously) or incrementally; often quite simply, but sometimes in more complex ways. Moreover, staying in control represented a further component of perpetuating a stable and dynamic lifeworld because of the future-directedness of the activities involved.

### *Staying in Control – Simple Scenarios*

In referring to simple scenarios I am not implying that the prostate cancer was experienced without difficulties, or that staying in control was necessarily a straightforward matter. Nor am I suggesting that the consequences of the prostate cancer experience did not impact on the social, emotional, and historical contexts of these men. However, some men in the study were able to enter the prostate cancer experience already in control of aspects of their lifeworlds, because their lifeworlds were situated in understood, stable, and predictable social, emotional, and historical contexts. Therefore, simple scenarios refer to lifeworld contexts that, at the very least, enabled these men to meet the prostate cancer experience with a cohesive self.

Cecil had demonstrated a clear ability to conform to the treatment regimen, and had remained uncomplaining until the end of the radiotherapy treatment. It would be reasonable to suggest that total conformity with the treatment process had the potential to disempower Cecil, because of the necessity to hand over control to another person or group of people. However, there was a sense in which Cecil was always able to stay in control; he was able to control the faith he invested in those providing treatment.

So that's the thing. As I say it could be any sort of disease. Once you've got a disease and you are diagnosed with it then as I say you've got to put your faith in the doctors and say, "Okay, that's the problem, how do you fix it?" (Cecil)

Also, Cecil was able to stay in control of the way in which he perceived or defined the prostate cancer. Sometime following the completion of his radiotherapy treatment Cecil suggested that he was cured.

Cecil: Well the problem is you know like I have got sort of cancer that's been cured but not the full blown cancer if you like. It's not-

David: What do you mean by that, not the full blown -?

Cecil: Well I mean, right, you've got cancer but let's, let's put it to you this way. If the cancer had got out of my prostate then I could be in real trouble you know, I'd be sort of worried sort of thing. (Cecil)

It is difficult to know if this had been Cecil's perception of the cancer throughout his experience. However, what he suggested was that the localised prostate cancer had been cured and that, in any event, localised cancer was not "full blown

cancer” (Cecil). Full blown cancer was defined as advanced or metastatic cancer; if he had full blown cancer he would have been worried. Therefore, Cecil stayed in control of the potential perceived harm of the cancer by differentiating between localised prostate cancer, which was curable, and advanced prostate cancer, which was not.

Herbert was unable to control directly the impact of the prostate cancer on his lifeworld, but he could make choices about the amount and type of information he received that had to do with the prostate cancer. Therefore, in the context of knowing about prostate cancer, Herbert remained in control.

Having those things on television I look at it and I think I don't want to know about this because they might tell me something that I don't want to know about, I don't want to hear about it I'm alright, but I don't want to hear about that, I don't want somebody telling me that there's something nasty in front of me. (Herbert)

Moreover, Herbert was able to consider the possibility that the prostate cancer might eventually prove fatal, but recognised his inability to stay in control of the existential anxiety such a reality would create. He therefore suggested staying in control by accepting and managing information in stages.

Yeah, that's right, I guess if I got worse and I don't want to know how worse you get (sic), but if I got worse then I would want to know what the next step was, but I wouldn't want to know it all together. If you were to say to me, if this is the scenario, you feel great then you start feeling worse, then you go to bed and then you die, now if you said all that to me I'd say God! I'd want to know that much [signifying a small amount] and when I get to there I want to know that much, I want to know that much after that because if you're half way there you know you're on the way. (Herbert)

For Robert, staying in control represented an imperative because of the PTSD. However, Robert recognised that had it not been for the PTSD he would have probably been more blasé about seeking advice from the doctors about the prostate cancer, or less immediately active when confronted with the diagnosis. Therefore, much of Robert's ability to remain in control of the prostate cancer experience was a direct result of the imperative to stay in control of the PTSD.

Yes I probably would be the same as anyone else, I suppose the PTSD was you know, part of all, I had to learn to cope with life and that was probably came into it (sic), so yes I'd have to agree with that. (Robert)

Gerry felt as though his lifeworld had disintegrated when he was confronted with impotency. He felt as though he had lost control of his lifeworld as he experienced his relationship moving through a process of transition. Therefore, although he was unable to control the impotency or its consequences, he at least was able to control who read his mail.

[I said to my wife] “but if it’s addressed to me, it could be anything, and it might be something that I don’t want you know,” and then she went off and huffed about, “I don’t want to know about you,” shit. But the thing is, maybe there is (sic) some things I don’t want you to know about. I mean. I don’t care if people know how much money’s in my bank whether it be my wife or anybody else. You know, it’s not very bloody much as is with most people. But just with things like the mail, if it’s addressed to me and it’s sealed up, it’s for me and that’s it. (Gerry)

Gerry was also able to control the extent or depth to which he reflected on the prostate cancer experience. Gerry had wanted to be up and active from the time he returned home after the radical prostatectomy, just as he tended to rush past any discussion that dealt with difficult issues. I suggested to him that he did not appear to slow down long enough to sit and think about difficult thoughts, feelings, or events.

Yes, that hits, that hits the nail on the head I think. I [am] only going to agree with you, maybe that is true, maybe that’s the reason I don’t look so concerned because I don’t stop and look at the facts and just say right oh, maybe I don’t want to stop and look. I don’t know. (Gerry)

Gerry’s comment was important because it highlighted the idea that some issues were extremely difficult for him to spend time with. Moreover, there were some issues, like Gerry’s impotency, which, at least in the short term, were insoluble. Staying in control was therefore possible by choosing which issues to attend to, and which issues to leave behind.

Though Gerry stayed in control by choosing what information he attended to, Otto stayed in control by managing the information he shared with others. Otto was a very private man, a very exact man, a man who valued order. Therefore, it was important to Otto to preserve the orderliness in his world, and part of that orderliness was not to stand out against the crowd.

Otto: Oh no, we, I mean we’ve discussed it out, I mean I’ve told my son and daughter and I’ve also told the neighbours but not in the way that as if it was, well one of the biggest announcement of the day. No, none of that at all.



David: So you kind of downplayed it?

Otto: Well not really downplayed it but I don't feel it's always necessary to always say, "Well look I've been having treatment for the last eight weeks." (...) I think it is a very intimate situation the problem that one has. (Otto)

Richard, on the other hand, felt as though he was losing control when health professionals were not direct with him. Richard was able to stay in control when he believed that he was engaging with direct and open communication, verbally and non-verbally. Therefore, staying in control for Richard had to do with openness, truth telling, authentic communication, and a genuine regard for him as an intelligent individual. That is, he felt in control of the experience when he was able to see clearly what it was he needed to manage.

I, well it's like me talking to you now. I mean I look forward to your visit because I can communicate with you and you can communicate with me and we can say, "Hey what's this or what's that?" If they're going to tell you something, I want them to look you in the eye and say, "This is it, this is black and white," and then I'll say, "Alright, I can understand that, what you're on about, where you're coming from," but when they start this business of, well looking down there and talking to you, they've got something to hide or there's something they don't want to tell you. (Richard)

Being able to see what was coming, being in receipt of as much accurate predictive information as possible, was equally valued by Robert. However, Robert added a further dimension to the idea of predictive information. Robert suggested the importance of not acting too far in advance of an issue becoming an issue. Therefore, for Robert, staying in control was defined by using predictive information in a measured and controlled manner; as a way of controlling necessary resources.

I said you know, the prognosis at this stage they can't guarantee it til they go in but I'm very confident looking at alternative cases or whatever that I was told by doctors, that yes, there's a good chance that we'll get it all and I said and I'm not a person, and she knows that, I'm not a person that even though I think ahead, I don't jump that hurdle until I get to it. (Robert)

Therefore, staying in control, in the context of what I have called "simple scenarios", represented an approach to controlling events or preventing anxiety that emphasised the use of familiar and stable contexts. That is, these men tacitly knew that some major experiences, like prostate cancer, were more effectively controlled by

managing familiar events, which although peripheral to the prostate cancer experience, helped to maintain the cohesive self.

### *Staying in Control – Complex Scenarios*

Just as simple scenarios referred to lifeworld contexts that enabled some men in the study to enter the prostate cancer experience with a cohesive self, complex scenarios refer to lifeworld contexts that contained, or had the potential to contain, the capacity for causing fragmentation. As such, the prostate cancer experience was sometimes superimposed on lives already compromised, or potentially compromised, by other demanding or traumatic events. Therefore, and as a result of these pre-existing contexts, staying in control in complex scenarios was often more indirect and more subject to unconscious processes.

Staying in control, for Winston, was complex. Indeed, staying in control was not something that Winston believed he had ever managed to achieve, at least not in a way that recognised his authorship or his individuality. His business of twenty five years had been taken away from him, he had been made bankrupt, and he had lost control of his life. Winston believed he had been duped and abandoned by a social system that was self interested. Therefore, if Winston was able to stay in control this time, then he would be provided with the energy to conquer the prostate cancer and, in so doing, he would prove his worth.

Because I've realised now for the first time in my life I haven't been in control of anything, I've only been in control of what I've been taught to be in control of and what other people have expected me to be in control of and taught me to be but it's never been in control of Winston. (...) I believe that if I'm in control of myself and I have got courage and confidence to accept my responsibilities then all of a sudden there's no struggle because the control is the energy to disintegrate the struggle [the cancer] and what ever the problem you're faced with. (Winston)

I asked Winston if it would be possible to achieve the type of control he was referring to within the traditional medical system.

No [I can't stay in control by accessing traditional medicine] because I don't; no I couldn't because something in my spirit tells me that I don't need to have a sunburned bum and I don't need to be incontinent and I don't need to be impotent and I don't need to be growing hair and things like that and I don't need my testosterone to be taken away from me because it's perceived to be the enemy um; because if those things are taken from me I'm no longer the person that I'm now in control of (...) because if you don't work it out you've again not

controlled the issues of your life you've used other people to persuade you and to control you to do these things (...) (Winston)

Traditional treatment, for Winston, included too many potential losses and, in the context of so many prior losses, he felt the need to draw the boundary. Once again I must emphasise that Winston was not deluded, albeit that his allegorical style sometimes confused his meaning. It is important to recognise, in the context of this thesis, that Winston's experience of prostate cancer impacted on a real man, with a real social history. Indeed, prostate cancer always impacts on a heterogeneous population of men, some of whom lead complex lives, in ways that are not always predictable, and with consequences that are not always desirable.

### *Robert – A Vignette*

To illustrate the complexity of the lifeworld, and the inter-relatedness of the categories that formed the context of the prostate cancer experience, I would like to offer an analysis focussed on some of Robert's "staying in control" experiences. Apart from just their richness, the reason for choosing Robert's experiences is associated with an earlier observation that his pre-existing PTSD acted as an amplifier for his responses to the prostate cancer experience. As such, this important category of staying in control stands to be illuminated just that little bit more.

Robert talked, in the following narrative about going to the shops, and about training his wife. Fundamentally, however, he was talking about staying in control. Recall that Robert has PTSD, and that staying in control of the prostate cancer experience was intimately linked with staying in control of the PTSD.

I don't make that many blunt urgent decisions like even that new cabinet out there. I bought her that two or three weeks ago but she'd been nagging about it for about a month or so and I thought, and I'll have a look, then I measured and seen what'll fit and then we went down and looked. I didn't, I wouldn't go near a shop for weeks. I let her look around. So I let the, the bullshit of looking at ten or twelve different shops until she gets to a situation that she's, this is the one she wants, then I go down, then I'll negotiate price and it was a special size, I wanted this size made. I wanted this cut off this and yes, we can make this special size and we got what we wanted so that's how I deal with life all the time so she knows that. So she goes and does her bit and she's confident that once I make a decision it will – she's actually very happy because I've made it to size. So she's very confident in me. (Robert)

In trying to maintain control over his world, Robert used a hegemonic approach, not necessarily because he was a hegemonic male, but because all his work experiences

within the prison system had shown him that strength and control were important. Moreover, he knew that he had to avoid interpersonal conflict, so as to avoid the anxiety that would ensue.

Therefore his wife did the looking, and he did the bargaining and deciding. His wife did the data collection and he did the decision making. Through this division of labour he avoided what he called the "bullshit of looking" and thereby reduced the probability of interpersonal conflict. Of course there were two possible scenarios for his wife: she either had actually been trained to work in the way Robert described, or she knowingly colluded with Robert because she knew it to be a way of limiting potential anxiety for him (and therefore for her). Either way, Robert was able to maintain the stability of his close relationship as well as other external interpersonal interactions.

On another occasion Robert reported that he had not complained to his wife, following a sleepless night due to the irritable bowel syndrome associated with the PTSD.

Well, that's, that's, probably my make-up, man's man, you know, I've got to deal with it and talking with the psychiatrist you know, I'm not going to be a hypochondriac and getting up every day (sic) and whinging to the missus, I'll finish up worse. You know, if I didn't learn to cope with the problem, why should I push the problem onto someone else when the problem is yourself?  
(Robert)

I would like to make two observations. First, Robert suggested the reason he did not complain or mope was because it was his "make-up", he saw himself as a "man's man"; the assumption being that "real" men do not mope or complain. Second, had he complained about the difficult nights he would have become a hypochondriac, and someone identifiable as a "whinger", both of which he perceived as unacceptable.

Of course the hegemonic male is stoic in the face of adversity, and would probably not choose to complain to a woman. On the other hand it was socially acceptable to talk to his psychiatrist about issues, he was a man, and also Robert was paying him. Therefore, Robert could say what he wanted because he knew it would remain confidential and "hidden", even beyond the point where he had learnt to cope with the issues. Hence, he remained in control of information about his feelings, avoided being perceived as a "whinger", and was once again able to preserve the integrity of his self-esteem and his closest interpersonal relationship.

Bearing in mind the intricate relationship between staying in control of the prostate cancer experience, and staying in control of the PTSD, Robert suggested that he did not allow himself to become emotionally involved when engaging with a particular problem or issue.

Robert: If, once I'm in the process of dealing with the problem I don't get **emotionally** involved at all. Or I don't, I don't allow it.

David: You don't allow it?

Robert: I don't allow it. No I don't, I don't allow myself to become **depressed** because it, it would fog my idea of how to deal with it. (Robert) [Emphasis added]

In the first part of the narrative Robert talked about not becoming emotionally involved. However, in the second part emotionally was transformed into "depressed". I would suggest that what Robert was referring to was the distinction he had set up between interpersonal conflict and practical issues; whereby interpersonal conflict elicited depression, but practical issues did not. Therefore, as prostate cancer or surgery were not categorised as interpersonal conflicts Robert was able to avoid the anxiety or depression (emotion) that would have arisen had the experience been categorised as such. Essentially, this was another way of preserving control, by allowing some feelings but not others; personal conflicts were equated with emotion and practical issues with control. So, in part, Robert was able to stay in control of the prostate cancer experience by carefully defining some experiential components as emotive and some as practical, and then diligently avoiding the emotive.

Furthermore, and most importantly, Robert also talked about stopping his wife from worrying, as a way that allowed him to continue avoiding his emotional responses to experiences. He described the elimination of worry as an active process.

Robert: So her worrying I quickly eliminate. I do it with everything.

David: So is, is the elimination of her worrying also a product of you dealing with [the prostate cancer?]

Robert: I'd say yes, yes, I'd say it's from me yes that's she's learnt to and, and you know, I don't go out much. (Robert)

Although Robert suggested that he prevented his wife from worrying, my sense is that what he eliminated was her overt expression of worrying rather than her internal feeling of being worried; an outcome that I would suggest involved some collusion on her part. This notwithstanding, what Robert was able to control was an environmental cue that would otherwise have triggered the uncertain, the unknown, and the unpredictable experience of dealing with an interpersonal event (viz. his wife openly worrying). So there was a sense in which Robert, once again, was able to control his local environment to prevent anxiety; essentially by controlling the cues he was presented with.

There was almost certainly a relationship between this response and the PTSD, and therefore with the experiences that caused the PTSD, and pre-dated the PTSD. Consequently, it is problematic to say, for example, "well this is how Robert managed the prostate cancer" without understanding that this was also how he had learnt to manage life events post PTSD. In a general sense then, I would observe that it is difficult to understand fully how any of the men in the study managed their prostate cancer experiences, without understanding how they had learnt to manage other previous life events. It is important to acknowledge this observation because, in the absence of macro events like PTSD, or IHD, and so on, how men "usually" manage events fades into the fabric of the whole of their lives up to the point of the new experience. It is important, therefore, to think about how large, often finite events, come to be so defining, prostate cancer qualifying as one of those defining events.

Robert also talked about how he encouraged his wife to go out with her friends. He said he did not want his wife sitting around at home because it had the potential for making him feel anxious (an interpersonal event), and he wanted her to have some life. He did not tell her to go out because doing so would have generated interpersonal conflict and anxiety.

And see she's out again today, looking after the grandkid and you know she goes out for dinner tonight with the girls and whatever and I take her out for tea maybe once a month or something we go out but I've never gone out much so I've, I've encouraged her to, "I don't want you sitting around home here," because it probably, it does get me anxious or whatever, if she's sitting around doing nothing and, and having no life. So you know, we've got ourselves a relationship now where you know, I go to my bowls or whatever and I go- we don't do, we don't do very much together. Probably twenty percent. The rest of the time we both do our own thing but we still both, there's no animosity between us, we both love each other deeply – so I mean this is the coping, I, I

prefer to be on my own; if I have any problems I can deal with it on my own, interference I can't. (Robert)

My sense is that this narrative spoke about the conscious management of Robert's and his wife's relationship boundaries. It also spoke about inclusive synchronicity because, as he said, there was no animosity and "we both love each other deeply" (Robert). However, Robert identified that he preferred to be on his own, implying that being on his own was a more controllable event. He also implied that he was able to increase the chances of being on his own by always encouraging his wife to "have some life". As such, the imperative to be alone was converted into an altruistic intent directed towards his wife. Therefore, Robert was able to maintain the emotional quality of his closest interpersonal relationship while reducing the risk of interpersonal conflict.

Robert also suggested that he was able to deal with problems on his own, without any discussion with his wife or anyone else (other than the psychiatrist). I would suggest that this was a gate-keeping strategy directed toward Robert limiting his access to other peoples' responses to events, responses which might have caused him to become confused or, more critically, confronted. I would suggest, however, that it was his response that Robert was trying to stay in control of; a response triggered by other people thinking about issues differently to him, or triggered by sudden exposure to behaviours that in some way reminded him of his underlying fears.

Late on in the interview sequence I asked Robert how he would respond to the possibility of the prostate cancer's recurrence.

Robert: No, no. I don't think the what's ifs (sic), they don't exist for me.

David: And has that always been the case or is that something once again that's been caused by the post traumatic stress?

Robert: Oh I think probably the post traumatic stress has caused that. The jobs caused that. No, well you can't afford to, if in the situation I was in we'd have that many things on your plate, you had to work a quick way of dealing with it and not have that worry to go to bed with three or four items. You had to, it would be done to a stage, that that's that and I'll deal with that tomorrow. This is what you go through with the psychiatrist you know. It's no good sitting there all night thinking a lot about how you're going to deal with it because before you go to bed you then, you say to yourself, okay, it's in your mind. You're trained to say okay, look I've got planned what I'm doing tomorrow, I've done

that up to a certain stage, you can lay in bed and even say this to yourself. You know, I've done it to a certain stage, I'll go to sleep and I'll know when I'll start, what I've got to start doing the next morning and bang you're off. (Robert)

The "what ifs" refers to a process of speculation about what might occur in the future. Robert suggested that the treatment for the PTSD had played a role in his ability to restrict his thoughts to the present, and what he was able to achieve in the present, rather than projecting onto the future and speculating about the unknown.

More importantly, however, Robert was constantly engaged in reducing the affective burden by converting the potential for future worry into the practical and actionable present. For as long as Robert was able to transform the affective into the practical, he could offset the potential for emotional catastrophe. That is, only when events ceased to be immediately controllable would the possibility of the affective and the emotional become real. Therefore, speculating about the future contained the potential to generate anxiety because the future was not immediately controllable.

Of course, in the context of the PTSD and the prostate cancer experience, such a strategy was useful and effective for Robert. However, in the context of understanding Robert's affective and existential experience, such a strategy had the effect of stonewalling enlightenment. That is, not only had Robert's emotional self been impacted on by the PTSD, and subsequently by the prostate cancer experience, but the treatment for the PTSD had further limited Robert's access to his emotional self as an iatrogenic consequence.

### **Getting on with Life**

Most of the men in the study offered little insight into this phase of the post-diagnostic experience. My sense was, for most of the men, that getting on with life represented no more than a subtle change to the ways in which they had been responding following the end of their respective treatment regimens. That is, getting on with life was, in effect, representative of the transition experienced and all the responses provided by the men in the study from the time of diagnosis onwards.

However, for those few men who did offer some insight, the idea of "getting on with life" personified the way in which they made the transition towards a process of continuing assimilation. Getting on with life was defined by an externalising awareness, a kind of "waking up", in which some of these men became less self-absorbed and more able to observe the world and the people around them. Furthermore, getting on with life



became increasingly less about preventing the fragmentation of self and the reconstruction of a lifeworld, and more about trusting the cohesive self within the context of a reconstructed lifeworld.

Robert reached the point in the treatment trajectory where he needed to get on with his life, to accept the success of his treatment, and dispel the possibility of future doubt with respect to potential recurrence. Importantly, the prostate cancer represented a moment in his life, one needing to be incorporated, but not one to remain in. Moreover, Robert was getting on with his life carrying the more pervasive PTSD experience with him. For the sake of the PTSD it was important for Robert to move on with the prostate cancer experience, but unhindered by the prostate cancer. However, to understand Robert's final comment, it is important to appreciate the source of his use of the term "hypochondriac". We had been talking together about the reasons why, generally, men did not discuss the prostate cancer experience.

[Men holding back and not talking] Oh it's the macho thing isn't it? It's the, "It's not going to happen to me." Women are a lot, a lot different because they, they can't stop talking to each other about things. Men don't discuss these, unless you're a hypochondriac and I've met a few of them in the run, but they actually, they absolutely give you the shits and they give everyone else the shits. So we're not interested in them. They've got a crook fucking back or his necks going or whatever. I've just come here to have a beer and you're all talk, I don't want to hear your fucking life's history, tell it to your doctor. (...) If a blokes got a plaster on his leg, "How you going? Going all right. Oh yeah, alright, it'll come good, finish." Not a three page story about it okay? And men don't want to listen to blokes like that. (Robert)

When I asked Robert whether he believed the cancer was gone he provided a very clear and unambiguous statement; he told me that the cancer was a myth.

It's a hypochondriac's myth. You can quote that one. That would be, it's a hypochondriac's myth if a person thinks or hasn't got the confidence in the people that have done the operations and specialists and the people that have done the biopsies and that and given you the results. If you aren't strong enough to accept their opinion and move on with life, you're a hypochondriac. (Robert)

What Robert superficially meant by "a hypochondriac's myth" was that once the surgery was done the prostate cancer was gone. There was of course a sense in which he was also saying that had he not believed the prostate cancer to be gone, it would have made him a hypochondriac, and hypochondriacs gave real men "the shits". So as not to be classified as a hypochondriac, men had to have the "strength" to believe

the doctors and the pathologists, and so on. Therefore, having the strength made one a real man, not having the strength made one a hypochondriac.

Taken literally Robert's meaning was clear. However, I would suggest that Robert was also providing himself with an admonition. This was another strategy to prevent uncertainty; he was constructing another barrier against uncertainty and the anxiety created by uncertainty. He was unable to control uncertainty directly, but he could control the type of "man" he was, and he was not a hypochondriac. Therefore, Robert presented a contextual reconstruction of masculinity that provided him with a gender appropriate "safe zone"; where the imperative not to be a hypochondriac and give other men the "shits" acted to maintain the integrity of that safe zone. In this way Robert was able to move on from the prostate cancer experience with a cohesive self and a reconstructed lifeworld.

Moreover, there was a sense in which some of these men reached an energy threshold, whereby they were able literally to lift themselves out of the undeviating routine of lifeworld reconstruction; something demonstrated well in Gerry's experience.

Yes, I do think I should get on with life. No use being stuck in a bloody rut you know feeling sorry for myself because that's not going to help anybody. It's only going to drag me and the kids and my wife down. You know, it's only going to make life, you're going to get grumpier and grumpier if you keep doing that (Gerry)

There was also a sense of gained perspective, a coming to terms with a reality that was not necessarily optimistic, but one which presented a workable, pragmatic, and everyday approach to getting on with life. Herbert offered such a view, a way of suggesting that even though the status quo may not have represented his ideal, it was as good as it was going to get, and therefore needed to be lived with.

I've, when I say I've come to terms with it, I've grown to accept it I've accepted that I've got it and I've accepted that I'm not going to get any better uh and all I hope is that it will remain the way the way it is and I can live with that, I'm living with it, I'm living with it now. (Herbert)

Furthermore, there was a sense in which Herbert was finally able to contain the existential anxiety attached to his earlier fears of imminent death.

I'm not allowing it [the prostate cancer] now to interfere with my general way of thinking I'm not letting um the thought that it's probably terminal but I'm not

letting that interfere with my normal thinking, I'm taking it along with me but I'm not making a major issue out of it, that's really what I'm saying I'm not making a major issue out of having a terminal cancer. (Herbert)

Herbert described not allowing the terminality of the cancer to interfere with his “normal” thinking, implying that he normally perceived himself as perhaps less pessimistic, and more able to manage, than he previously imagined. My sense was that Herbert had assimilated the prostate cancer into his life, and was once again able to review his life in the context of his age and his time in the world. He talked of the quality of his life and of enjoyment.

[The way I see things now, well] it's changed in as much that (...) the way I look at it now is that if I'm still enjoying life whether I'm 90 or 102 or, it's my quality of life, really I would have to say it, it's my quality of life. If I was going to lay in bed in agony then I wouldn't want that. (Herbert)

In the end I asked Herbert to summarise his journey during the first year following the diagnosis of prostate cancer.

As a graph, the graph would be very low [at the beginning of the year] and the graph has gone up gradually, the graph of acceptance has gone up. (Herbert)

### *Dixon – A Vignette*

As a life in transition, and as an example of getting on with life, Dixon's experience of deciding to have a radical prostatectomy traversed the entire first year following his diagnosis of prostate cancer. I have offered exemplars of Dixon's experiences throughout this thesis, in those places where I believed his experience best illuminated the category under discussion.

However, in much the same way that I provided a vignette of some of Robert's staying in control scenarios, I would now like to offer an analysis of the end phase of Dixon's first post-diagnostic year, at the end of which time he made his decision to accept surgery. The reason for suggesting such a focus on Dixon is associated with the idea that, in many respects, Dixon was unable to get on with his life until he decided to accept treatment. Equally, however, Dixon represents a good example of a man who did indeed get on with his life even during a prolonged period of transition.

The following analysis is based on Dixon's final interview at the end of the first year when, in fact, he had just made his decision to have a radical prostatectomy. At the

start of the year Dixon had struggled with the idea of losing his potency, so much so that it formed the basis of his original predicament with respect to making a decision about treatment. However, by the end of the year Dixon had equalised the importance of mobility and potency, and had recognised that dissemination of the prostate cancer was a real possibility.

[Making a decision], it came down to probably going on the net as well and looking at the testimonials of guys in Australia, there's also quite a few testimonials there from the United States and I see a different trend in the two, and probably the thing that sticks out in the United States when someone's diagnosed with prostate cancer is the fact that it's dealt with within six weeks, and I was amazed at that that surgery would take place so quick then I [looked at] the testimonials of the people in Australia and there seemed to be a different view as to which course to take; some would take the course of the local prostatectomy, some would take the course of watch-and-wait and some would take the course of the various forms of radiation so, there was one thing in there that I feared and that was if I left it too long it would spread to the bone and to my back, and then it comes down to what I said previously I still had my mobility, and I probably treasure that more or just as much as my sex life; so that probably got me thinking and I was thinking; the watch and wait period is over I've had 12 months, I went to see the urologist. (Dixon)

Furthermore, at the beginning of the year Dixon's well established sense of independence had distanced him from his wife's expressed desire to be involved, with him, in the prostate cancer experience. This does not suggest that Dixon did not care or have concern for his wife, rather it pointed to life experiences that had generally pushed him towards solitary vantage points. However, by the end of the year he had become far more inclusive of his wife, and implicitly recognised the concern she must have been feeling.

Since then I guess the relationship with my wife has probably been a little bit better, that I've made a decision and she hasn't got it hanging over her head and she is probably very concerned about the experience like she went through before, I've got no doubt about that so I guess that's where we stand now. (Dixon)

Needless to say Dixon's wife was relieved when he decided to have surgery, but he camouflaged his good feelings, derived from her concern for him, through the interjection of humour.

Oh she was relieved that I'd made a decision because I can be such a stubborn pig (laughter) and she didn't want the worst at the end of the day. (Dixon)

Indeed, during my first interview with Dixon he had clearly identified his solitary and independent intent to manage the emotional burden of the prostate cancer experience without support. Dixon identified himself as a private person and was hesitant to reveal his emotional self to anyone. Moreover, Dixon managed his emotional self by compartmentalising issues and people. At the end of the year he expressed relief that he had made a choice about surgery, but continued to camouflage his feelings.

David: So when you say you felt relieved what kind of relief was it? relief that you'd finally made the decision, relief that you didn't have this process to go through anymore, what kind of relief was it?

Dixon: Before we go to that is um probably the lead up to the point where the urologist was- couple of nights there where I felt the Flowmax wasn't working, in my brain I thought I'd gone three times last night, maybe this has moved on that little smidgen more as well, because previously the Flowmax has been excellent. So getting back to your question, sorry what was it? (Dixon)

Instead of answering my question he talked about his recent perception that the cancer may have moved on a little. Indeed, Dixon had moved on, and moved me on, from the question by losing the question, just in case he might have to talk about his emotional self. Equally, Dixon continued to minimise, or avoid, potentially difficult feelings when he talked with his daughter about having surgery.

I told her oh yeah going into hospital to have the operation, a bit of a hiccough; she said for God's sake it's not just a hiccough it's a bit more serious than that, you know the way I sort of relayed it to her and that's how I, that's how I still see it, a hiccough a little obstacle and we move on from that it's not the end of the world it's far from it, FAR from it. But she goes back to when I had this [Hiatus hernia repair] because that was pretty close, I was on the edge there, that was just a hiccough as well. (Dixon)

Dixon described surgery as a hiccough, a word he frequently used to facilitate the side-stepping of emotion. Dixon reached a point, however, when he did reveal his emotional self, albeit that it was not directly associated with him or the prostate cancer. He talked about his relationship with his grandchildren, and suggested that having grandchildren had made him mellower. I was curious to know how much of this revelation, as well as the reflective process it implied, resulted from the prostate cancer experience.

Dixon: Yeah well you do [become mellower] with your grand-children (chuckle).

David: Yes, I understand that but um I'm just wondering I suppose how much or if at all the prospect of cancer was a stimulus for some of that, or whether you really feel that it had nothing to do with it?

Dixon: I was probably partially going down that road but I dare say that it's [the prostate cancer] softened me more towards the grandchildren.

David: In what way?

Dixon: Um, probably the realisation that if you're going to get something done (chuckle), (...) you don't want to be hindered by something that could have been fixed a couple of years previously, or four or five years previously and that's probably the same with the grandchildren as well. (Dixon)

I would suggest that this represented a pivotal moment for Dixon. For the first time he had openly associated a feeling state with the prostate cancer experience, albeit that his grandchildren had been the catalyst. Dixon had also identified a strong desire for the future of his relationship with his grandchildren; what better reason to have surgery than to protect such an important and emotionally rewarding relationship. Furthermore, Dixon, the man who had insisted that he would stand alone, openly recognised the importance and value of his wife's commitment to him and their relationship. I had asked Dixon what his wife's presence during the first year had meant to him.

Dixon: [It was] Positive

David: Positive, in what way?

Dixon: Um ... I'm very reluctant to ask for support but it's been nice knowing that it's there and if she wasn't there I wouldn't be asking anyone at all. (Dixon)

It is important to recognise that Dixon always used understatement when referring to his affective world. It is also important to appreciate that such understatement concealed a great depth of feeling for his family and his other interpersonal relationships. This concealment was not about being the archetypal hegemonic male. Rather, it was about maintaining a defended emotional position as a result of his early life experiences, in general, and the stark realities of his daily work as a police detective in particular. Indeed, he maintained his defended position, and his use

of understatement and concealment, when I enquired about the degree to which he would allow his wife to provide emotional support following surgery.

Dixon: Oh yeah, I like to think I'll; have to be pretty careful here um, yeah it will be nice to see her there when I come to yeah, and the reason I say that is that when I had this [hiatus hernia repair] when I went in the second time it was nice to have someone tapping me on the hand to wake me up (...)

David: It's your reconnection with life?

Dixon: YES, yes (Dixon)

A tap on the hand, as he was waking up from the anaesthetic was, he agreed, a reconnection with life and, I would suggest, with his emotional world. Dixon's final comment summarised much of his emotional journey with the prostate cancer experience.

Yeah she [my wife] has probably made me realise that hey there's more than one guy here that's going to be affected by this, it's not just you being your stubborn self there's other people around as well that includes me and that includes my wife as well. (Dixon)

Therefore, Dixon was able to get on with his life on three levels. First, on a practical level and in the context of his everyday world, Dixon had managed to work and live through a process of transition, while maintaining the structure of his social world and the relationships within it. Second, on an emotional level, Dixon was able to engage with the emotional challenge of the prostate cancer experience, and the transitional state it caused, in a way that preserved his integrity, and his ability to remain in control of his thoughts and actions. Also, and significantly, he was able to engage with such an experience in a way that honoured his innate human capacity for emotional development, while maintaining a cohesive self. Third, on a future level, Dixon was able to get on with his life from the moment that his decision to have surgery ended a prolonged period of transition, but moved him into the next phase where he would be required to manage the potential experience of long-term impotency.

### **Thinking about Dying**

I have referred to the idea of existential anxiety in other parts of this thesis as a way of framing aspects of anxiety or the process of reflection generated by the prostate cancer experience. However, I would observe that the men in this study did not

demonstrate the stark or prolonged existential anxiety associated with the fear of dying. One man in the study (Herbert) did, initially, describe prostate cancer as “just death” (Herbert), and did demonstrate some early existential anxiety, but his response was not prolonged, nor was it taken up by the other men in the study. This observation notwithstanding, some of the men in the study did think about death and dying.

Placing this analysis, of the way in which the men in the study thought about dying, in this chapter about the post-diagnostic experience implies that these men only thought about dying during this period. Such, however, is not the case; the men in the study referred to the idea of dying throughout the peri- and post-diagnostic periods. I placed the analysis in this chapter, and in this position in the chapter, because it felt as though conceptually, emotionally, and chronologically, this was the right place to end.

### *You Will Die of Something Else*

Some of the men in the study were told by their treating urologist, or another doctor, that they would die of something other than prostate cancer. This aphorism, “you won’t die of prostate cancer, you’ll die with prostate cancer”, is, like many aspects of the treatment of prostate cancer, equivocal. Indeed, Bostwick, MacLennan, and Larson (1999) identify the aphorism as a myth.

Nevertheless, “you will die of something else” is an aphorism that the men in this study interpreted literally, and took to heart. Therefore, even though the word cancer may have incited some degree of existential anxiety, it is difficult to know the extent to which the use of this aphorism attenuated some men’s responses to the possibility of dying. Cecil, for example, never contemplated dying of prostate cancer at any time during the prostate cancer experience.

David: So at no stage did you feel, did you go through a stage where you felt I'm going to die?

Cecil: No, I didn't feel that at all, No. I've heard it said that men don't die of prostate cancer they die with it, so as I said a lot of people don't even know they've got it when they die. (Cecil)

Even Herbert, the one man in the study who believed he would die within a short period of time, had it in his mind that his heart disease was more likely to kill him than the prostate cancer.



[The urologist] had said you'll probably die of something else, and having a bad heart I thought ... ohh ... I would probably die of a heart attack ... (Herbert)

Richard was adamant that he was not going to die of prostate cancer, and had received the aphorism from a gastroenterologist who he trusted, and who had been treating his Crohn's disease for many years.

I think it was my gastroenterologist who explained to me, he said, Richard, he said, "Prostate cancer won't kill you." He said, "It's where it goes from there," he said, "That's the one that will come along and claim you." He said, "I, well," he said, "I've never known anyone yet die of prostate cancer." He said, "It's a secondary or something else." He said, "Your heart may give up, pneumonia might get hold of you but," he said, "Prostate cancer won't kill you." And I thought, "Well that's fair enough," I said, "That's nice to know." I said, "I've got a sixty-forty chance," so I said, "I'll take the sixty." (Richard)

It was Cecil who attested to the ubiquitous use of the aphorism when, at the end of his radiotherapy, the radio-oncologist reiterated the urologists admonition that Cecil would not die of prostate cancer.

Cecil: I asked the radio-oncologist, I said, "Am I cured?" He says, "Well when you die we'll know." I said, "Well that's a funny answer." He says, "No." He says, "You'll die of something else."

David: Well, he's pretty, he sounds almost certain he's correct.

Cecil: That's right, that's right. I could die of a heart attack or deep vein thrombosis or something like that sort of thing. It won't be the prostate that kills you, but they all say that don't they? It's, I mean 80% of men in Australia might have it, but not many die of it. (Cecil)

Cecil had completed his treatment and was feeling confident about the future. He asked the radio-oncologist if he was cured; the radio-oncologist told Cecil he would know when Cecil died. The radio-oncologist meant by this that Cecil would die of something else. Now this was interesting because the phrase "you'll die of something else" has appeared at two points in the prostate cancer treatment trajectory; at the outset when being reassured that even if one had prostate cancer, death was likely to be from some other cause, and at the conclusion to reassure that even if the prostate cancer returned, one was still more likely to die from a different cause.

I would suggest that the aphorism was used as a form of reassurance. As such, the power of the prostate cancer to generate uncertainty and existential anxiety was

diminished. Therefore, there was a sense in which the aphorism chanted by the doctor became a kind of secular talisman, the power of which was amplified by the silence of prostate cancer. Moreover, there was no need to think about dying because the doctor had told men that they would not die of prostate cancer. I have noted previously about the faith invested in the doctor by Cecil.

No, no, as I say you know, that's what I said to you, you've got to have faith in your doctors and that sort of thing ... (Cecil)

If "You'll die of something else" was taken as a talisman then the caveat to this may have been "but you have to believe". Cecil was clear about the imperative of having faith in the doctors, and Robert also suggested that men had to have the strength to believe the doctors; faith and strength.

The notion of having faith, or trusting, the doctor is by no means a new one, "my life in their hands"; handing over responsibility for ones wellbeing to another individual requires an enormous amount of faith and trust. Therefore, I would suggest that what was happening was that a synergistic process was set up between the man with prostate cancer and the doctor, aimed at the mutual reduction of existential anxiety; for the man, the experience of it and, for the doctor, talking about it. In this highly symbolic process the doctor would present the man with the secular talisman, "You'll die of something else", and the man would invoke it using the magic phrase "I believe [because you are the doctor]".

My sense is, that the use of such a phrase, and indeed such an aphorism, is not dissimilar to Dorothy, in "The Wizard of Oz", closing her eyes, tapping her heels together, and saying "there's no place like home, there's no place like home". This slightly sardonic view notwithstanding, the man would be conferred with some kind of protection which acted to limit uncertainty and reduce anxiety, thereby maintaining the stability of his emotional world. Of course, such a process begs the question about the relative merits between opening up the subject of existential anxiety, so as to engage with it, and using mechanisms to attenuate such feelings as a way of avoiding them.

### ***Rejecting the Prospect of Dying***

Perhaps inevitably, regardless of men accepting the truth value of "you'll die of something else", some men found the concept of dying difficult to engage with. For

these men, it was necessary to reject the idea, at least during the peri-diagnostic period, so as to be able simply to engage with the prostate cancer experience itself.

That won't be happening, that won't be happening um, and uh, no no that won't be happening. Maybe it will, but my attitude is that it won't be happening and I'm here for a while yet, I want to enjoy my retirement I want, my grandchildren and that sort of thing, I don't know if that's a positive attitude or it's an ignorant attitude but- (Dixon)

On the other hand Gerry did think about the possibility of dying, although he did so in a sporadic way, as if there was only so much existential material that he could assimilate at any one time. Furthermore, Gerry made an effort to dismiss the prospect of dying by adopting the more action oriented, and future focused, activity of seeking treatment.

David: So really your thinking about cancer and dying was something that has either been short lived or sporadic-

Gerry: Sporadic I think it probably is yeah. I don't think about it a lot I suppose we've thought about it and said yes there is a definite possibility, but we're going to do something about it so let's get on and do it. (Gerry)

Winston would not talk directly about dying but did, in his allegorical way, imply that he thought about dying. Whether this was triggered by the prostate cancer experience is difficult to know, however, there was a sense in his narrative in which he rejected the idea of dying and made the statement that he would always get up and fight.

I feel as though I'm just beginning but the calendars say I'm coming to an end. I feel as though it's natural physically to have a disease because after all Winston you're sixty-two but I feel as though I don't need it because I'm going to live to one hundred and twenty-four so you know, there's all these things and then I say to myself, "Well look, how do I feel about this, because that's the only thing that I've really got and that feeling must have been there all through my life because as I [have] been rebellious and I've come across hither thither, I've always managed to get up and have another go at it. (Winston)

Herbert, on the other hand, was quite open about his thoughts on dying. Bearing in mind that Herbert was 77 years old, it is important to recognise that his desire to live on was strong. However, perhaps because of his age, he was willing to consider some of the issues surrounding the activity of dying in a way that younger men were not. On this basis, Herbert was clear that the only criteria by which he would find dying acceptable

was if he was no longer mentally competent. As such, Herbert rejected the idea of dying on the basis that he was mentally competent and still had tasks to achieve.

Herbert: I just think that sometimes, If I'm 85 or away with the birds, I don't think it matters what you die of, whether you die of prostate or heart or, if you're not thinking straight or your bloody head's not right, the quicker you die of something the better off it'll be, but I just don't think I've got to that stage yet that I'm not lucid and can't see what is going on, I don't want to have any of those things, but if I was 80 or older it wouldn't matter, people would say, oh shit, you're going to die of something, and your use-by date has gone.

David: But you don't feel you're at that point yet?

Herbert: I don't feel I'm at that point, I feel I've got some living to do yet, I'm not, I still think reasonably well. (Herbert)

### ***Accepting the Reality of Death***

It is important to make the point that the men in the study both accepted and rejected the idea of dying at various times, and in various contexts. There was no sense in which men went through stages in which, at one stage they were rejecting, and at another stage they were accepting. However, I would make the general observation that as the time from diagnosis moved on, the acuity of existential anxiety decreased, and some men became more accepting of their ultimate mortality from whatever cause.

However, it is also important to recognise that it was possible to be moving towards an acceptance of mortality while, concurrently, making future plans or wishing for more time.

Some say "oh look I'm going to die because I have cancer" something like this you know (laughter) I mean we're all going to die one day so whether you're going to die today or tomorrow it's uh that's the way I look at it anyway you know; I mean I'd like to live another 10 years sort of thing you know. (Cecil)

Furthermore, it was possible to appear to be accepting of one's mortality, but in fact to be offering an evaluation of one's life as a way of mitigating the future possibility of mortality. Dixon couched this in terms of not complaining, and of adding up the good relationships (the credits) that had come his way, as if to offset this against the deficit associated with dying.

Fifty-four years, I can't complain. I've been healthy in those fifty-four years, gainfully employed and there hasn't (sic) been too many hiccoughs on the way. Like my children are grown up from my first marriage, the boys not what I expected him to be but he's still my boy and children there, grandchildren there. My wife's come along with the boys, so I can't complain and I don't think that I've got a right to complain but if for some reason I walk out the door tomorrow and something happens, I can't complain. No one, no-one can, no-one can complain. (Dixon)

Dixon also singled out his wife's ability to recover from loss as another way to mitigate his mortality, and adopted an intellectualising position as a way of removing the emotion from the contemplation of his dying. Somehow, if he knew his wife would recover from his death, he would be able to accept its inevitability, should that become necessary.

Oh she would probably be devastated but I guess that is where I come to bat, looking at things in black and white. I suppose I should be looking at it with a little bit of emotion but I sort of look at in black and white and she probably thought she'd never move on from the last time and I mean she has and I don't think there should be reason to stop her from moving on should there be a next time. (Dixon)

Of course some men were able to recognise the inevitability of dying, regardless of whether one reflected or did not reflect on its nature. Herbert, the one man in the study who had had genuinely feared for his life as a result of the prostate cancer, was able to reach such a position.

I'm still philosophical about it, but when the time comes it will happen, it happens to us all. There are only two certain things, when we are born and when we die. (Herbert)

Equally, Cecil, one of the men who had rejected the possibility of dying at the outset of his treatment process, was able to recognise the natural order of things. However, Cecil was also able to recognise that accepting a natural order did not equate with acquiescence and, in any event, there was always the chance for a little more.

I believe, not that I'm a sort of religious person [or] anything like that, but our lifespan is three score and ten, for a horse or something it's twenty-five years and for a chook it's ten years, and it's laid down, I mean that's nature. Let's put it to you that way. So I mean, why mess about with it? I mean anything you get over seventy, that's a bonus. I mean I've been playing snooker this afternoon with a ninety-two-year-old lady. And she's as thin as a rake, healthy and all there which I think is marvellous and she's got diabetes too. I mean that's a bonus for her, twenty-two years bonus. (Cecil)

## *Time Moves On*

I have made the point previously, in the context of some men's experiences of "getting on with life", that some responses to experience changed subtly over time without necessarily attracting any cognitive or emotional attention. This idea of the attenuation of, or shift in, responses as a transitional phenomenon applied equally to the way in which most men's early thoughts about dying were replaced, over time, with thoughts about "getting on with life"; my earlier observation about it notwithstanding.

However, for Herbert, there was a sense in which, as I have also generally observed, the acute existential anxiety he (and other men) originally experienced was replaced over time with an acknowledgement that he no longer perceived the prostate cancer as imminently terminal.

Well now I know what I've got and uh what I've got to put up with um yeah probably is a bit different you know I thought about it originally as fairly terminal now I don't (Herbert)

I would suggest that such a perceptual shift allowed Herbert to experience not just an attenuation of existential anxiety, but also a decline in anxiety associated with other aspects of the prostate cancer experience. I would also observe that this reduction in anxiety allowed Herbert to re-establish a normal perception of time; dying becoming something that will happen in the future, the future being less than imminent in a perceptual sense.

I'm in more of a relaxed place than I was three months ago when you first saw me, I mean I am in a more relaxed [place] I don't know whether you can see it, I certainly can feel it myself, in other words I don't think I'm going to die tomorrow; when I first got this I didn't know if I was going to see the next three months (Herbert)

Moreover, the way in which Herbert understood truth telling, and the original evidence provided by his lifeworld, also changed over time. So much so, that he was able to adopt the aphorism of "you'll die of something else".

Yeah, yeah each day it was reinforced that you know while somebody told me I wasn't going to die in the next three months and I might live for another two years or three years or whatever, uh I began every day that went on I began to believe you, maybe there's a bit of light at the end of the tunnel in as much as a few more years would go and then the story is that something else will kill you before this does (Herbert)

Finally, at the end of the first year, Herbert was able to reflect on his experience, on his early belief that he would die within a short period of time, and on the meaning of his advancing years, and feel a sense of balance. He had responded and survived, and every day in the future would be a bonus.

Herbert: That's right, you're right, I really thought that probably within a year that I would die, but I didn't.

David: No you didn't because it's a year now since the first time I saw you, so here you still are.

Herbert: And I guess you'd have to say probably every year's a bonus, I would think so, but even living to my age is a bonus. (Herbert)

## **CHAPTER SIX**

### **THE CRITICAL BEYOND PORTRAYAL**

#### **Introduction**

This study began with an observation regarding the paucity of longitudinal interpretive knowledge about the experience of men with prostate cancer. As such, this study set out with the intention of furthering insight into what I have termed in this thesis as the process of “lifeworld reconstruction”, as men responded day-to-day to their experiences of prostate cancer. Using the constructivist inquiry paradigm, this study presented one portrayal of the experiences of a group of men, all diagnosed with localised prostate cancer, as they responded to the cancer and “reconstructed their lifeworlds” during the first post-diagnostic year.

Placed in the context of the constructivist inquiry paradigm, it would be apposite to leave the reader with the portrayal of the experiences of these men, supported by their words and the trustworthiness of the study, without adding further commentary. That is, it would be judicious, and methodologically appropriate, to allow the portrayal of the experiences to represent itself. Of course, and at this point, in the reading of the previous two chapters it is reasonable to assume that such a process of self-representation has already occurred, and that the multiple realities of both participants and readers have been honoured. As such, and again at this point, this study has achieved the purposes of the constructivist inquiry as described by Lincoln and Guba (1985).

However, there is a more critical sense in which the portrayals, the narratives of the men in the study, contain elements that are indicative of their social and personal contexts, both proximal and distal; but which are veiled by the social, cultural, and personal façades created to normalise them. That is, while a thick description facilitates a type of global comprehension it also refers, perhaps less obviously, to particular phenomena and organising principles that shape the ways in which men respond, or are perceived to respond, to the prostate cancer experience. In this sense, Holstein and Gubrium (2004) provide the salutary warning that an over-focus on context, as the overarching force obligating action, can distract attention from the structures that “provide the scaffolding of everyday life” (p. 310). In this regard, the types of situated



structures, both explicated and implied by this study, included, for example, gender, understanding the experience, coping, the management of the emotional, reflecting, and staying in control. It is therefore in this critical sense, and to these types of situated structures that this chapter now turns. As such, it is not my intention to re-describe the experiences of the men in this study. Rather, it is my intention to explore the nature, and dominance, of social contexts that act to subvert the individual process of lifeworld reconstruction, and to offer one construction of how the men in this study responded.

### **Understanding and the Contextual Façade**

It is relevant to note that the men in this study did not talk about a process concerned with understanding their experiences. That is, they did not explicitly acknowledge any attempt to understand or explain to themselves the nature, meaning, or purpose of the prostate cancer and the experiences it induced. Therefore, these men did not report any overt engagement with the process of sense making and, at least in the context of this study, neither family nor health care professionals sought to enquire if such a process was operating. Of course, the observation that these men did not report overt engagement provides no evidence that engagement with a process of understanding did not occur. Indeed, there is adequate evidence contained within the narratives of these men to suggest that such a process did occur. However, it is the indirectness, or fuzziness, of such evidence that evinces questions about the possibility of an overarching context that acts as a façade to camouflage, or perhaps subvert, direct access to an intramental, and emotional, process concerned with understanding. To some extent, this camouflage is created by the dominance of an outcomes literature that emphasises the manifestation of external behaviours, rather than the construction of internal experiences.

Albeit that some of the men in this study did report experiences, and behaviours, consistent with those described by the outcomes literature, most did not. However, the literature, with some notable exceptions (See for example, Gray, 2003, 2004; Gray, Fitch, Fergus et al., 2002; Helgeson & Lepore, 1997), is generally silent about the ways in which men construct their understandings of the prostate cancer experience. Indeed, I have observed previously (see Chapter Two) that the literature emphasises the idea of psychosocial outcomes, such as distress; which has been described, for example, as a stressful experience resulting from the uncertainty of diagnosis and treatment (Burke et al., 2003). Regarding the impact and magnitude of distress resulting from the prostate cancer diagnosis, the literature refers to raised serum cortisol levels (Gustafsson et al.,

1995), reports anxiety as a common occurrence (Essink-Bot et al., 1998), and suggests that the most distressed patients use denial and disengagement as mechanisms of adjustment (Perczek et al., 2002). Post-diagnosis, there is reference to fears described as the “7 D’s” incorporating death, dependency, disfigurement, disruption of social relationships, disability, discomfort, and disengagement (from the sick-role) (Burke et al., 2003); and to men feeling uncertain or shocked (Maliski, Heilemann, & McCorkle, 2002).

As an example of the way in which the experience of men in this study was not consistent with the outcomes literature, one of the men in this study (Robert) only considered distress in the context of an extant diagnosis of PTSD. This man sought to control the potential for elevated anxiety as a result of the prostate cancer diagnosis, not because of the diagnosis *per se*, but because of the potential for the diagnosis to exacerbate the PTSD. That is, the cancer diagnosis presented as a secondary threat that potentially added to the effect of the PTSD when placed in its emotional vicinity. Therefore, the meaning of the prostate cancer was modified by the prior existence of the PTSD, and did not at any time represent a unitary event. Yet, the health care professionals treating the prostate cancer did not seek to understand how, or if, the PTSD acted synergistically with the prostate cancer (if indeed they even knew about the PTSD), but assumed by default, that the primary cause of any distress must be due to the cancer experience *per se*. As such, the significance and importance placed on the PTSD by this participant was never revealed or understood.

There is a sense then in which ontology and epistemology play an important role in defining how the prostate cancer experience is understood by those external to the experience, and therefore the ways in which it is subsequently framed clinically. That is, much of the psychosocial prostate cancer literature tends towards describing the consequences of the prostate cancer experience, as a unitary event, and therefore places emphasis on end points such as distress, anxiety, coping, adjustment, HRQoL, and so on. As such, much of this literature presents prostate cancer as a homogeneous experience, which has the effect of marginalising or submerging patterns of individual meaning and behaviour. Furthermore, even those interpretive studies that describe the experience demonstrate a capacity to portray behaviours and feelings, rather than the understandings, meanings, and interpretations that contribute to the particular construction of what is being observed or reported. Therefore, in this sense, the significance of the emotional silence demonstrated by the men in this study was not

understood or interpreted as distress (or anxiety, or maladjustment etc.), by health care professionals, because silence is not generally interpreted in mainstream clinical practice, or presented in the mainstream literature, as an indicator of distress (or anxiety, or maladjustment etc.).

Thought of in this way, the idea of context as façade begins to make some sense. I have already observed (see Chapter Four) that the insidious nature of prostate cancer acted to render the emotional experience mute. As such, and as a precursor to understanding the experience, the men in this study were required to reveal the cancer as a concrete and social reality, albeit privately. However, these men found themselves in a type of double bind. On the one hand, what I would call the “conventional view” of institutional health care provided a social, cultural, and institutional understanding of the prostate cancer experience, contained within a context of end points. By “conventional view” I am referring to the organising principles of a health care system dominated by bio-technical medicine that expects “patient” compliance. Such a system is cure-oriented, and fundamentally concerned with a process of diagnosis and treatment, based on objective signs and symptoms, as opposed to the patient’s feelings and impressions of what is wrong (Hart, 1985).

On the other hand, the men in this study generally did not demonstrate feelings, behaviours, or understandings consistent with this view, and certainly did not do so over time. Also, there is no evidence to suggest that the health care professionals involved in the care of these men sought to understand their experiences in any way other than that defined by what I am calling the “conventional view”. In this sense, and most importantly, the relatively silent response of these men to the prostate cancer experience was interpreted by health care professionals as adjustment, strength, and perhaps even stoicism. That is, it was assumed by health care professionals that the ways in which these men understood their experience complied with the understanding of the “conventional view”. Hence, a complex and highly personal process of lifeworld reconstruction was subverted, transformed into a normative process of adjustment (or maladjustment), and evaluated by reference to “objective” and normative illness and adjustment behaviours.

Therefore, at least for the men in this study, the expectations generated by the conventional view acted as a contextual façade that camouflaged the personally meaningful experiential process of these men. That is, the contextual façade of end

points acted to disenfranchise these men, because the possibility of an individual process of understanding, not dependent on end points for its emotional or cognitive expression, could not be envisioned, incorporated, and used appropriately in the provision of care.

### **The Silence of Lifeworld Reconstruction**

My sense is that the contextual façade created by the literature, and operationalised in institutional health care systems, is based on a process of understanding that privileges closure. That is, for experiences to comply with the temporal sequencing of health care they are ideally expected to demonstrate increasing external order as the various health care milestones are reached (e.g. diagnosis, treatment, recovery, rehabilitation, and discharge). Indeed, most of the men in this study demonstrated an experiential trajectory consistent with such expectations, at least externally. In using the term “external”, I am referring to behaviours that have the capacity to be observed (or not observed) and interpreted in a public sense, and which therefore hold a public meaning (e.g. adjustment or maladjustment). In contrast, when using the term “internal”, I am referring to thoughts, ideas, feelings, and processes, both cognitive and emotional, which are tacit, obfuscated, or deliberately hidden.

Consequently, the men in this study were able to traverse the process of care without attracting any default psychosocial pathologising labels such as anxiety, depression, or maladjustment. It is interesting to note, however, that the two major potential iatrogenic outcomes of the treatment for localised prostate cancer (urinary incontinence and erectile dysfunction) appeared to become almost invisible to the treating health care professionals prior to treatment. Therefore, the ramifications were never explored, by health care professionals, with any of the participants in advance of treatment, other than as iatrogenic possibilities. Nor was detailed information about the options for follow-up care or counselling provided by the health care professionals, or sought by the men in this study. Yet, the potential for these two iatrogenic outcomes to cause maximum chaos in the process of lifeworld reconstruction was manifest and is well reported in the literature (Fan, 2002; Freedman et al., 1996; Perez, Skinner, & Meyerowitz, 2002; Schover et al., 2002).

Externally then, the men in this study demonstrated an increasingly ordered trajectory from diagnosis to recovery, throughout the peri- and post-diagnostic periods, during their first post-diagnostic year. Importantly; however, I have been reminded that

the internal is impure, as it is always infiltrated by the external (A. Shafer, personal communication, January 13, 2005). Moreover, it has also been pointed out to me that this relationship, between the internal and the external, sets up a dichotomy between the “impure” or inauthentic internal and the pure or more authentic and, hence, dominant “external” (C. Fisher, personal communication, January 17, 2005). This is an important observation, because such a dichotomy always privileges the dominance of the “purer” external and allows it (by which I mean its agents, and the systems established by its agents) to claim a non-maleficent intent towards the “less pure” internal (by which I mean the individual self).

As such, I have already made the point about a highly individualised process of lifeworld reconstruction being transformed into a normative (or external) one. Moreover, earlier in this thesis, I observed that even in the context of contiguous experience the men in this study appeared to apprehend a discontinuity between their lifeworlds before and after the diagnosis of prostate cancer (see Chapter Four). Linking these two ideas, discontinuity may be viewed as a disruption to the ways in which the men in this study understood the relationship between their selves and their external worlds. That is, the internal networks of understandings that provided a cohesive interface between the man and the stability of his external identity within the larger social and cultural group were disrupted, rendered discontinuous, by the advent of the prostate cancer. Although this observation of discontinuity is perhaps not surprising, and is implied in other descriptive studies (See for example, Gray et al., 2000a, 2000b; Hedestig et al., 2003), it has not been explicitly described or discussed in the psychosocial literature.

This apprehension of discontinuity acted to disrupt the cohesive self (see “Definition of Terms”, Chapter One) and triggered an internal process described in this study as lifeworld reconstruction. I have referred to lifeworld reconstruction as an internal process partly because the men in this study talked about their experiences, thoughts, and feelings in ways that were not generally representative of their dialogue with others, including health care professionals, their partners, and other family members. That is, most of the men in this study worked hard to keep their thoughts, feelings, and experiences internally contained while continuing to demonstrate, externally, their abilities to manage the discontinuity created in their lives by the prostate cancer experience. This, what I would describe as a disingenuous relationship between the external and internal, is well demonstrated in the approach taken by the

men in this study to minimise their emotional experiences. I have observed (see Chapter Four) that one interpretation of minimising the emotional might be that it represented a method of regaining control of a potentially life threatening experience.

As an example from the literature, Gray et al. (2000a), in their study about how men and their “spouses” managed the prostate cancer experience, observed that some men withdrew emotionally and verbally for a while, to regain control of their emotions. The idea of control is well represented in the psychosocial literature, although it is generally associated with coping (Aldwin & Revenson, 1987; Lazarus & Folkman, 1984; Manne & Glassman, 2000; Watson et al., 1991). In this sense, Aldwin and Revenson (1987) refer to withdrawal (they use the term escapism) as a less adaptive coping response, and Perczek et al. (2002) identify withdrawal as a response used by the most distressed individuals. There is, of course, a sense in which prostate cancer might be viewed as a loss of control. Maliski et al. (2002), for example, report that the men in their study perceived prostate cancer as a loss of control, which was regained partly as a result of modifying the meaning of the threat (the prostate cancer). As a cognitive strategy it begs the question of which meaning is being modified; the individual’s meaning based on an understanding of his internal world, or that of the external world with its social and political agendas?

Although this question is perhaps unanswerable, there is a general sense conveyed by this literature that paradoxically frames withdrawal, and therefore silence if associated with withdrawal, as maladaptive and perhaps even pathological, an interpretation that would almost certainly carry the external judgement of non-control. As such, the meaning of control (or non-control) for the individual man, and the internal networks of feelings and understandings that create it, becomes lost in what amount to external value judgements about the social meaning of non-control (see Chapter Five, “Staying in Control”). Indeed, many partners of the men (and some of the men) interviewed by Gray et al. (2000a) described emotional withdrawal as dangerous, although some did not, and often associated it with depressed feelings, almost certainly the introjection of an external judgement. Although none of the men in this study demonstrated withdrawal, in the sense described by Gray et al., they did assiduously avoid revealing their internal experiences and feelings.

However, my sense is that there is a difference between the types of behaviours demonstrated by the men in this study, and the withdrawal behaviour described by Gray

et al. (2000a). This difference turns on the distinction between what might be described as legitimate and illegitimate silence. That is, silence such as that demonstrated by the men in this study, would be classified externally as legitimate silence because it is not revealed externally as silence (silent silence). However, when it is revealed as silence, such as when men obviously retreat or withdraw, it becomes illegitimate because it potentially hinders closure and the achievement of the milestones expected by institutional health care, because it predisposes to psychosocial morbidity. Therefore, lifeworld reconstruction, in being at the interface between the internal and the external, is legitimate in the context of institutional health care only for as long as it remains a silent process that operates behind the façade of institutional health care. Yet, in being silent it becomes difficult to understand as an internal process, and therefore is explained and evaluated, and almost certainly oversimplified in the psychosocial literature, by reference to other normative structures such as, for example, those stereotypes associated with hegemonic masculinity.

### **Identity and Lifeworld Reconstruction**

The inferences and ideas I have presented, thus far, rely on a constructivist ontology that accepts the possibility of multiple realities and the relativity of context. As such, it has been possible to extend ideas about the overarching nature of context, and the way in which it potentially hides the underlying structures (Holstein & Gubrium, 2004), into a discussion about a façade created by the outcomes literature and operationalised by institutional health care. In this sense, lifeworld reconstruction has been presented as a potentially silent process that operates behind the institutional health care façade. To this extent, the argument has relied on the narratives of the men in this study to support the trustworthiness of these ideas, and has also depended on an assumption that the reader has interpreted the previous two chapters in a way that approximates my own. There is sense, then, in which the external understanding of this thesis parallels the process being explicated. That is, what becomes understood and evaluated externally, lies at the interface between my representation of lifeworld reconstruction, based on my internal networks of understanding, and those understandings defined by external worldviews.

I have observed above that all the men in this study who received a diagnosis of localised prostate cancer and conventional treatment, traversed the diagnosis-treatment-recovery process, as managed by the institutional health care system, without manifesting psychosocial morbidity. That is, all the men in this study demonstrated an

increasingly ordered external experience that allowed for appropriate closure at each health care related milestone. It would therefore be reasonable to conclude, at least given the standards of institutional health care, that the health care provided was both timely and successful, certainly as measured by the absence of psychosocial and physical morbidity; the iatrogenic consequences of urinary incontinence and impotence notwithstanding. However, the men in this study also demonstrated the complex, continuing, and concomitant process of lifeworld reconstruction, which I have suggested was subverted and submerged by institutional health care.

In suggesting that lifeworld reconstruction operates behind the façade of institutional health care there is a sense in which I have implied that it was appropriated. I believe this implication to be incorrect and unhelpful. Indeed, although I believe it to be a collusive and disingenuous relationship, lifeworld reconstruction was not rendered mute as a result of any primordial attempt by institutional health care to silence or marginalise its expression. In part, the silence was created because of the insidious nature of the prostate cancer experience and, in part, because of the social construction of masculinity, and in part because of the nature of biomedicine, and so on. Moreover, there is a sense in which lifeworld reconstruction, in being an essentially silent process, also acted to maintain the shroud that surrounded it. I will consider the case of masculinity in more detail below.

The men in this study responded to their prostate cancer diagnosis by providing the cancer with a physical and social presence, and subsequently became immersed in a more prolonged process in which they re-plotted the reference points that had, prior to the prostate cancer, represented the markers of their stable lifeworlds. That is, the men in this study engaged in an internal (and essentially unconscious) re-configuration process aimed less at understanding the nature of the cancer, and more at recognising the ways in which the cancer had altered the continuity and configuration of those reference points representing their internal identities.

As an example, for one man in the study (Herbert) his prior good experience following a heart attack had facilitated the use of his recovery as the stability marker for future illness experiences. That is, his prior experience became a marker that could be used as a way of measuring his response to the prostate cancer, and his confidence in a good outcome. However, a mismatch between his understanding of the heart attack experience and that of the prostate cancer, based almost entirely on a “feeling”,



precipitated a state of internal disorder that ricocheted against other stability markers and disrupted his internal sense of identity. Consequently, his belief that he was a pessimist exacerbated, and his view that he was less capable of managing uncertainty because he was a man, also deteriorated. This process of what might be called “collapsing identity” continued until the end of the peri-diagnostic period, at which time Herbert began to show evidence of reconstructing his identity by re-configuring the markers of stability.

At first glance, there is a sense in which some of the ideas contained in the Lazarus and Folkman (1984) model of coping are congruent with the process of re-configuration suggested above. That is, Lazarus and Folkman suggest coping represents a process that incorporates changes to thoughts (and feelings) and actions as the episode identified as being stressful unfolds. For example, Trauma survivors, when asked what social support they need, frequently say they need to be able to tell their story as a way of understanding their feelings (Lehman, Ellard, & Wortman, 1986; Silver & Wortman, 1980). Indeed, there is evidence to suggest that confiding in others does facilitate recovery (Lepore & Helgeson, 1998; Lepore, Silver, Wortman, & Wayment, 1996; Pennebaker, 1989, 1993), and also to suggest that those providing support may help individuals to “work through” questions about the meaning of events, (Nolen-Hoeksema & Davis, 1999).

However, although “telling the story” or “working through”, as a response to a particular type of (stressful) change, provides a useful interface between the internal and external, it provides no information about the purpose of understanding thoughts and feelings, in a teleological sense, or the way in which re-working meaning changes internal structures (if it does). Most importantly, however, there is a clear sense in which the internal markers of identity remain tacit or obfuscated. As such, reconstructing identity, as a component of lifeworld reconstruction, continues to be expressed and understood externally and therefore socially. That is, the experience of identity connected to the internal self is always subordinated to its external construction and expression. Such an idea is consistent with the position taken by Hochschild (1979) who suggested that the expression of feelings (and I would add identity) is indigenous to the social system. I therefore disagree with Janoff-Bulman (1992) who suggests that repetitive story telling helps shape the story to comply with internal beliefs. More accurately, repetitive story telling helps shape the story to comply with external beliefs, which helps shape internal beliefs to comply with the story. Therefore, in the context of

the social construction of masculinity, complying with external beliefs means not telling the story at all, and not telling the story (legitimate silence) means that the social construction of hegemonic masculinity remains safe. Therefore, identity connected to the internal self continues to be subordinated to its external construction and expression and is, to that extent, rendered non-existent. The men in this study did not engage in repetitive story telling; not with their families and friends, or with health care professionals.

There is a sense then in which the internal identities of the men in this study had to be submerged as a pre-requisite to membership of the large group; in this case membership of the institutional health care group, in the role of patient. Indeed, Turquet (1975) clearly identifies threats to identity in the large group, suggesting that the individual is always under threat of being converted into a group member, where membership always predominates over individual self-definition and results in the loss of identity. The alternative to membership, suggests Turquet, is withdrawal and the isolated state of the “singleton”. As an example from this study, one man (Winston) decided to forgo hormone ablation and external beam radiotherapy in favour of a self-managed and non-medical approach to treatment. Winston received a letter from his treating doctor telling him that he, the doctor, did not agree with Winston’s decision, albeit he recognised his right to make such a choice, but would be willing to re-offer treatment if Winston changed his mind. Therefore, Winston was obliged to withdraw and adopt the isolated role of the singleton because he preferred to choose a strategy that privileged individual self-definition and the cohesion of his internal identity.

I have used the term “obliged” in referring to Winston’s position of singleton, a term that implies constraint, as if to suggest he was confronted with an imperative. However, although the role of singleton may be marginalised and isolated in the context of the large group, there is a sense in which it also represents the product of a trade-off. That is, there is a sense in which Winston traded-off his membership of the institutional health care group against the integrity of his internal identity; in other words he recognised and acted on his own authority. On the other hand, the other men in the study appeared to make their trade-off in the opposite direction.

Gould (1993) suggests that personal authority is a central component of a mature sense of self or identity, and yet most of the men in this study appeared to subjugate their personal authority to that of the putative benevolence of institutional health care,

and the desire to be cured. As such, the de-authorisation and the loss of a sense of self experienced by the men in this study is consistent with the concept of colonisation experienced by subordinated cultures (Shafer, 1999). Moreover, the idea of a benevolent system is referred to by Chattopadhyay (1987) who describes one of the strategies by which the “invader” sustains belief in their superiority, and thereby promotes the process of de-authorisation and identity loss, as the “illusion of patronage”.

Even though the starkness of Winston’s position as the singleton was not demonstrated by the other men in the study, his experience suggests two important points about their responses to institutional health care. First, Winston’s experience, in being diametrically opposed to the other men in the study, suggests that a general response to institutional health care may occur on a continuum. Second, there is an obligation attached to group membership that asserts the importance of homogeneity. That is, group membership imposes the obligation for individuals to be the same, feel the same, and respond to events in the same way. Indeed, such an expectation represents a major large group defence against dissension, difference, and individuality (Turquet, 1975); and, I would suggest, provides a fertile seeding ground for prejudice (e.g. against the so-called “alternative” therapies).

In this thesis, I have postulated a theoretical separation between the internal and external worlds of the men in this study that act to demarcate private and social experiences and, in this context, I have considered the role of legitimate and illegitimate silence. Moreover, in describing this private and social separation, I have suggested that the pressures created by the homogeneity of group membership, although powerful, may provide an opportunity to trade-off group membership in favour of maintaining personal authority which, I have suggested, reinforces internal identity. If these ideas are accepted, they present the possibility that the process of lifeworld reconstruction, although silent, may not be as socially submissive as it appears externally to be.

### **False Identity and the Façade of Hegemonic Masculinity**

In postulating a theoretical separation between the internal and external it has not been my intention to suggest two separate realities, where one (the internal) actually exists separately to the other (the external), at least not in any kind of physical sense. However, we know, from our own lived experiences, that what we experience internally as individuals is often different from what we show, or express, in the external social world; even if it is not always possible to articulate the differences. As individuals, we

also know about the external social pressures to conform, even if only unconsciously, and the sanctions that can be applied if we do not. Therefore, to this extent we carry a template, an identity, that when applied to external reality provides us with a sense of who we are, and what it is about us that separates us from the often imposed homogeneity of the social world. However, when exposed to an unforeseen existential event like prostate cancer, my sense is that we feel invaded and ask the partly rhetorical question, “who am I now?”. I say partly rhetorical because there is a sense in which, even though we know that “who” we are and “how” we will respond in the context of institutional health care is socially defined, we also know that we are quintessentially different from that person we see being acted on. I make these points because this was my sense as I read and re-read the experiences of the men in this study, and as I developed the argument presented in this thesis.

I also make these points, because one of the quintessential differences demonstrated by the men in this study had to do with the ways in which the gender attributes of masculinity were constructed and expressed externally, compared with how they were reconstructed and experienced internally. That is, there is a sense in which the men in this study complied with the expectations of the archetypal male (external identity), but used this as a façade to protect, and allow for the re-configuration of, their individual masculinities (internal identity). It is to this further sense of the internal/external dichotomy, and the notion of façades, that I would finally like to turn.

With regard to this study, masculinity was presented as one of a number of intra-personal reference points and, in this sense, some men described their experiences with reference to what might be regarded as typical markers of masculinity (e.g. strength, gender roles, the symbolism of the penis, and sexual taboos). For example, one man compared his ability to manage uncertainty and sickness against his perception of the ability of women, who he perceived as being more accomplished in this respect because of their early socialisation as child-bearers (see Chapter Four). This observation is consistent with the findings of Gray, Fitch, Fergus, Mykhalovskiy, and Church (2002), who identified that some men with prostate cancer defined their masculinity in opposition to typical female characteristics.

Superficially, the observation that one man defined his masculinity in opposition to the archetypal female might be interpreted as a judgement about how men differentiate between being male and being female. Indeed, such has been the traditional

perception; the terms masculinity and femininity have been used to represent a stable and “essential” set of gender attributes distinguishing between men and women (Martin, 1994; Sabo & Gordon, 1995). As such, the gender attributes attached to men have included: restricted experience and expression of emotion; toughness and violence; self sufficiency (no needs); being a stud (heterosexism); no emotional sensitivity; powerful and successful stoicism; and misogyny (Cheng, 1999; Frank, 1991; Kiss & Meryn, 2001). These attributes are also signifiers of hegemonic masculinity, which refers to a dominant form of masculinity that subordinates femininities and other masculinities, and shapes relationships between men and men, and men and women (Courtenay, 1999). Using Holstein and Gubrium’s (2004) terms, hegemonic masculinity represents the overarching force obligating (gendered) action.

Regarding this study, and the ways in which these men responded to the prostate cancer experience, the idea of a common “overarching” perception of masculinity is important. It is important, because there is sense in which the men in this study entered the prostate cancer experience pre-exposed to a default external (social, cultural, and institutional) expectation of how they would respond as men. That is, such an expectation would have applied regardless of how they, as individuals, had previously constructed their masculinity, or might have reconstructed it with the passing of time.

It is relevant to note, in this regard, that the nursing literature does not describe, and has not investigated, the influence of masculinity as men diagnosed with prostate cancer traverse the prostate cancer experience, at least not overtly. Equally, however, the men in this study did not refer to the influence of masculinity directly, that is, they did not talk about the meaning for them as men, of being men with prostate cancer. Therefore, a parallel process is suggested between the experiences of men, and the ways in which those experiences have been described and explained, which has acted to subordinate explanation, and the expression of experiences, to hegemonic masculinity. In this way the experience, expression, and interpretation of masculinity has been rendered unconscious and mute.

For example, in a study about the met and unmet nursing needs of men with prostate cancer Jakobsson, Hallberg, and Loven (1997) described two main types of care recipients; active and passive receivers of care. The passive receivers simply accepted the care they were given, did not ask for additional care, and did not complain. The active receivers tended to receive the care they required (and wanted) because they

interacted directly with the health care professionals. Regardless of the ways in which gender certainly operated in these interactions, Jakobsson et al. failed to refer directly to masculinity in their formulation. Indirectly, however, they observed, albeit almost in passing, that men minimised the severity of their problems (suggestive of stoicism); and further observed that elderly men, especially, experienced problems sharing deeper thoughts with young women (suggestive of self sufficiency and misogyny).

The point has been made that hegemonic masculinity shapes relationships between men and men, and between women and men, and also shapes the ways in which the masculinity construct is investigated and described (See, Wall & Kristjanson, in press). However, returning once more to Holstein and Gubrium's (2004) differentiation between context and structure, there is a clear sense in which the default, or entry, masculinity referred to above formed the shaping context within which the individualities of men were constrained. If this is so, and the experience of the men in this study supports such an idea, then it was the situated structures that defined the individual expressions of masculinity. That is, for the men in this study, the default masculinity shaped not only the nature and quality of their experiences of prostate cancer as men (the gender group), but also their experiences of prostate cancer as individuals. In this way, the default masculinity provided a façade behind which was hidden the structures that formed each man's individual masculinity and which, to that extent, rendered them homogeneous. Therefore, hegemonic masculinity, if taken to be the default masculinity, and if established as a cultural, social, or institutional façade, stands to obscure the many individual ways in which men understand and manage their prostate cancer experience. To this extent, these ideas are consistent with the argument presented above.

However, when the façade is removed, what this study actually describes is consistent with Speer's (2001) idea that men construct and reconstruct their gender identities from moment to moment, and from context to context; as such, men are revealed as being increasingly heterogeneous. That is, the idea of an individually constructed masculinity is confirmed by the observation that the default masculinity represented only one of a number of reference points and processes (the situated structures), which enabled the men in this study to reconstruct stable lifeworlds. Indeed, the men in this study demonstrated a shift in the expression of their individual masculinities (see in particular Dixon), commensurate with the ways in which they

reconstructed the situated structures that acted to reconfigure their individual masculinities.

This observation is generally consistent with a similar observation made by Gray et al. (2002). However, Gray et al. suggest that expressions of masculinity remain within parameters set by hegemonic masculinity, the implication being that hegemonic masculinity represents the limiting factor, as opposed to the façade. I would contest this observation, at least in regard to this study, and suggest that the individual expression of masculinity is constantly modified by other situated structures, one of which is the overarching context of hegemonic masculinity, but is not limited other than apparently. That is, when hegemonic masculinity is socially, culturally, or institutionally dominant, the façade it creates provides no more than apparent parameters that apparently contain the expression of masculinity. Such would be the case in the context of institutional health care described above. Therefore, and on the contrary, the expression of masculinity is consistently chameleonic, and transformable, rather than consistently contained and hegemonic, albeit that it often operates behind the façade of masculinity in its hegemonic form.

There is a sense, then, in which hegemonic masculinity represents the “invader in the mind” (Shafer, 1999) during those times when the expression of masculinity is socially required, or expedient, in its hegemonic form. That is, there are times when men introject hegemonic masculinity (or other social discourses) into that part of the split identity that I have referred to in this thesis as the external identity, and which Shafer describes as the false identity. In this sense, Shafer suggests that the maintenance of a false identity, although expedient for the large group, brings with it individual psychic pain and impoverishment that, in the long term, is unsustainable. While I would agree with Shafer’s observation in the context of the colonised culture, my sense is that the process of lifeworld reconstruction, as it relates to the individual man, represents a temporary protective mechanism. Such a mechanism, I would suggest, allows for the safe use and management of the false identity (e.g., the hegemonic man, the compliant patient, etc.) in specific situations and for finite periods of time.

### **A Last Word**

I have, perhaps by necessity, presented a somewhat polarised and over-simplified construction of an important process in the lives of a group of men who responded to their experiences of prostate cancer. In reality, of course, their experiences

and their responses were far from polarised, and far more colourful than this formulation has been able to transmit. I have been saved, to some extent, by having included, in the previous two chapters, the words of these men as I attempted to provide a portrayal of their journeys. I say saved, because it is only in the midst and depth of their words that the intrinsic process of lifeworld reconstruction may be glimpsed, and it is in such a glimpse that the reader is able to begin to comprehend the magnitude and importance of such an experience.

In this chapter I have stepped away from the portrayal of their experiences and provided another construction that has explored, albeit incompletely, the social mechanism that lies behind, and in front of, the individual process of lifeworld reconstruction. In this sense I have revealed a response on two levels. On the first level, the men in this study responded to the experience in a way that approximated the expectations of institutional health care and the identity of the hegemonic male; stoically, compliantly, and silently. On the second level, however, the men in this study responded in ways consistent with their authentic selves, and it was on this level that the intrinsic process of lifeworld reconstruction occurred.

The one conspicuous flaw in the above construction concerns those men who, even after the resolution of the prostate cancer experience, continued to express obvious attributes consistent with hegemonic masculinity. There were two such men in the study. Yet, in the process of talking with these men throughout the course of their first post-diagnostic year I reached the conclusion that hegemonic masculinity is always a façade, always a false identity, and therefore never a true reflection of the individual beneath. There may be occasions when some men, in some contexts, do not have the private or social opportunities to differentiate or choose, and therefore always maintain the façade of the hegemonic male. Nevertheless, I would assert that all men always have the capacity and the right to seek out their authentic selves. Therefore, I would further assert that it is the responsibility of health care professionals to adopt the philosophy of the possible by always searching for the individual beneath.



## **CHAPTER SEVEN**

### **SUMMARY AND IMPLICATIONS**

#### **Introduction**

Although the consequences of prostate cancer and its treatment, and their impact on HRQoL, are well represented in the psychosocial literature, little is known about the individual experiences of men as they respond to localised prostate cancer. This research study was based on the premise that, if healthcare professionals are to provide care congruent with the lifeworlds of men engaging with localised prostate cancer, an understanding of how men reconstruct their lifeworlds is necessary. The purpose of this study was to explore and elucidate the lifeworlds of men as they responded to localised prostate cancer during the first post-diagnostic year.

To achieve this end, a prospective longitudinal study guided by the constructivist inquiry paradigm explored the process of lifeworld reconstruction with eight men, all diagnosed with localised prostate cancer, during their first post-diagnostic year. In this chapter the main insights gained from the portrayal of the experiences of these men are summarised, implications for health care practice and for research are presented, and the strengths and limitations of this study are elucidated. Finally, I would like to offer a short ethnographic fiction (Gray, 2004), spoken in the voice of one man, to represent what the men in this study might have said collectively, if they had been able to articulate a message about the essence of their experiences. As such, it is an attempt to bring this study back to its starting point, to acknowledge it as a co-construction, and therefore to honour the voices and experiences on which it has depended.

#### **Responding to Prostate Cancer – Insights Gained**

One of the central insights gained from this study followed from two observations. First, participants talked with me, the researcher, about their internal experiences more openly, and less superficially, than they did with others, including health care professionals, partners, and other family members. Second, neither health care professionals, nor family members, generally enquired about the internal experiences of men, beyond the superficial. As such, lifeworld reconstruction was revealed as a predominantly silent or shrouded process that operates behind social

façades and, in this sense, is recognised as a complex, multifaceted process that is at once both individual and social.

In this obfuscated context, men do not generally seek out a diagnosis of prostate cancer because they are troubled by specific prostatic symptoms, but rather “stumble upon” the diagnosis obliquely, and frequently unexpectedly. Similarly, the silent nature of the prostate cancer creates the necessity for men to reveal it as an entity amenable to emotional and physical engagement, by operating a primary process that concretises the cancer and provides it with a social presence. However, even when revealed as a social entity the prostate cancer is contained by a generally muted emotional response that reveals little information about derivative feeling states. As such, men either do not “know” how to respond affectively and emotionally to a diagnosis of prostate cancer, or mitigate their responses by complying with the implicit expectations operating behind social façades.

The reports of the men in this study suggest that they respond to the destabilisation of their lifeworlds, caused by prostate cancer, by recognising, re-defining, and re-configuring internal, and often existential, reference points that help to re-establish lifeworld stability. Related to this process, men also construct and use responding mind-sets that enable them to adjust and re-adjust their contextual responses to the prostate cancer experience. However, even given these adjustment mechanisms, men consistently minimise their emotional responses to the prostate cancer experience by hiding or attenuating difficult feelings. Men hide feelings through a process of removal or conversion, and attenuate difficult feelings through the use of strategies that reduce their intensity. Moreover, regarding emotional support, men do not seek such support outside the boundaries defined by close relationships, and even then do not refer directly to their emotional support needs. However, in the context of close relationships, men communicate their emotional support needs through the application of inclusive synchronicity, another silent process based on the tacit knowledge that develops out of the reciprocity of long-term, intra-relational understanding.

Perhaps because of the silent effectiveness of inclusive synchronicity, as treatment and recovery progress, men maintain their externally muted and minimising emotional stance. This is particularly noted in the context of iatrogenic impotency, where men discount their feelings by deferring to the “normal” ageing process, or by trading off potency against longevity. During difficult times such as these, there appears

to be a renewed emphasis on exhibiting the characteristics of the hegemonic man. However, the psychosocial protection induced by such an introjection does appear to be useful and important, but generally temporary.

As the dangers of the peri-diagnostic period recede, some men become reflective. As such, their talk about the prostate cancer is less urgent and they accept, albeit tentatively and privately, the prostate cancer experience as part of their lives, and the cancer as a reality. This type of reflection, which is at times existential, does not appear before the end of the peri-diagnostic period, and remains essentially private. Furthermore, as the lifeworlds of men are reconstructed, and become increasingly stable, men become future-directed. That is, men look towards the certainty of a future, as opposed to being over focused on managing the present, and direct their activities towards perpetuating the stability of their lifeworlds. Although monitoring activities are important at this time, often using PSA as a marker of stability, there is no evidence of undue anxiety associated with serial measurements of PSA levels.

Part of the maintenance of lifeworld stability is connected to the ways in which the metaphorical relationship between each man and his prostate cancer changes over time, and is similar to the ways in which social relationships change over time. That is, as each man comes to “know” his prostate cancer, he is more tolerant of it, more familiar with it, and less concerned about it. Moreover, a central function of the post-diagnostic period, which further adds to ongoing lifeworld stability, is to enable men to reflect on, and assimilate difficult experiences by removing them from their original emotive contexts. That is, as men reflect on the difficult in the context of an attenuated emotional presence, they are able to revisit safely actions or decisions that contain the potential for self-recrimination and emotional harm.

The observations made during the course of this study suggest that lifeworld reconstruction, although a useful, central, and adaptive process, does present as an essentially silent and internal process, situated as it is behind limiting social façades. Furthermore, even though there are indications that maintaining the silence of lifeworld reconstruction greatly benefits social institutions, and perhaps even men from time-to-time, there are also indications to suggest that the relative balance of such benefits requires further exposure and challenge.

## **Implications for Health Care Practice**

Challenging the relative balance between those groups most advantaged by the extant social construction and operation of lifeworld reconstruction is central not only to issues of social equity and justice, but also to the effectiveness and humanity of health care practice. In this regard, it is appropriate to identify that the prostate cancer experience does not represent a unitary event in the lives of men. Therefore, it is relevant to suggest that health care professionals (HCPs) develop an understanding of the synergistic effects of other extant life events, and integrate these understandings with all classes of therapeutic intervention. Moreover, this awareness of interactivity between events places a responsibility on HCPs to recognise the situated contexts of men with prostate cancer, especially regarding the façades created by institutional health care and the social construction of masculinity. As such, it is incumbent upon HCPs to recognise, and take account of, the obfuscation caused by these façades, especially as it relates to the diminished expression of physical and psychosocial suffering.

Regarding masculinity, it is worth suggesting that HCPs develop an understanding of gender identity as a heterogeneous construct. That is, it is appropriate for HCPs to develop approaches to care that are synchronous with the ways in which men contextually construct and reconstruct their masculinities, regardless of the apparent homogeneity created by overarching façades. It is also appropriate for HCPs to improve their understanding of masculinity as a heterogeneous process involved in lifeworld reconstruction. Equally, however, and to preserve a sense of balance, it is appropriate for HCPs to recognise the relevance for men, of using an introjected hegemonic masculinity as a temporary protective mechanism, and learn to use this knowledge sensitively and therapeutically.

Relevant to the emotional safety of men, and related to ideas about sensitivity and therapeutic action, is the recognition and understanding by HCPs of the significance of emotional silence. That is, although emotional silence may be interpreted as an expression of strength and stoicism, it does not follow that men do not also experience occult distress. Therefore, it is problematic, and perhaps dangerous, for HCPs to assume that emotional silence signifies the absence of internal distress. Furthermore, in the corresponding domain of emotional support, it is appropriate to suggest that HCPs understand, recognise, and facilitate the operation of inclusive synchronicity as an emotional support mechanism, especially if men habitually construct support in such a way. In principle, and especially during moments of acute distress, it is not appropriate

to remove or drastically redefine habitual coping responses unless they are causing self-harm.

This study has highlighted the silence that surrounds the experience of prostate cancer and the process of lifeworld reconstruction, a silence that almost certainly privileges social institutions more than it does the individual man. If, however, HCPs are to recognise the heterogeneity of men, and the importance of internal experience, then it is reasonable to suggest they develop interventions supportive of lifeworld reconstruction, as opposed to responding predominantly to adverse psychosocial outcomes such as overt distress or psychopathology. In this regard, it is appropriate for HCPs to use the understandings, meanings, and interpretations of men to construct a therapeutic alliance that optimises the process of support. The value of the therapeutic alliance is also relevant when considering the iatrogenic psychosocial harm that may result from the side effects of treatment for localised prostate cancer (viz. urinary incontinence and erectile dysfunction). As such, the ability of HCPs to understand and recognise such harm, and to act in advance of such side effects, to diminish or prevent it, is paramount.

Inevitably, some men will opt out of mainstream treatments for localised prostate cancer, in favour of adopting the isolated role of the singleton. However, rather than presenting HCPs with scope to marginalise these individual men, opting out presents an opportunity to be more inclusive and more supportive; and to protect the right of men to enact their personal authorities without let or hindrance. Indeed, it is reasonable to suggest that the greatest opportunity to develop therapeutic sensitivity occurs in the context of minority groups. Therefore, it is appropriate for HCPs to be sensitive to, and curious about, the nature and process of lifeworld reconstruction. The development of curiosity, and the understanding that follows, contains the capacity to privilege the internal process of lifeworld reconstruction, and therefore to facilitate its emergence from behind social façades.

### **Implications for Further Research**

In general, more empirical work related to understanding the heterogeneous nature of the prostate cancer experience is warranted. In this sense, there is a need to understand better the relationship between the literature, particularly the framing contexts of ontology and epistemology, and the subsequent ways in which the prostate cancer experience is clinically understood.

Unavoidably, sampling choices made at the outset of this study precluded some potentially important avenues of investigation that emerged during its course. In particular, it became increasingly clear that the role of men's partners in the process of lifeworld reconstruction is pivotal. Therefore, further work is required to examine the role of partners in more detail, especially in regard to the ways in which they mediate between the experiences of men and the expression and management of suffering.

This study describes one mechanism by which men with prostate cancer are socially encouraged to adopt a position of "legitimate silence", a position resulting principally from exposure to expectations contained behind the façades of institutional health care and hegemonic masculinity. Even though this study reveals lifeworld reconstruction as an important heterogeneous process, little is known about the short or longer term heterogeneous psychosocial effects of social façades that emphasise the external, the utility of closure, and emotional silence. More work is required in this regard.

One of the important processes identified by this study is that of re-plotting the reference points of a stable lifeworld. Most, if not all, of the reference points described represent configurations of understanding that help to link the internal and external worlds of men. Although this study has begun the process of describing the relationship between, and the function of, these reference points, further work is required to understand these relationships in more depth, and to establish the precise mechanisms by which the process of re-configuration occurs.

This study has presented the possibility that the constraints imposed on the expression of individual masculinities, by the façade of hegemonic masculinity, may be no more than an illusion. Therefore, prospective longitudinal studies are required to develop a better understanding of how men with prostate cancer, especially those confronted with erectile dysfunction, manage their gender identities over time. Moreover, given the potential for iatrogenic psychosocial harm created by erectile dysfunction and urinary incontinence, more intervention studies are required to identify appropriate methods of providing pre-treatment counselling, linked to post-treatment care.

## **Strengths and Limitations**

At the time of writing this thesis no other study has been identified that explicates, and prospectively investigates, the process of lifeworld reconstruction in a group of men responding to localised prostate cancer, during their first post-diagnostic year. This study provides useful insights into the internal process of lifeworld reconstruction that operates behind external social façades. However, although this study provides useful insights, it is limited by not having included homosexual men and men of colour in the sample.

### **A Lifeworld in Transition – An Ethnographic Fiction**

What follows is an ethnographic fiction (Gray, 2004), a story derived from the transcripts of the interviews that provided the data for this study. The story presents the key impressions of one man with localised prostate cancer, during the first post-diagnostic year. His purpose is to transmit the feelings and thoughts that were never articulated externally. His words are therefore tentative, as if deriving from an experience still in transition towards a new understanding.

I am 65 years old, I really never thought I would get prostate cancer, there were no signs that it was there, and I didn't go to my doctor with any real intention of finding out. When I found out that prostate cancer was a possibility, when the doctor said "well you're at the age for prostate cancer, so let's just check", I was frightened, frightened about having to face the possibility of cancer, and frightened about having the doctor stick his finger up my back passage; men don't do that kind of thing, well not real men, and I didn't want it to happen to me, but it did. I don't know how I felt about it afterwards, I never thought about it, and I didn't tell any of my friends, it seemed important at the time to keep it quiet, to keep my feelings to myself. I told them about the biopsy though; I mean you have to be selective about what you tell people, about being exposed, people don't always understand.

The diagnosis came back, it was prostate cancer, my wife was with me when the urologist told me, he said he was sorry, he said it was not the end of the world, and he sat behind his desk and drew me a diagram of what the operation would do, if I chose to have the operation. He gave me a book to read, told me about the options, but would not say what treatment he thought I should have. He said not to make my mind up now, he said to come back in ten days and let him know what I wanted to do. I really would have liked him to give me his opinion about what was best. He didn't ask me how I felt about things, he didn't ask me if I had any fears; we both seemed to know that we needed to protect my wife, she was crying, and I said to her not to worry, it would work out. I don't know, I don't know why, but it kind of felt important to be strong, just to accept that this had happened, and get on with doing something about it, to be practical. What was the point in talking about the fear and worry I felt inside, what could I say,

how could I describe it? My wife let me be, she didn't ask me any questions, she seemed to know it was best to just let me be. I knew she was there, my rock, she knows how I feel, we don't have to tell each other anymore, we just know.

Looking back I think it would have been better if I had talked to my wife, or to someone, about my feelings. But the system just seemed to grind on regardless and once I had decided to have the prostatectomy, well it all just happened, like clockwork. So I just kept on being strong, and shared nothing, I wish I had shared some of that stuff now. Sometimes it was useful to be strong, useful to just go along with what the doctors and nurses wanted, not to question, or say I was worried. Somehow, being male meant I had to hide from what I felt inside. Sometimes though, well sometimes I was scared, confused about what was happening, especially about not being able to get an erection again; but then I thought, "Well look, I am alive", and anyway that part of my life should be coming to an end at my age, good things can't last forever, better to be here than not here; well, you know what I mean. Maybe if I don't complain things will work out better. Even so, I really miss the intimacy me and the wife had, but I can't complain.

It's a fact; I'm impotent now. I tried to make love with my wife the other day; you know just to see kind of thing. God it was awful! Nobody told me that I might leak urine; leak urine! Christ it went all over the place, I made a real mess of things! I was impotent, but nobody told me I might leak urine, I felt so, we felt so humiliated! I wish I could have known before, I wish someone had helped me to understand before I made a mess of things! I don't know how it feels to be impotent; I don't have the words to describe it, I don't talk about feelings, I have hidden from the feelings and the words. Maybe, just maybe it would have been good if someone had talked to me about the possibility of feeling this way, maybe I wouldn't be finding it so difficult now to describe my feelings about impotency. Mind you, I never asked about the feelings thing either, maybe I should have; yes, maybe I should have tried to be more open about these things?

Time has moved on now, I feel as though I have accepted the cancer, well I'm getting there, I don't think about it so much anymore, in fact I make sure I don't think about it. I am getting on with my life, trying to keep everything stable, you get the picture. But you know, looking back, I reckon the experience really turned my world upside-down. It changed things forever. It really made me think about stability, made me wonder about all the things I always took for granted, the cancer really had me going for a while there. The thing is, nobody knew, well I think my wife knew, but we didn't talk about those kinds of feelings or confusions; maybe we should have, yes, I think we should have, at least sometimes. Like I know it was ok to be strong sometimes, the real man, but yes, sometimes I think it would have been good to just talk to someone else, someone not involved, sort of thing. I think I would do that, talk to someone, if I had it to do again. Yes, if I had it to do again I would make sure that I was more open; yes, more open.



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# APPENDIX ONE

## INFORMATION SHEET

**Research Project:** Responding to Localised Prostate Cancer: Lifeworld Reconstruction During the First Post-Diagnostic Year

**Researcher:** David Wall  
MSocSc(Cnslg), BSc(NursSt), DPSN, Cert Ed(FE), RN, PhD(Nurs)  
Candidate  
School of Nursing, Midwifery and Postgraduate Medicine, Edith Cowan University, Pearson Street, Churchlands, WA

### THE RESEARCH PROJECT

The research project *Responding to Localised Prostate Cancer* is being undertaken by David Wall, a Registered Nurse and Counsellor with experience working with men who are living with prostate cancer. David is a part time PhD student at Edith Cowan University, Perth. This study forms part of the work towards his PhD thesis.

### OFFICIAL APPROVAL

This project has been approved by the Edith Cowan University Human Research Ethics Committee. However, involvement in this research is voluntary. There is **no** pressure on you to participate in this research. If you decide not to take part you will receive the exact same care.

### WHY THIS PROJECT

This research study will look at how men with prostate cancer cope with their experience. In particular, I am interested in how men manage feeling unsure about treatment and the future. The study will increase the very small amount of knowledge we have about these issues, will help men with prostate cancer to have more choice about how they cope, and will help health professionals better understand what men with prostate cancer experience as they live with the disease.

### WHAT IT WILL INVOLVE

The researcher, David Wall, will be interviewing men about their experiences of living with prostate cancer during the first 12 months following diagnosis; these interviews will be recorded. David will also be keeping notes about his observations during these interviews.

The research will cause as little disturbance as possible. Nobody will be observed in order to judge them in any way. Management of the care of patients and their families/friends will not be undertaken by the researcher, and any requests for clinical advice will be referred to the appropriate health professional.

### WHO IT WILL INVOLVE

The study will only involve you, the patient, directly. Other people who may be interacting with you will not be the focus of the study. However, confidentiality for all people is promised. Records of the observations made will not include personal details that would allow identification of any particular person. Any publications resulting from the research will also not allow identification of any of the participants.

#### TO FIND OUT MORE

Any questions you may have regarding the research can be directed to David Wall (*Telephone number provided*) or his academic supervisor *Name Provided (Telephone number provided)*.

#### IF THERE ARE PROBLEMS OR ISSUES

If you feel, at any time during the study, that there are problems or issues you would like to discuss with an independent person, then please feel free to contact *Name Provided (Telephone number provided)*.

#### IF YOU DO NOT WISH TO BE INVOLVED

If you do not want to be involved in this study you may say so at any time by notifying David directly. Whilst it will be impossible to spend time with you and not observe other people, their activities will not be recorded for inclusion in the study, and these people will not be approached to discuss issues arising from the research. A choice not to be part of this study may occur at any time.

#### FURTHER RESEARCH

Later in the research, David may ask permission from particular people to discuss issues at length. Agreement to participate in these interviews will be discussed individually and separately from the observation, and informal talks, described in this information sheet.

## APPENDIX TWO

### CONSENT FORM

**Research Project:** Responding to Localised Prostate Cancer: Lifeworld Reconstruction During the First Post-Diagnostic Year

**Researcher:** David Wall  
MSocSc(Cnslg), BSc(NursSt), DPSN, Cert Ed(FE), RN, PhD(Nurs)  
Candidate  
School of Nursing, Midwifery and Postgraduate Medicine, Pearson Street, Churchlands, WA

**Informant:** .....  
(Please Print Name)

This research study plans to look at how men with prostate cancer cope with their experience. In particular, the study is interested in how men cope with feeling unsure. The study will increase the very small amount of knowledge we have about these issues, will help men with prostate cancer to have more choice about how they cope, and will help health professionals better understand what men with prostate cancer experience as they live with the disease.

I would like you to take part in a face-to-face interview with me, in private, at a place and time of your choice. This session will last about one to two hours. I will also ask you to participate in further interviews three months after your treatment, six months after your treatment, and one-year after your treatment.

I will ask you to provide me with some personal information, such as your age and the treatment that you have decided to have. You do not have to give me with this information if you do not wish to.

The interviews will be tape recorded using a digital recorder and later transcribed for analysis. I will give you the opportunity to look at the transcriptions of your interviews, and you may ask me to remove any information that does not meet with your approval. You may also request that the digital recordings be erased. The digital recordings will be kept on an encrypted computer hard drive. The transcripts will be kept in a locked filing cabinet at all times when not directly being used by myself.

The final research may be published, and any names used will be fictitious. I will make every effort to protect the identity of all informants.

I am required to tell you that all information will be kept in a secure and locked place for a period of five years, after which time it will be destroyed by shredding or incineration. Information will be stored at the university in locked offices allocated for archiving research.

I am also required to tell you that any risks to yourself will be fully disclosed. During the interviews, talking about your experiences may cause some concern, feelings of

sadness or anxiety. I will treat any reactions with sensitivity. It may be appropriate to consider seeking further support, and I will help you with this if you would like me to.

You do not have to take part in this study if you do not want to. If you do agree to take part, you may choose to withdraw at any time without it making any difference to your treatment. I would like you to be sure about this point. Your decision not to participate, or later to withdraw, will not affect any present or future treatment.

If you have any queries concerning this project *Responding to Localised Prostate Cancer* please contact me, David Wall (*Telephone number provided*) or my academic supervisor Name Provided (*Telephone number provided*).

If you agree to take part in interviews related to this project, it is necessary that we complete this Consent Form.

Please think about your consent. You will be agreeing to take part in interviews with me.

---

I ..... have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in the study *Responding to Localised Prostate Cancer*, and understand my role as an informant.

**I agree to be interviewed and to have those interviews tape-recorded.**

I agree that the research data gathered for this study may be published provided I am not identifiable. I also understand that I may withdraw at any time from the study without it affecting me in any way.

Informant's Signature: ..... Date: .....

Researcher's Signature: ..... Date: .....

# APPENDIX THREE

## DEMOGRAPHIC QUESTIONNAIRE

DO NOT WRITE YOUR NAME ON THIS PAPER

### DEMOGRAPHIC QUESTIONNAIRE

Please note that the information contained in this form will be transferred to a computer database. The form will then be destroyed. The database will **not** contain any identifying information. You will be given a code number, and this will be stored in the database. Only the researcher will have access to the file containing your name and code. This will not be stored on a computer, but in a locked filing cabinet. The database will be stored on floppy disks, which will be stored in a locked filing cabinet when not being used.

**Research Project:** Responding to Localised Prostate Cancer: Lifeworld Reconstruction During the First Post-Diagnostic Year

**Researcher:** David Wall  
MSocSc(Cnslg), BSc(NursSt), DPSN, Cert Ed(FE), RN, PhD(Nurs)  
Candidate  
School of Nursing, Midwifery and Postgraduate Medicine, Pearson Street, Churchlands, WA

Please answer the following questions or place a tick (✓) in the appropriate  :

1. Age last birthday .....years
2. Never Married  Married  De Facto  Divorced/Separated   
Widowed

3. Highest level of education:

Completed Primary School	<input type="checkbox"/>
Year 10 High School	<input type="checkbox"/>
Year 12 High School	<input type="checkbox"/>
Trade or TAFE	<input type="checkbox"/>
University – diploma or degree	<input type="checkbox"/>
University – Higher Degree	<input type="checkbox"/>

4. Your Diagnosis

..... Date of diagnosis .....

5. Type of Treatment

Radical Prostatectomy  Radiotherapy  Watchful Waiting

6. Do you belong to a support group?

Yes  No

Thank you for completing this questionnaire.