

**A Heideggerian hermeneutic study of the meaning of
living with prostate cancer**

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ATTESTATION of AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of an university or other institution of higher learning.

Signed:

Rosana Eteia Vasconcelos

Date: 13 November 2009

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ABSTRACT

Prostate cancer is the most commonly diagnosed cancer in New Zealand men and the second highest cause of male deaths. This Heideggerian study explores the experience of six men with prostate cancer: five of whom were approximately five months post a robotic prostatectomy and one man post brachytherapy.

The purpose of the study is to understand and describe the meaning men attach to the disease using a hermeneutic existential phenomenological approach to research. Four themes emerged from the interviews: 1) Disappointment, 2) Being-a-man, 3) Sense of Control, and 4) Life-Threatening Disease. The findings of the study suggest men's identities changed due to the side effects of treatments, the need for a sense of control to deal with the disease, and the importance of understanding prostate cancer as a potentially life-threatening disease within the Heideggerian concept of "being-towards-death". Using this concept future research was also identified.

The outcomes of the study suggest implications for health professionals in promoting existential care to the men by listening and taking into account their concerns.

CHAPTER 1: INTRODUCTION

Purpose and Aims

This thesis is a Heideggerian hermeneutic study of the meaning for men of being-in-the-world with prostate cancer. It explores the living experiences of six men who are facing the side effects of prostate cancer treatment. The study will describe and interpret the existential themes emerging from their experiences.

Prostate cancer is the most commonly diagnosed cancer in New Zealand men and the second most common cause of male deaths. Although it is considered a life threatening disease, the advent of effective advances in treatment can increase life expectancy among patients. But more emotional and psychological support is required to clarify men's confrontation with the conflicts that can be triggered by this disease.

My purpose has been to understand men's experiences of having a potentially life-threatening disease, within the Heideggerian concept of 'being towards-death'.

Working as a neuropsychologist for over 15 years in Brazil, fuelled my curiosity to learn how people deal with the impact of being diagnosed with stigmatised and life-threatening diseases. In my reflections of how such a diagnosis leads a person to think about his/her own finitude as a human being, I wanted to investigate deeply this phenomenon in men's lives and shed light on unpredicted meanings attached.

Being aware of mortality enables a human being to face his/her own existence in its totality and complexity (Mansbach, 2002). Death is not a specific event that someday will occur to us, but an inescapable possibility that must be taken into consideration

when caring for humans. Being aware of our finitude enables us to take care of ourselves in an authentic mode, that shows the way to improve our quality of life in any situation we are facing.

We must assume our existence as broadly as we in any way can; everything, even the unheard-of, must be possible in it. (Rilke, 2008).

Furthermore, death here must be understood in its existential sense, instead of morbid death preoccupation. Heidegger describes death as the “impossibility of further possibility” (p.162), which, according to Yalom (1980), means that existence must not be wasted while we are alive, because there are still possibilities to live.

Erectile dysfunction has been reported in almost all men with prostate cancer treatments (Darst, 2007). Thus, another aim of the study has been to uncover the effects of treatments on the men’s sexuality in terms of how they understand themselves as men. In my assumption that sexuality plays an essential role in men’s lives, which can be described as a cornerstone of their masculine identity, the reality of having to cope with erectile dysfunction and impotence is an important issue to be addressed in prostate cancer treatments. I will describe a range of meanings given to sexual behaviours.

The method I chose for this exploration is ‘hermeneutic’. The word derives from Hermes the Greek messenger, god of shepherds, weight and measures, poetry and literature, and travellers, who crossed the boundaries to steal something that was otherwise unobtainable. Thereby, hermeneutic makes possible unique investigation into the unexplored world of human beings. It requires openness to listen to people’s experiences without prejudice, but an openness to see individual’s experiences and be

touched by them. Fernando Pessoa (2006) illustrates:

My gaze is clear like a sunflower.
It is my custom to walk the roads
Looking right and left
And sometimes looking behind me,
And what I see at each moment
Is what I never saw before,
And I'm very good at noticing things.
I'm capable of feeling the same wonder
A newborn child would feel
If he noticed that he'd really and truly been born.
I feel at each moment that I've just been born
Into a completely new world...

My rationale for choosing this methodology is because I use the phenomenological approach in my psychotherapeutic practice – Daseinanalysis (analysis of being-there). According to Cohn (2002) Binswanger describes Daseinanalysis as “concerned with a fuller description of the patient’s existence”. As an existential psychotherapist, I use hermeneutics to interpret my clients’ experiences and to understand the existential themes that emerge within the context of human beings’ lives.

The kind of understanding I refer to here is not related to an intellectual comprehension, but it is, as Heidegger states, “...the openness towards the possibilities of whatever we meet, and this include our own possibilities” (as cited in Cohn, 2002, p. 44). In this sense, I will seek to clarify men’s interpretations of the phenomenon of living with prostate cancer by unfolding what is already known by them in their own context.

Significance of the study

This study holds significance for prostate cancer patients, medical professionals,

psychologists, and mental health practitioners and encourages men with prostate cancer to talk about their inner feelings, in order to clarify their own concerns about the disease, and to overcome psychological conflicts that might be triggered by this diagnosis and side effects of treatments. It provides a voice for men to unfold their own thoughts and feelings, which can lead them to find broader possibilities of life. Thus, men can feel empowered to manage this disease by finding meaning in their everyday life.

On the other hand, the need for information regarding prostate cancer disease and its treatments requires health professionals to rethink their assumptions that men do not talk about their feelings in order to explore the meaning of prostate cancer for each man. As Heidegger (1996) declared, “Beings can show themselves from themselves in various ways, depending on the mode of access to them” (p. 25).

Moreover, given the challenges facing health professionals in communicating such diagnoses, this study may help in the decision-making processes around treatment choices and care. It also provides resources for further intervention aimed towards existential well-being.

My assumptions and pre-understandings

In my longing to understand my own feelings, and searching for answers about life, I decided to be a clinical psychologist in my early adolescence. Thus, I experienced different types of psychotherapy from psychoanalysis to psychodrama where I could start to comprehend the complexity of life and the importance of self knowledge. However, I felt that some kind of understanding was missing in such approaches.

Later on, doing my course in psychology in Brazil, I began my own phenomenological existential analysis. Then, I realised that what I was seeking is related to the depth of the meaning of being-in-the-world which I found in this therapeutic approach.

In existential psychotherapy there is an emphasis on awareness of the givens of existence whereby a human being comes to be what he/she is. Therefore, in my process of becoming who I am, I learned how to listen to my inner feelings, dwelling on my thoughts and reflections on the quality of being human.

For over seven years, my psychologist and supervisor Lucia Maria Zuppi went along with me in my learning process of becoming who I am by clarifying the embedded meaning of my everyday life. At the same time I was a member of a Clinical Studies Group of Existential Phenomenology where I learned to develop and refine my phenomenological thinking. The group was running by Nelson Cassiano, clinical psychologist and lecturer, who taught us not just how to read and understand the Greek, German, and French thinkers and philosophers, but how to reflect upon their words. The aim of the group was to develop our own process of self-reflection as a sine qua non condition to be an existential psychologist and psychotherapist.

I bring to this research my experience of being a listener. I have always believed that for a psychologist to really understand a human being and enter into a client's world, the ability to listen is essential. Working as a supervisor I trained psychologists to be existential psychotherapists, emphasising that the meaning of what a client says can only be grasped by listening carefully to his/her words.

As an existential psychologist I am concerned with the conflicts that are considered an inescapable part of the human beings' existence in the world. Being-in-the-world relates to the ultimate concerns of existence which encompass the awareness of being-towards-death, the freedom of transcendence in a responsible way, existential isolation, and life purpose. Therefore, the way a human exists can be understood through the relationship this human establishes with others and with the world. According to Heidegger (2001) "...this way of existing consists of 'pure', invisible, intangible capacities for receiving-perceiving what it encounters and what addresses it" (p. 4).

My personal growth journey has been phenomenological. Therefore, I am aware of my pre-understandings in the process of learning to be a researcher, trying to integrate my phenomenological ideas into the scientific world, where prostate cancer is mainly studied. I bear in mind that I bring to this study biases that have shaped my understanding of human beings which make me very concerned about how human beings make meaning out of their lives, and also how they confront the lack of meaning of things and others.

In an article of how understanding is related to our own prejudices, Smythe (2007) states that "We cannot escape our prejudices. We all have them, about everything" (p. 401). I am aware of my biases on my views towards death and illness and also as a woman, on my expectations of men's sexuality.

Over the last seven years, since I have been living in New Zealand, I have learnt how to express and communicate my knowledge accumulated in 26 years of practising psychotherapy in a different language. The challenge has been exciting, as my understanding, especially of Heidegger's philosophy, was developed in my mother

tongue, Portuguese.

Definitions

As this study is based on Heidegger's philosophy, I will use his terminology; therefore, a clarification of terms will help the reader to understand their meanings. I am aware that it is not an easy task because Heidegger uses words in their primary ontological signification, i.e., the literal meanings of the words.

Dasein is a German word usually not translated into English. Heidegger uses this word referring exclusively to human being. It means literally 'being-there', but 'there' does not refer to a location, rather it designates openness to the way we affect and are affected by what we encounter in the world.

Being-in-the-world refers to Dasein as inseparable from the world. As human beings, we cannot be explained apart from the world, and, at the same time, the world cannot be explained apart from human beings.

Being-towards-death is related to an awareness of our finitude and totality. As Mansbach (2002) states "Confronting its death frees Dasein for itself, for the possibility of giving meaning to its world and to its self. The disclosure of mortality allows human existence to focus on itself as its own self" (p. 50).

Authentic and inauthentic are words using by Heidegger to describe both modes in which Dasein exists. Authentic existence can only be acquired when a human being

realizes the uniqueness of his/her being. Thus, one takes responsibility to fulfil his/her own destiny. In an inauthentic existence one draws his/her self-understanding from what the public says (Harman, 2007).

Lived body (embodiment) refers to the phenomenological fact that the body is not separated from existence.

Lived time (temporality) is related to one's inner perception of time in contrast to chronological time.

This thesis is divided into six chapters:

Chapter 1 is an introduction of my rationale and aims of the chosen topic, some of my personal and professional life experiences which include my pre-understanding and biases.

Chapter 2 sums up a previous literature review on prostate cancer that I performed. I have introduced information about prostate cancer, such as definition of the gland, incidence of the disease, diagnosis, its treatments and side effects.

Chapter 3 is a description of the methodology based on Heideggerian hermeneutic existential phenomenology, the methods used to select and interview participants, the data analysis, and the ethical considerations pertinent to this study.

Chapter 4 presents the findings as phenomenological themes revealed in men's stories, using quotes from the interview material.

Chapter 5 contains a discussion of the themes described in the previous chapter. I have introduced more literature, pieces of poetry and quotes from existential authors to support my findings.

Chapter 6 is a conclusion of my study where I address its strengths and limitations, and also recommendations for practice for health professionals and for further research.

CHAPTER 2: LITERATURE REVIEW

This chapter is a summary of the review of the literature I performed to increase my knowledge about prostate cancer. The chosen themes are related to those found in the material from the interviews. I have also included information about the disease that pertained to my study: a) definition of the prostate gland, incidence of prostate cancer, diagnosis, age risk factor, treatments and its side effects; b) masculinity identity; c) coping with urinary incontinence; d) couples' experiences with prostate cancer; e) patients' relationship with doctors and nurses; f) life-threatening disease.

To capture the broadest psychological and existential aspects involved in prostate cancer, this review considered quantitative, qualitative, phenomenological, and hermeneutic studies related to meaning, sexuality, and life-threatening disease.

Definition of the prostate gland

The prostate is a walnut-sized gland located behind the pubic bone, just below the bladder, and surrounds the beginning of the urethra. The urethra is a tube that in males, carries urine from the bladder to the outside the body through the penis, and also carries semen during ejaculation.

As part of a man's reproductive system, the prostate's job is to make some of the fluids that contain nutrients for the sperm and carry sperm out, during the ejaculation, as part of semen (American Cancer Society, 2008).

The prostate gland grows until a man reaches adulthood. This growth is fuelled by male

hormones, or androgens. The main androgen is testosterone, which is a hormone that plays an important role in controlling all aspects of men's body change known as virilisation (Bostwick, MacLennan, & Larson, 1996). As long as the hormones are present in an adult man's body, the prostate's size remains the same (American Cancer Society, 2008).

The enlargement of the gland occurs with ageing and it is influenced by testosterone hormones. Autopsy studies show that approximately 29% men aged 30-39 years have microscopic evidence of the disease, which increases to 65% by age 70 (Chodak & Warren, 2006). When the prostate grows too large, it squeezes the urethra, which can cause problems with urinating (National Cancer Institute, 2008).

Incidence of prostate cancer

Prostate cancer is the sixth most common cancer worldwide (O'Rourke, 2004).

According to the American Cancer Society (2008), prostate cancer is the most common type of male cancer in the United States. There was predicted in 2008 to be an estimated 186,320 new cases of prostate cancer and 28,660 deaths from this disease in the United States (National Cancer Institute, 2008).

Prostate cancer remains an important health issue in New Zealand, where it accounts for 14% of male cancer deaths, with two-thirds of these deaths occurring in men over 75 years of age (New Zealand Ministry of Health, 2008). The New Zealand Ministry of Health (2008) reported that prostate cancer is the third most common cause of male cancer deaths, after lung and bowel cancer respectively.

According to Madjar and Tingle (2008) Maori men are 16% less likely than non-Maori men to develop prostate cancer, however they are more than twice as likely to die from the disease as non-Maori New Zealand men. In a national study of ethnic differences in New Zealand, Sneyd (2008) reports that “Maori and Pacific men had higher mortality particularly in the first year after a diagnosis of prostate cancer than did European men” (p. 993).

In the early 1990s, in the United States, there was a dramatic rise in the incidence of prostate cancer due to early detection techniques, the screening for prostate specific antigen (PSA) (Prior & Waxman, 2000; Fergus, Gray, & Fitch, 2002). However, testing for prostate cancer is a controversial issue among medical organizations and government departments due to the uncertainty about whether the benefits outweigh the harms. Therefore, a national screening programme has not yet been established in most countries around the world, including New Zealand and Australia. The New Zealand Ministry of Health (2008) reports that “there is currently no evidence that shows a population-based screening programme for men with no symptoms of prostate cancer would improve outcomes for men, however men who are concerned can be tested if they choose to” (Cancer control in New Zealand, para.3).

According to Lin, Lipsitz, Miller and Janakiraman (2008), tests may be associated with potential harms such as “additional medical visits, adverse effects of prostate biopsies, anxiety, and over diagnosis” (p. 192). Moreover, the treatments for prostate cancer have possible side effects, which make it more difficult to decide whether it should be treated

or left alone. This is because some prostate tumours grow very slowly and are not life-threatening. Therefore, overtreatment may lead to unnecessary side effects that adversely affect men's quality of life (Lin et al., 2008). In addition to the physical pain and suffering derived from the procedures, a man has to deal with the psychological side effects of the two main long term issues: urinary incontinence and sexual impotence (O'Rourke, 2004).

By contrast, Lamb et al. (2007) state in their review of prostate cancer screening that "...in recommending the establishment or not of PBS programmes (population-based screening), it is important to make evidence-based health decisions and not decisions based on lack of evidence" (p. 538). These authors' arguments for suggesting a screening programme are based on evidence that cancer diagnosed by screening when still in its early stages, can mostly be cured or treated successfully by different treatment options. Furthermore, early detection is important because prostate cancer can develop and spread asymptotically, because it usually starts at the back of the gland. Thus, once the prostate cancer is diagnosed, it may have developed metastatic tumours, i.e., it has spread to other organs and is usually no longer curable (The Cancer Council Queensland, 2007).

Another important argument for screening, is that the familial risks of prostate cancer are well recognized in men with one or more first-degree relatives diagnosed with the disease. In this situation, screening is highly recommended (Lamb et al., 2007; Madjar & Tingle, 2008).

Nevertheless, there are two consultation resources available to doctors and patients in

order to provide them with information that contributes to decision-making about treatment. These are guidelines developed by the New Zealand Ministry of Health, New Zealand Guidelines Group, Cancer Society, Prostate Cancer Foundation, and the Royal College of GPs. The guidelines aim to stimulate discussion between men and their doctors of the issues involved in this disease by providing balanced information on prostate cancer.

Diagnosis

The two common screening tests for prostate cancer are the Prostate-Specific Antigen (PSA), which tests for protein blood levels, and a Digital Rectal Examination (DRE), which can detect abnormal growth of the prostate gland. When abnormality is detected on DRE and PSA, a prostate biopsy is recommended in order to explore likely areas where cancer might be present (Lamb et al., 2007; Madjar & Tingle, 2008).

When the initial findings of the screening show high serum PSA or suspicions from the DRE, more tests may be needed, such as Trans-Rectal Ultrasound (TRU), Gleason Score, imaging scan, bone scan, Computerised Tomography (CT) scan, and Magnetic Resonance Imaging (MRI) (Madjar & Tingle, 2008). Likewise, when a tumour is detected, the use of those tests makes possible grading and staging of the tumour, in order to decide which treatment is best for a man (Bostwick et al., 1996).

Although the currently available tests do not provide a definitive diagnosis and can trigger anxiety due false positive results, men who are tested regularly are less likely to be diagnosed with advanced or metastatic cancer than the ones who are not tested (Madjar & Tingle, 2008).

Age risk factor

Increasing the emphasis on screening men who are more likely to have cancer treatments, i.e., the ones who get most benefits from screening, Lamb et al. (2007) recommend age for screening takes into account "...both the projected over-detection rate and the projected risk of dying of prostate cancer" (p. 540). This is because young men have less chance of contracting prostate cancer, but when they do, are more likely to die of the disease (New Zealand Ministry of Health, 2008).

The chances of a diagnosis of prostate cancer increase with age, thus the probability of the development of the disease is very rare before the age of 40. However, the chances of having prostate cancer rises rapidly after age 50, and two thirds of prostate cancers are found in men over 65 years old (American Cancer Society, 2008).

Treatments and side effects

The decision-making about treatments should involve the clarification of side effects of all treatments for prostate cancer. The American Cancer Society (2008) recommends taking into account a patient's age, life expectancy, risk of cancer recurrence, the stage and grade of cancer, general health and most importantly, what side effects a patient can put up with. This may involve the elucidation of risks/benefits of treatments, which a patient can get from more than one medical opinion and also talking to his wife/partner, family, friends, and other patients.

On the other hand, Madjar & Tingle (2008) point out that important challenges face

doctors and researchers in deciding whether a tumour is an aggressive one, which needs to be treated, or an indolent one, which can be present for a number of years without spreading or causing any problems. Hence, both patient and doctor should be aware of the uncertainties surrounding prostate cancer. The reinforcement of information available can minimize the stress involved in the decision-making process.

The main treatments available for prostate cancer are discussed below.

Surgery

Surgical approaches include radical prostatectomy, transurethral resection of the prostate, and cryosurgery (Eton, & Lepore 2002). Radical prostatectomy is recommended when the surgeon believes that the tumour has not spread outside of the gland, thus there is a chance of cure by complete removal of the prostate gland (American Cancer Society, 2008). It can be done as open surgical removal or robotic interface called the da Vinci system. The difference is that open surgical removal requires a large incision in the patient's abdomen whereas robotic-assisted laparoscopic only requires four to six small incisions which leads to less blood lost and shorter recovery time (American Cancer Society, 2008; National Cancer Institute, 2008).

Transurethral resection of the prostate is a surgical procedure aimed at alleviating symptoms rather than providing a cure (American Cancer Society). Here, the surgeon removes the inner part of the prostate tissue that surrounds the urethra. This option is mostly used with men who have serious health conditions or advanced age (Eton, & Lepore 2002). The main side effects for both treatments described above are urinary incontinence and erectile dysfunction (American Cancer Society, 2008). Postoperative

pain is also frequently reported by patients, but it can be managed by pain relieving medication (Bostwick et al., 1996; Madjar & Tingle, 2008).

Cryosurgery is considered a less invasive procedure which involves freezing targeted malignant tissues, avoiding injury to normal tissues (Bostwick et al. 1996). The possible side effects after surgery are soreness in the perineum area, swelling of the penis or scrotum. Further, the bladder and intestines can become irritated which leads to the need to empty them often, and impotence can occur in up to 80% of men (American Cancer Society, 2008).

Non-surgical approaches

Non-surgical options for prostate cancer include external beam radiation, internal radiation, and watchful waiting. Radiation is used as the initial treatment for cancer that has only spread to nearby tissues of the prostate gland or recurrent tumours, and it employs high-energy rays to kill cancer cells (American Cancer Society, 2008).

External beam radiation therapy delivers high doses of radiation to the tumour and uses computer-driven technology to ensure as little damage as possible to the healthy tissues around the prostate (Madjar & Tingle, 2008). Internal radiation, or brachytherapy, uses tiny radioactive pellets surgically implanted within the prostate gland (Eton & Lepore, 2002). The possible side effects of radiation are: bowel problems, bladder problems, urinary incontinence, and impotence (American Cancer Society, 2008).

Another possible procedure is called Watchful Waiting, where no treatment is administered, but there is close monitoring for symptoms progression. This is also

termed 'active surveillance' and it is recommended to older men who have lower stage and grade disease (Chapple et al., 2002).

Masculine identity

As a consequence of having been treated for prostate cancer, every man has to deal with side effects which directly affect his sexual life. The reality of having to cope with erectile dysfunction and impotence leads them to re-think their masculine identity.

Many studies reviewed have identified the impact of prostate cancer and its treatments on men's sexuality.

Radical prostatectomy and external-beam radiotherapy are two major therapeutic options for the treatment of clinically localized prostate cancer, i.e., the cancer confined within the gland. Erectile dysfunction following these treatments is a particular concern as it occurs in up to 80% of patients (Meuleman & Mulders, 2003). Although sexual dysfunction is a major complication of radical prostatectomy, little research exists about the patients' experiences of the impact of impotence and their views of themselves as sexual beings (Butler, Downe-Wamboldt, Marsh, Bell, & Jarvi, 2001).

In several studies reviewed, the authors have found that sexual function was influenced by age and older men are more likely to accept impotence than younger men (Berterö, 2001; Hashine, Azuma, Koizumi, & Sumiyoshi, 2005; Lee & Owens, 2002; Navon & Morag, 2003; Ollife, 2005; Schover et al. 2004 Steginga et al. 2001;). This finding was statistically supported by Sánchez-Ortiz et al. (2000) who reported erectile dysfunction was slightly lower in men younger than older men after cancer therapy.

On the other hand, although sexuality is diverse in old age, older people have been stigmatised as they are stereotyped as asexual (Fergus et al., 2002; Nay, McAuliffe, & Bauer, 2007). In a narrative reconstruction of sexuality among prostate cancer patients Arrington (2003) suggested that some elderly people have rejected the notion that sexual drive diminishes or disappears with age.

In most cultures there is an assumption that males have to perform penile-vaginal intercourse as a 'real' sexual activity. The theme of sex as penetration has appeared in many studies (Arrington, 2000; Fergus et al., 2002; Hedestig, Sandman, & Widmark, 2005b; Jakobsson, Hallberg, & Lovén, 2000; Navon & Morag, 2003; Oliffe, 2005). In these studies men relied on penetrative sex to express their sexuality, but, following prostatectomy they experienced unexpected physical changes and impotence as side effects of treatments which led them to redefine their sexuality. The difference between these studies is that Oliffe (2005) focussed on men who had to deal with a discordant relationship between libido, which remained intact, and erectile dysfunction that was lost. On the other hand, other studies explored the consequences of treatments where sex life was missed at the same time as the desire for it diminished (Jakobsson et al., 2000; Navon & Morag, 2003).

In the United States, the Nation's Medical Research Agency (The National Institutes of Health, 1991) defines impotence as a consistent inability to attain and maintain a penile erection sufficient to permit satisfactory sexual intercourse. However, published studies of sexual dysfunction show that the definition of potency is lacking in detail (Incrocci,

2006; Kao, Jani, & Vijayakumar, 2002). In order to improve interventions for erectile dysfunction post-treatments, most participants in different studies have tried to restore their potency by using mechanical devices, Viagra and/or injections. Eventually, however, they abandoned these interventions due to the artificial nature, ineffectiveness and lack of spontaneity in achieving, maintaining and using their erection (Arrington, 2003; Bokhour, Clark, Inui, Silliman & Talcott, 2001; Chapple & Ziebland, 2002; Dahn et al., 2004; Fergus et al., 2002; Oliffe, 2005; Shover et al., 2004). Thus, when faced with sexual impairment, men tried to find new possibilities to reclaim their sexuality which is related to their identity: the way they understand themselves, particularly in terms of all forms of male-female relationships. For example, a grounded theory study by Fergus et al. (2002) involved 18 participants treated for prostate cancer with radiation therapy, prostatectomy and/or androgen deprivation therapy, indicated that to affirm manhood the frustration was less intense if men set their sights outside of achieving penetrative sex when potency was lost and were open to redefining their approach to love-making.

Chapple and Ziebland (2002) explored the experience of 52 men and the effects of prostate cancer and treatments on their masculinity. The authors reported that the participants (n=32) treated with hormones experienced greatest change to their libido, they had lost all interest in sex and felt changed, not only physically, but also psychologically. Based on their study, Chapple and Ziebland suggested that gender was largely a social construction, but as the concept of masculinity is sometimes confused with potency, their data suggests that male hormones may play, at least a small part, in how gendered roles are enacted. This finding also appears in an ethnographic study of

16 Anglo-Australian men treated with androgen deprivation therapy, where libido and erectile performances are seen as synonymous of hegemonic male sexuality (Oliffe, 2006). In this study, Oliffe (2006) found that due to side effects of androgen deprivation therapy, most participants experienced loss of libido and potency, but impotence was not so difficult to accept because sexual desire had also vanished. Chapple and Ziebland findings reveal grief and reduced masculinity were related to the loss of sexual desire, whereas Oliffe suggested that a masculine self and intrinsic desire was preserved, because the physical body (biological) is referred to in social constructionist gender terms rather than only dominant social gender constructions.

Conversely, a grounded theory study by Arrington (2000) focused on an analysis of sex talk among prostate cancer support group members. The author stressed that sexual experiences are not just the products of biology, as they encompass social and historical attitudes expressed by medical, psychological, religious communities, and attitudes the media impose on human lives. Arrington reported that although men with erectile dysfunction might be not able to achieve or maintain an erection, they made a choice regarding how to negotiate their sex lives with partners. Thus, some couples decided to continue their relationships without sex; whereas others redefined sexual contact and maintained sexual lives.

Increasing the emphasis on the social construction of sexuality, Arrington (2003) used narrative analysis to examine sexuality among prostate cancer survivors taking into consideration the role of culture in definitions and experiences of sexuality. This author found in a prostate cancer support group, narratives in which the men's sexual lives

were socially organised with significant stigma and threats to individual identity.

Arrington describes several survivors' stories in which their sex lives were altered but not finished by prostate cancer and, as a result, they redefined their sexual identities and discovered new possibilities for expressing their sexual desire.

Given the complexity involved in sexuality, in a phenomenological investigation of African American men diagnosed with prostate cancer, Abel (2002) states that sexuality cannot be confined by cultural interpretations and its descriptions alone do not reach the depths of the meaning of lived experiences. In this study, participants revealed that having a diagnosis of prostate cancer meant becoming peculiarly aware of a life changing attack on the self, which is a male sexual person in transition. Several qualitative studies have found that, as a consequence of the experience of becoming changed men, the participants needed to find new meaning in the new life situations (Berterö, 2001; Hedestig, Sandman, Tomic, & Widmark, 2005a; Hedestig et al., 2005b; Hedestig, Sandman, & Widmark, 2003; Jakobsson et al., 2000; Lindqvist, Widmark, & Rasmussen, 2006; Maliski Heilemann & McCorkle, 2002; Westman, Bergenmar, & Andersson, 2006). Moreover, sexuality is an important value in life as it is connected with masculinity and existence. Westman et al. (2006) found that men who have lost their potency did not only lose quality of life but also that life itself lost its meaning.

Coping with urinary incontinence

Prostate cancer patients may continue to experience treatment-related late side effects.

Although urinary and sexual symptoms are the most common and long-lasting effects of treatments, there is a paucity of studies examining the psychological impact of these

significant potential physical sequelae (Clark, Wray, & Ashton, 2001; Kunkel, Myers, Lartey, & Oyesanmi, 2000; Pateman & Johnson, 2000). Moreover, it is not clear from the literature how these physical side effects of treatments are experienced by men in terms of their masculinity (Wall & Kristjanson, 2005). For example, Chapple and Ziebland (2002) present a study of the way in which prostate cancer and its treatment affects men's bodies, their roles and sense of masculinity. However, as far as incontinence is concerned, the study describes problems associated with lack of control over bodily functions, such as urgency, or frequency, but does not explain any clear effect on masculinity.

Likewise, in a study of experiences of prostatectomy, Pateman and Johnson (2000) suggested that urinary-related problems seem to be a social construct rather than based on objective criteria. This suggestion was based on men appearing to put up with or not recognize the 'problem' until they were validated by others, or until they considered the incontinence symptom indicative of a life-threatening condition. Similarly, Chapple and Ziebland (2000) suggested that masculinity is, to some extent, a social construction because men in their study felt hesitant about consulting their doctors with their symptoms due to the 'macho' image whereby men cannot display signs of weakness.

The same can be seen in the results from a landmark national survey in the United States indicating that an enlarged prostate is the most common diagnosis for moderate to severe urinary symptoms in men aged 50-79 years, although approximately 20% do not consult a doctor (Roehrborn, Marks, & Harkaway, 2006). Urinary symptoms can be considered an important issue to be addressed in cancer treatments, as Wareing (2005)

pointed out, failures in the past have led men to believe that their prostate symptoms were just consequences of ageing, and as a result they have lived and suffered with their symptoms far longer than necessary.

Urinary incontinence is often associated with embarrassment of being with others, which can lead to social isolation, diminished quality of life and depression (O'Rourke, 2004). Embarrassment is a common theme permeating most studies investigating participants' feelings about urinary dysfunction (Berterö, 2001; Chapple & Ziebland, 2002; Clark, Bokhour, Inui, Silliman, & Talcott, 2003; Pateman & Johnson, 2000; Wareing, 2005). This is related to the inconvenience of having to go to the toilet more regularly, leaking of urine, buying pads, and men's personal hygiene. Although these studies have indicated that urinary dysfunction caused physical and emotional discomfort and complex behavioural problems for men, only a study by Berterö (2001) explored the effects on men's image of manliness.

Berterö (2001) reported that urinary incontinence was traumatic to participants who felt their manliness affected, made them feel ashamed and preoccupied with keeping themselves 'clean and fresh', thus leading the men to manage their problems by themselves. Moreover, urinary incontinence was also considered an obstacle for sexual intercourse because they felt ashamed and did not want to involve their wives in washing their dirty linen (Berterö, 2001). The altered view of their wives and married life, appears in other studies where men expressed opinions that urinary incontinence affected their sexual lives and, as a result, their sexual desire was lost (Jakobsson, Hallberg, & Lovén, 1997a; Roehrborn et al., 2006). On the other hand, Fergus et al.

(2002) described participants who had to contend with prolonged urinary incontinence as being better able to adjust to sexual dysfunction, as they stated that “as much as impotence is a nuisance, incontinence is worse”.

The effects of lower urinary tract symptoms and erectile dysfunction are reported in quantitative studies as factors that can reduce patients’ quality of life. Therefore, incontinence may contribute to lack of confidence, anxiety and lower sexual desire, which affected the men’s relationships and frequency of intercourse (Barqawi, O’Donnell, Kumar, Koul, & Crawford, 2005; Katz, 2007; Roehrborn et al., 2006).

Patients’ relationship with doctors

Regarding the decision-making process, the men’s account of how they made their treatment choice, focused on their interaction with doctors rather than with their wives (Boehmer & Clark, 2001). In examining the meaning of being a patient and patients’ experiences with physicians, Hedestig et al. (2003) stressed how important it is for patients to have a friendly relationship with their doctor. In addition, Jakobsson, Hallberg and Lovén (1997b) suggested that when the patients were able to comprehend and formulate their needs in words to the staff (medical and nurses), they were also able to make sense of their present illness and experience a sense of coherence.

As prostate cancer and its treatments are surrounded by uncertainties, it is likely that patients need more information in order to make sense of their illness and to guide them in the decision-making process. However, physicians are more focused on curing disease and, as a result, they ignore the meaning the illness holds for the patient

(Arrington, 2000). This is an issue for physicians where lack of communication between them and their patients have been reported by Arrington (2000), who found the men in his study were forthright in discussing sex and the physicians' avoidance in talking about sex, led them to be misinformed about their patients' needs. This is further revealed in a survey investigating support and psychological care of 210 prostate cancer patients (Lintz et al., 2003). In this study, 49 % of men reported having some need in the domain of sexuality. The authors found that those who had sexual health-related needs expressed a greater necessity than those who have reported their needs in other domains. Similarly, Steginga et al. (2001) reported that sexuality was identified as a primary support care need for men with prostate cancer, particularly younger men.

The combination of patients' limited disclosure of their concerns and physicians' focus on medical conditions, contributes to information needs remaining unmet. A study of information needs in prostate cancer patients (Feldman-Stewart, Brundage, & Mackillop, 2001) regarding number of information items necessary for them to make a treatment decision, found a significant variation among men's needs and little agreement on the need of specific items. Therefore, their findings suggest that physicians cannot expect to predict the information requirements of every patient and patients should be specifically asked what information is pertinent to their decisions.

The Support Care Needs Survey (Lintz et al., 2003) reveals in which domains the highest percent of patients reported having some need: psychological (65%), health system/information (59%), and physical and daily living (58%). Due to the ambivalence involved in prostate cancer treatments, these authors found a significant number of

patients reported having used or desiring support services, such as information about their disease, one-on-one counselling, and a series of talks by staff members about aspects of prostate cancer.

Oncology nurses provide care for prostate cancer patients from diagnosis through to alleviation for possible metastatic disease. Therefore, they need to be aware of the role they play in assisting the patients' decision-making process taking into consideration their quality of life. Supporting men and their partners, nurses can reinforce information about the treatment modalities, helping them to weigh the advantages and disadvantages of each treatment. At the same time, nurses can work to minimize the stress involved in this process (Katz, 2007).

Westman, Bergenmar and Andersson (2006), in a hermeneutic study, described cancer patients' reflections on the disease and how these reflections were met by the nursing staff. The researchers started seeking for existential issues patients related to, in the experience of having cancer. Three major themes were found: life, illness, and death.

Although not all patients related the cancer diagnosis with reflections on the meaning of life, they account for other existential and emotional issues. For example, in an investigation of met and unmet nursing care needs, Jakobsson et al. (1997b) found that existential nursing care needs were interpreted by patients as information and education about the disease and treatment-related side effects, and professional support and communication.

Furthermore, patients lacking information about their disease expressed more vulnerability in finding meaning in their illness (Westman et al., 2006).

In a study of the experience of living after external beam radiotherapy of localized prostate carcinoma, Hedestig et al. (2005a) found that patients striving for control in a new situation in terms of the mystery of radiotherapy, control of the disease progression, and a struggle for control over daily life, expressed a wish of sharing their experience with other men. This was describing as a coping strategy to bear the burden of being a patient. Thus the meaning of becoming reconciled encompasses comparisons related to, for example, side effects, symptoms, and treatment. Moreover, patients suggested the importance to talking to other prostate cancer patients because they preferred to discuss sexual problems with other men, as they considered this a masculine experience (Hedestig et al., 2005b).

Asking patients about their desire in talking about their difficulties with cancer, Fitch, Gray, Franssen, and Johnson (2000) found that 39% of the respondents expressed the need to talk. These authors identified men who wanted to talk about their difficulties with the disease but they did not have anyone with whom they could talk. Thus, the authors suggested the need of oncologist nurses to identify these patients and provide appropriate assistance early in their illness. Given the importance of sharing concerns related to prostate cancer and the reluctance expressed by participants talking about their own concerns because they are shy or want to keep their privacy, researchers have suggested that electronic access to the Internet represents an excellent tool for meeting the need for information, yet allowing anonymity (Roger, 2006; Ziebland, 2004).

The need for information regarding prostate cancer and its treatments requires health professionals to rethink their assumption that men do not talk about their feelings, in

order to consider exploring the meaning of the disease for each man. An illustration of this assumption is seen in Westman et al. (2006) study, where the researchers needed to contact more women than men to include the same number of both genders. The authors explained that 15 women but only one man refused to take part in the study, therefore, they assumed that men have had less opportunity to talk about existential issues than women.

Couples' experiences with prostate cancer

Partners of men diagnosed with prostate cancer have reported significantly greater psychological stress than the men themselves. This can be related to cancer diagnosis where the wives are involved from the treatment decision, to living with the side effects and concerns about physical limitations (Crowe & Costello, 2003; Heyman & Rosner, 1996; Katz, 2007; Kirschner –Hermanns & Jakse, 2002; Phillips et al., 2000). In an interpretive phenomenological study, Berterö (2001) identified men's views of their manliness in terms of their role as partners in intimate relationship, with their wives playing an important role in their acceptance of the problems within their sexual lives. Partners may be most helpful by focusing on putting issues such as impotence into perspective, which enables them to modify the significance of the cancer (Maliski et al., 2002). Moreover, in order to maintain a positive relationship, all participants in a qualitative analysis of couples' experience with prostate cancer, spoke of the need for open communication about the issues affecting their relationship (Harden et al., 2006). These findings are supported by Banthia et al.'s (2003) study which suggests that the relationship between coping and distress depends on the quality of dyadic functioning for prostate cancer patients. Thus, a strong positive relational dyad can buffer against

psychological distress for the sufferers.

A diagnosis of prostate cancer can exert an immeasurable effect on a man's family (Arrington, 2000), with pressure sometimes coming from families supporting the patient to pursue active treatment (Chapple et al., 2002). Family and partnership are the most important systems supporting the patients throughout the cancer treatments, therefore providing them with information can help patients both directly and indirectly (Butler et al., 2001; Docherty, Brothwell, & Symons, 2007; Feldman-Stewart et al., 2001; Jakobsson, Hallberg, & Lovén, 1997b; Willener & Hantikainen, 2005). Pressure sometimes comes from families supporting the patients to pursue active treatment (Chapple et al., 2002).

Life-threatening disease

Prostate cancer is considered a potentially life-threatening disease, therefore the impact on men following this diagnosis leads them to think about their own finitude as human beings. In the studies reviewed, most participants expressed a sense of shock, anxiety, disbelief, anger, and fear when they found out about the cancer (Abel, 2002; Maliski et al., 2002; Walton & Sullivan, 2004; Westman et al., 2006). Thus, health professionals need to take into consideration that the highest level of stress in cancer patients is after diagnosis and before treatment (Walton & Sullivan, 2004). In a cross-sectional survey on men's perspectives on the impact of prostate cancer, Fitch et al. (2000) reported that 31% of respondents expressed a change in lifestyle since their diagnosis and treatment.

The diagnosis of prostate cancer compelled men to rethink the way they were looking at

their lives (Abel, 2002), which leads them to start considering the meaning of life. Some patients expressed problems in finding meaning in going on living (Westman et al., 2006). On the other hand, many participants have reported that the threat to their mortality altered their view of life significantly (Butler et al., 2001). Facing mortality issues makes patients reflect about the meaning of their past lives, enables them to accept their present and also prepares them for the future (Harden, 2005). As a cancer diagnosis can be considered a 'death sentence' for some patients (Maliski et al., 2002), and for most patients a deadly threat, scientific knowledge and metaphysical beliefs about cancer are important for patients to cope with the disease (Westman et al., 2006). Westman et al. (2006) reported that all patients in their study talked about death, although their focus was reflecting upon what will come after death instead of the meaning of having a potentially life-threatening disease. The patients rarely discussed their existential issues with the nurses and the main reason given was lack of time to build trust between them and caregivers to talk about personal issues.

Addressing spiritual issues in cancer interventions might be particularly important to patients in the terminal phase of the disease because dying patients face psychological distress. Thus helping them develop or improve a sense of spiritual well-being might be a crucial aspect of coping with terminal illness (McClain, Rosenfeld, & Breitbart, 2003). Moreover, some authors have found that understanding the patient's concerns can improve not only the clinical care of the patient but also the nurses' and physicians' sense of satisfaction and meaning in caring for the dying. In a broader sense, both patient and professional might be changed by the experience (Albaugh, 2003; Block, 2001). Tamura, Kikui, and Watanabe's (2006) phenomenological investigation on how

patients facing death, create life experience in the context of care, reported that when a nurse is able to share and interpret the meaning of the patients' concerns, both are able to confront their own death, which compels them to rethink their values. Moreover, these authors suggested that this kind of relationship between nurse and patient makes spiritual pain care possible for cancer patients.

Summary

Findings of an extensive literature search of the meaning men attach to their experience of having a life-threatening disease and the side effects of its treatments, suggest that although prostate cancer can exert immeasurable effects in men's lives and can profoundly alter their sense of masculinity, interventions can be made to support them to make sense of their own psychological concerns. Thus, this review emphasizes knowledge generated from holistic investigations focused on giving voice to men's experiences which encompasses psychological, sociological, phenomenological, and scientific approaches.

Much of the research on prostate cancer is focused on the effects of treatments on quality of life. Therefore, this review has shown that there are many areas in prostate cancer to be explored. For instance, I was unable to find a hermeneutic study focused on the Heideggerian concept of 'being-towards-death', which I will introduce in Chapter Five: Discussion of findings. Furthermore, I will refer back to the findings of this review in the final chapter, relating them to the findings of my study.

CHAPTER THREE: METHODOLOGY

Introduction

I have a desire to better understand men coping with the side effects of treatments of prostate cancer: hence the methodology chosen for this study is Heideggerian hermeneutic existential phenomenology. This approach allows me to enter into a males' world in order to clarify and understand the meanings they attach to their experiences of living with prostate cancer. I believe that this is the most appropriate methodology to give voice to men to express their inner feelings and concerns and, at the same time, it enables me as a researcher an introspective reflection of the meaning-giving of the phenomenon being experienced by them. Furthermore, the phenomenological approach challenges the researcher's ability to involve him/herself with the phenomenon to be explored in a mode where understanding is related to the researcher's skills of being with the participant as a listener.

Interpretive phenomenology or hermeneutics is based on Heidegger's philosophy where interpreting and understanding human experiences is stressed (Polit & Beck, 2006). Phenomenology uses naturalistic methods of inquiry where researchers are focused on how humans create and shape their own experiences, and they attempt to capture the meaning of the phenomenon under investigation, according to the context of those who are experiencing them (Polit & beck, 2006). For the naturalistic inquirer, reality exists within a context; therefore, there are multiple ways to interpret humans' views of the world. This requires the researcher getting as close as possible to the essence of people's experiences (Grbich, 1999). This can be achieved by listening carefully to the

spoken words.

Research question

When I formulated the research question my intention was to explore men's experience with prostate cancer in its totality in terms of what is relevant to them to be told. Thus my question is: "What is the meaning for a man living with prostate cancer". The essence of the question 'living with prostate cancer' refers to all experiences from the beginning, when they were diagnosed, to treatments and its side effects. As Gadamer (1989) explains "The essence of the question is to open up possibilities and keep them open" (p. 299).

Heideggerian phenomenology

Doing phenomenological research, exploring medical phenomena, there is one particular Heideggerian concept to be considered: "facticity", which means the meaning of everyday life cannot be understood in a scientific reductionism approach (Svenaesus, 2006). According to Heidegger (1996) facticity entails Dasein (Being-there) inseparable of the world, therefore the meaning of being can only be explored on the basis of the interconnectedness to what is encountered in the world. In other words, 'Being' is fundamentally being-in-the-world where everything encountered in our experiences has an implicit meaning.

In *Being and Time* (1996) Heidegger defines the term 'phenomenology' in its two components, phenomenon and logos. He goes back to the Greek roots of the word where phenomenon means "...what shows itself, the self-showing, the manifest" (p. 25).

In this sense, phenomenon is what shows itself in itself, what it is manifested, disclosed, and therefore, capable of being investigated. The concept of 'logos', Heidegger draws from the primary translation of the word meaning speech, thereby logos as speech means "...what is talking about in speech" (Heidegger, 1996, p. 28). He rejects the translation of logos as judgment especially in situations where "...by judgment we understand 'connecting two things' or 'taking a position' either by endorsing or rejecting" (p. 28). Judgment is a fundamental concept to bear in mind while doing phenomenology, whereby the importance of the awareness of our own pre-understanding and prejudices allow us to put them aside in order to grasp the meaning hidden in the spoken words.

Similarly, Gadamer (1976) relates understanding to dialogue by stating that to really understand a text we need to establish a kind of dialogue with the text to such an extent where we become the interpreter of the text. According to Gadamer (1977), "Interpretation belongs to the essential unity of understanding" (p. 57).

Heidegger (1996) also describes phenomenology as a concept of method, which characterizes the 'how' of the content of the objects in philosophical research. He states that "we are dealing with something 'self-evident' which we want to get closer to, insofar as that is important for the clarification of procedure in our treatise" (Heidegger, 1996, p. 24). As the focus of this study is to unfold the meaning men give to their experiences of living with prostate cancer, phenomenology is a consistent approach described by Crotty (1998) as one which allows the researcher to immerse with, and from his/her pre-understanding of the phenomenon, make explicit what was implicit in order to grasp the meaning of being itself.

Hermeneutic circle

As a phenomenologist I have my pre-understanding of the phenomenon I am investigating and to unfold this understanding I use the hermeneutic circle as described by Heidegger (1996) to grasp the existential issues involved in men's narratives. As a human being-in-the-world my background practices allow me to share my experiences with what I encounter in the world and to interpret human beings in a circular movement. This is the so-called hermeneutic circle where interpreting a text requires a circular structure where the process of understanding encompasses somewhat that is already understood. Therefore, interpreting is a matter of reinterpreting. Dreyfus (1991) describes this circle to the fact that "...in interpreting a text one must move back and forth between an overall interpretation and the details that a given reading lets stand out as significant" (p. 36). Thus, each detail revealed has the potential to alter the interpretation by revealing new other details in a circle that enriches the understanding of the text.

Methods

Ethics approval

The ethical approval for this study was granted by the Northern Y Regional Ethics Committee on 27 November 2008 (Refer to Appendix A). The Auckland University of Technology Ethics Committee (AUTEK) also granted approval on 3 March 2009 (Refer to Appendix B).

Participants' recruitment

First, I contacted the Clinical Director of Tauranga Hospital and we arranged a meeting where the aims of the study and the criteria for potential patient participants were discussed. The Clinical Director supported and guided the approval process and put me in contact with the administrator of Venturo Clinical Administration, the central agency for both private and public patients. Second, an oral presentation was given to the urologists at Tauranga Hospital where I explained the research project and provided them with the inclusion/exclusion criteria for selecting the participants. Thus, the locality assessment was assured by the Consultant Urologist, and a vacant consulting room was offered in the Clinic for the interviews.

Concurrently, a support letter was obtained from the Senior Manager of Te Puna Kaupapa Maori Services, in case Maori men fitting the criteria were selected.

Sampling

As the focus of this study is related to the side effects of treatments for prostate cancer, purposive sampling was used to select men according to the following inclusion criteria: a) men aged 50 to 75 who are in their first year of treatment for prostate cancer; b) men able to articulate what it is like to live with prostate cancer; c) men who have sufficient conversational English; d) men currently living in the Bay of Plenty area; and e) men referred for the study by a urologist. The exclusion criteria were: a) men in watchful waiting where treatment is not administered; and b) men in terminal stage of the disease (because the research focus is not on dying).

Potential participants were identified by the urologist who suggested men that had a

robotic prostatectomy in the last year as the ones who best fit the inclusion criteria.

Then the research nurse from Tauranga Urology Research contacted six men and asked their permission to provide me with their contact details. I contacted them by telephone and the participant information sheet (Appendix C) was sent to them. Five men agreed to participate in the study and one declined without any reason given. I then used snowball sampling (Polit et al., 2006) because one participant suggested another possible man who was interested in participating.

Of the six men, five were white New Zealanders of European descent and one was South African. Five were married and one was divorced with a partner. Four participants were retired, one was still working part-time and another was self-employed. They are aged from 62 to 73 years.

In the process of getting ethical approval for my study, I was questioned by different people if, as a woman researcher and having a woman supervisor, I was able to make men open up details especially about their sexual life. Interviewing the participants I found how keen all of them were to talk about themselves and some of them mentioned that it is was easier for them to talk to a woman, than a man, about themselves.

According to them, this was because as a woman I asked more questions and took more seriously the details of their experiences.

Data collection

The interviews were conducted in either the participants' homes or in the Venturo Clinic. The length of the interviews was approximately 80 minutes and all were

recorded on a digital wave player. These recordings were then transcribed verbatim.

Before each interview we discussed the information provided in the participant information sheet (Appendix C), and I gave the participants an opportunity to ask more questions in order to clarify the confidentiality and aims of the study. Then I asked them to sign a Consent Form (Appendix D).

Sometimes, at the beginning of the first interview, the participants wanted to know more about my background in Brazil and very often they asked me when I moved to New Zealand and how I felt living here. I was comfortable sharing with them some of my professional and personal experiences because this kind of dialogue opens the possibility of 'being-with' whereby the basis of understanding is constituted. For some of the men, who were visibly nervous, this was a way to relax them.

I started the interviews with an open-ended question "How has the diagnosis of prostate cancer affected your life"? This was enough for them to start telling me their experience with the disease. Further questions were made based on the feelings disclosed in their speech and here my openness to listen to them played a fundamental role, as Heidegger (1996) explains "Listen to each other, in which being-with is developed, has the possible ways of following, going along with..." (p. 153).

I completed the first interviews in a relatively short time period because three participants had scheduled overseas trips to escape from the New Zealand winter. Due to the constricted time between interviews, I did not start a thematic analysis before the second interview. However, I read the first transcripts, and this allowed me to add more

questions to deepen the investigation, such as: “Can you please tell me more about this?” My intention was to lead the participant to rethink, to reflect upon his experience and come up with his own interpretation.

Although I did not try to direct the participants to any particular aspect of their experience, I encouraged them to dwell on some feelings in order to clarify their meanings by asking them: “How did you feel in this situation”? or “What does it mean to you?”

Sometimes, when telling me their stories I prompted them to make a connection between the story and the disease, which helped them to describe their experiences in different fields of their lives.

Analysis

As previously mentioned, I am fluent in English, though it is not my mother tongue. Therefore, the interviews were transcribed by a professional in order to provide an assurance of the verbal accuracy. I read through the transcripts while listening to the audio and took notes of meaningful pauses, laughs, and hesitations involved in a thoughtful speech. On reading the transcripts I focused my attention on nuances of words that can only be understood within a social and cultural context. Thus, I needed to check the meaning of idiomatic expressions and slangs, with native English speakers.

I started data analysis following the steps suggested by Smith and Osborn’s (2008) Interpretive Phenomenological Analysis (IPA) article, which I found very useful to guide me in how to start to make sense of the material I had collected. At this stage I

felt like looking at a blank canvas that I must reflect on, feeling somewhat lost. I asked myself “what am I doing here?” Then I contacted my supervisor who, in a very inspirational manner, assured me that I was on the right track because such feelings are part of this process which is fundamentally a creative one.

I approached each transcript by reading them several times, annotating on the left hand margin what I thought was pertinent to the study. I did not divide the text into units; rather highlighted sentences that I felt were meaningful descriptions of lived experience. At the same time, I was guided by the four fundamental existential themes suggested by Van Manen (1990) for reflection in the process: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality).

Then I went back to the beginning of the transcripts and, on the right-hand margin, I wrote my analysis of the spoken words and some interpretation using more psychological terminology, as suggested by Smith and Osborn (2008). These notes were aimed to be translated into possible themes drawn from the men’s experiences, as Van Manen (1990) states “Phenomenological themes may be understood as the structures of experience” (p. 79).

I listed the emergent themes title on a sheet of paper as they came up in each transcript indicating the participants’ pseudonyms in order to identify commonalities and differences. At this stage the hermeneutic circle of interpretation was very clear to me because I could see the parts making sense in the whole text and the whole text being understood by its parts.

Ethical considerations

I have employed a number of ethical principles highlighted by Polit et al. (2006) in my study that I believe were worthwhile in protecting the participants. Each of these principles will now be discussed.

Informed consent

After contact the possible participants by telephone, I send out the participant information sheet (Appendix C), which is written in plain, understandable language, avoiding technical terms in order to provide participants with information regarding the study. The participants were given time to thoroughly read it and after one week, I contacted them again and made an appointment for the first interview. Before the interview, the participants had an opportunity to ask questions, I asked them to choose a pseudonym to assure the anonymity of the study, and a consent form (Appendix D) was signed.

Beneficence

Beneficence is one the most important ethical principles where, as researchers, we need to minimize harm and maximize benefits. It is related to the principle of nonmaleficence which ensures that participants will not be subjected to unnecessary risks or discomfort. By being aware of subtle emotional distress that can be triggered when talking about sensitive issues such as incontinence and sexuality, I used my experience as a psychotherapist to follow the participants' feelings during the interviews. Only one of them, who is suffering from major depression, showed emotional distress; however, he

acknowledged emotional relief by sharing his experience with me.

Self-determination

This principle is related to the participants' rights to decide voluntarily to participate in the study and to withdraw at any time. This information is clearly described in the participant information sheet. Self-determination also means that the participants can decline to answer questions according to their own will. However, it did not happen in any interviews.

Self-disclosure

The nature of the study is fully described in the participant information sheet which gives the participant the right to refuse to participate in the study without giving reasons.

Justice

All the participants received similar preparation for their participation in the study in order to ensure that the same rights and benefits from the study were distributed equally. The right of fair treatment included the information sheet which clearly details the criteria for inclusion of people into the study; respect for a participant's decision whether to participate or not; participant's access to free confidential counselling support if required during the research process.

Privacy

In order to minimise the inherent intrusion into personal lives involved in research,

before the interviews I reassured the participants of the anonymity of their stories by taking the following measures: calling them by pseudonyms; informing them of the confidentiality of data, which will be in storage for 10 years at Auckland University of Technology premises according to Retention of Health Information Regulations 1996; the storage of material in a safe electronic system; and a confidentiality agreement signed by the transcriptionist (Appendix E).

Treaty of Waitangi

I have not included Maori men in my study because all participants were referred by the urologist who did not refer any Maori patients. However, this study may benefit Maori men by echoing their own concerns.

Trustworthiness and rigour

As mentioned in Chapter One, I am a clinical psychologist who majored in Existential Phenomenology; therefore, self-awareness and reflectivity guide me in understanding and interpreting human beings. Doing hermeneutic research expands my awareness of prejudices and biases accumulated in my experience of being a psychologist, which opens my possibility of understanding the other. Koch and Harrington (1998) pointed out that, in a research as an ontological project, our values, history and interests play a central role in understanding. Thus, I have endeavoured to reflect on how my personal and theoretical pre-understanding interacts with the data collection and analysis. I am also aware of positioning the identified themes in the literature reviewed.

In order to establish the trustworthiness of data, I have followed four criteria suggested

by Koch and Harrington (1985): credibility, dependability, conformability, and transferability (as cited in Polit et al., 2006, p. 332).

Credibility

According to Polit et al. (2006) credibility refers to “confidence in the truth of the data and interpretations of them” (p. 332). The trustworthiness of my study can be seen in my ability to understand and interpret a phenomenon as it presents itself. In other words, the way I analysed data is based on the meanings that emerged from participants’ discourses within a phenomenological existential framework.

Another important aspect I considered while interpreting data is related to the existential presence. Koch (1996) emphasizes that openness to existential presence is vital for a hermeneutic study which means “... being aware of body language and concentrating on the process of attentive listening” (p. 179). After the interviews I made notes of important observations such as facial expressions, hands shaking, tone of voices, brightness of eyes, whereby the unspoken words were revealed. I have also used knowledge from the literature to keep me engaged in the most appropriate criteria to this study.

To enhance the credibility of a study, Koch and Harrington (1998) suggest the return of data to the participants in order to authenticate the accuracy of data collected. I sent a copy of the transcriptions to three participants for their comments. The other ones, for different reasons, did not want me to send them the transcripts; two were overseas and one other thought it was not relevant to for him to read the transcripts. Only one

participant commented on the transcript saying “In total I think the transcript is a true reflection of our discussions” (Joe).

Dependability

To demonstrate the dependability of data, which refers to the consistency of data over time and condition (Polit et al., 2006), I made an effort to clearly articulate the analytical pathways taken, thus, “...others can agree or disagree or question the decisions that have been made” (DePoy & Gitlin, 2005, p. 251).

Transferability

I endeavoured to provide thorough contextual information of the processes involved in my study which I believe allow the readers to make comparisons whereby the data can be transferred to other contexts. There are many similarities in the lived experience described by the participants that can be transferred to other prostate cancer patients. Although considerable differences were reported, the meanings revealed from a male’s perspective can easily be echoed among men.

In this chapter I have explained the Heideggerian hermeneutic existential phenomenological methodology I used in my study. I also described the methods used in selecting, interviewing the participants, and how I analysed the data. I have stated the ethical principles that I believe are pertinent in protecting the participants in this thesis.

In the next chapter, Chapter 4, I describe the findings from the interviews as existential themes. I use quotes from men’s stories.

CHAPTER FOUR: FINDINGS

In this chapter the data will be presented as existential phenomenological themes revealed in the men's experiences using representative quotes or statements from the interviews. The interpretation of data describes my understanding of that experience drawn from the interview material. I will use the men's pseudonyms in order to make it easier for readers to follow their stories. The thematic analyses are as follows:

Disappointment: This theme describes disappointment due to the objectification of the body; the denial of the body as lived experience; disappointment with the urologist.

Being-a-man: This theme reveals how participants see themselves as men; sexual identity; aging and sex; being impotent; and redefining sexual life.

Sense of Control: In this theme men expressed how they approach the disease, experiencing a sense of control; how they deal with the unknown; loss of control; and embarrassment.

Life-threatening disease: This theme is related to how men deal with the diagnosis of prostate cancer as a potentially life-threatening disease; the denial of mortality in the decision-making process; considering cancer as a life-threatening disease; fear of dying; and the meaning of life.

Disappointment

In this section, the participants describe a feeling of disappointment permeating different aspects and situations regarding prostate cancer.

The denial of the body as lived experience

When the men found out they had cancer, most expressed a feeling of disappointment and a similar rationale for this feeling was given by all participants: they were fit and healthy before treatment. Here it is important to comment that although most participants are retired, they all stated that they led busy lives spending their time engaging in physical activities. They reported doing different kinds of sport such as riding bikes and motor bikes, playing squash, swimming, diving, and doing outdoor activities like gardening, hunting, walking, and travelling. In this sense, the disappointment reported by them can be understood by the way they see themselves.

For example Tom expressed his disappointment thus:

I was disappointed when I got the phone call to say there was signs of cancer, because I didn't think there was much wrong with me. I was surprised that I had it, because I think I lead a fairly healthy life I thought well, you know, won't get it or shouldn't have it but, that's not the case at all. I thought because I was fairly fit and healthy that I wouldn't get it, but yeah I'm not different.

Although he expresses surprise at being diagnosed with prostate cancer, he was having checks on the prostate for the last two years because it was enlarged, which means that he knew there was a chance of having the disease. However, not seriously taking this possibility into consideration, Tom's disappointment seems to be related to how he sees himself, which means he is disappointed with himself. It can be seen in his next statement when asked if he sees prostate cancer as a life-threatening disease:

I've always been concerned about getting cancer. I've had a crook stomach for a couple of years and I kept worrying that it was going to be cancer.

He clearly contradicts himself with these two statements, which can explain his disappointment. Tom does not pay much attention to his own thoughts and concerns which leads him to frequent denial of his body as a lived experience. His avoidance of thinking about his experience with the disease indeed increased his disappointment throughout the process. It can be exemplified when he realises that, although he feels he is fairly fit, young and healthy, his body does not respond as he expected:

I thought well let's get it done (the operation) so the body will be easier for me to get over the operation.

Then he became very disappointed when he started to realise that incontinence and impotence will take much longer to deal with than he supposed. He says:

My body's healthy, it won't take that long but we're still yet to see, yeah. I am starting to get a bit itchy now, you see. Bit concerned about it.

In this situation, the disappointment is revealing a need to look at his body differently because it is reacting in an unexpected manner which requires him to be more involved with the changes. His resistance in acknowledging, for example, the recovery as a process causes him irritability, or, in his own words, “get a bit itchy”.

Tom repeats several times that he did not worry about the disease at all; however, he contradicts himself many times. The contradictions show he is trying to deny his own concerns due to his difficulties in dwelling on them. For example, he believed that once the tumour was operable he would get rid of the problem. He was relying on “take it out, get rid of it”, and therefore there was no need for him to think about it. He shows a rational approach by saying:

I knew that it was operable and they could do something about it. So I wasn't concerned about it at all. It never worried me. I thought well, they'd just take it out and get rid of it. End of story!

He thought that the operation was a complete solution to the disease (end of story), thus, he did not need to consider the possible side effects of the procedure. Tom says “couple of months things will get back to normal again”, meaning that he was unable to see the long term consequences of the procedure in his body as lived experience. Here it is important to point out that, although he is in the mid 60s, this is the first operation he has had in his entire life, though he cannot elaborate his feelings about his experience:

I don't dwell on it, I don't stop, and that's probably why I keep myself busy, so I don't think about it too much.

In this statement we might reasonably deduce that 'keeping himself busy' is a manner he found to defend himself against his own thoughts. It is because dwelling on his thoughts leads him to expand his body awareness, which is exactly what he is avoiding because it implies the presence of a threat. The same will be noted in the theme related to sexuality where Tom is struggling to deal with sexual dysfunction.

Shamus is another participant that reports self disappointment when diagnosed with prostate cancer and with dealing with incontinence because he was very active. He says:

That was a thing that I couldn't sort of handle being a person that haven't hasn't had any difficulties as far as that was concerned. In my life, I've always been pretty fit all my life and I like working in all like that. I like getting out in the garden, keeping fit.

His disappointment can also be considered as a kind of denial of his body as lived experience because he had melanomas taken off his body many years ago, and also he was having some symptoms (difficulties in urinating) of prostate cancer prior the diagnosis. Therefore, there were signs in his body showing that some changes were occurring, however he did not pay attention to the symptoms. When asked how he is dealing with the body's changes after the operation, such as incontinence and impotence, and whether these changes made him more aware of his body functions, he did not understand my question. When I explained to him that there are some activities, for example lifting, that can trigger incontinence he replied:

That kind of thing didn't cross my mind. Will I be able or, should I be doing this. Because one can get pig headedness and think oh no I can do this.

'To get pig headedness' is just a clear statement of being resistant to recognising the limits imposed by the side effects of the disease which can lead him to feel the disappointment with his body. It can also be illustrated when he stresses many times

that the pelvic exercise is very important to help improving incontinence. However he did not do many of the exercises and his rationale is:

I think I was a little lazy about it. I had my mind somewhere else and sometimes I wouldn't do them (the exercises).

Without paying attention to the body as embodiment (I had my mind somewhere else), where the body is not separated to existence, one objectifies him or herself (Gadamer, 1996). This can be seen in Shamus description of prostate cancer:

You (the researcher) asked me before 'how did you feel when you found out that you had it?' The thing was: get on and fix it! Just like a broken car you got say don't weep, got and fix it up.

Comparing his body with a broken car shows his view point about his body as a mere machine where there is no emotion involved (don't weep) and, as a result the disappointment was extended to his relationship with the urologist. By being unable to recognise his body as lived experience, he was unable to identify his own needs and address them to the urologist. He tells what happened when he went to see the urologist:

When we went to (urologist) I didn't know what kind of questions to eventually ask. I was like that expecting him to tell me.

This quotation exemplifies another theme: disappointment with the urologist. Shamus expected the urologist tell him about his own body because he does not count on his perception to see what is happening to him. In other words, his body awareness is connected to the knowledge of how things work, in a mechanical way. He says:

I am a person that likes to see things in picture form, no reading. If they had a diagram just say of your penis, your testicles, your prostate, your bladder and all like that and then saying well look, this is your prostate, this that and everything else... and what we do is, we insert the camera down here, we cut there and we take that piece out and then we join those two pieces... then do your pelvic exercise to build that muscle up in that part there.

This is a description of a sense of his body as bio mechanism in contrast to living body as “an expression of a conscious life, a stream of experiences” (Heinämaa, 2006, p.

504), which explains his need of someone or something outside of him to tell about his own health. For example, his wife tells him to watch out when he is working, the information about the disease he got from a friend who had the same operation before him, and regarding prostate cancer he made this comment:

They have ads on television about these women going for their checkups and all their scans. What about for men? Why don't they do it for men? I'm not a male chauvinist, but I think if they can do it for women, hey let's do it for men too.

In this sub-theme the men revealed their attitude towards having cancer as a self-disappointment, raising the question 'how can a fit and healthy body get cancer?' They also experienced difficulty in recognising their body as embodiment.

Disappointment with the urologist

Another situation in which the participants described disappointment was in their relationship with the urologist. Most of them refer to the urologist as a very good professional, the best surgeon, and very confident in his own ability, who gave them a sense of being in safe hands. On the other hand, the participants complained of a lack of communication and lack of time spent with them. The participants made the following comments:

The doctors were using big words... the urologist is a hard man to talk; he is always in a hurry. (Tom)

The urologist thinks that you know everything about the complaint. Well, he knows about it, don't they? Although they don't say it. (Nor)

All he (urologist) wants to do is take it out. He says 'you've got cancer, I will remove it'. Well, how to do that? So then he gets annoyed because I am wasting his time. (Mac)

I was disappointed when ... told me about the prostate and he told me the reading. It was just an everyday occurrence as far as I am concerned. (Shamus).

These comments show participants' needs to have a normal conversation with the urologist where their concerns can be addressed. By being in a vulnerable condition,

imposed by the disease, they expect the urologist to be more engaged in their particular situation rather than in the disease itself. As the urologist's focus remains mainly on the process of cure, they felt their human condition denied. As a result, Joe's experience illustrates the disappointment reported by them. Joe had a very disappointing experience with the health professionals because although he had treatment for kidney stones and complained of severe pain and blood in his urine, he was sent home with an undetected prostate cancer. This makes him feel angry:

I'm angry. He (the urologist) let's me walk out of his surgery with undetected prostate cancer. If he did his job it would have been diagnosed early. He didn't that, so I'm angry about that.

As a result of not being diagnosed and being dismissed by the urologist with his own concerns, he is facing severe depression. He could make sense out of the disease because he believes "cancer can be instilled in you the day you are born, in your DNA or genes", but he could not make sense of the doctors' attitude and actions. Therefore, he considered the whole procedure to be lacking in professionalism and care for patients. He tells how he feels:

I'm still angry by the lack of support and involvement and the unprofessionalism of the urologist. One walks out of here (clinic) feeling you've been treated like cattle at a meat processing plant. You're just part of the process, your health is not very important. The doctor gave me the impression he just wants to get the day's work done and he's not considering me.

Joe's disappointment with the urologist due to a lack of care of his own concerns regarding his body perception and also his emotional state, led him to feeling denied and alone in an uncaring situation as he states:

I'm really disappointed! I don't expect to be that special, oh you have prostate cancer now, and everyone must jump around and look after you. I'm not that special but really I'm a human being, I also need some help somewhere. Here in New Zealand there is no emotional support, no, nothing. My doctor nobody even said to me look you may suffer depression, anxiety, expect it, there's no surprises. When it happens you should see so and so forth you should come and see me.

Here one can recognise his need for emotional support, but he also explains what makes him particularly angry with the urologist in this sentence "expect it, there's no

surprises”. Joe cannot handle uncertainties that disclose the vulnerable situation he is in. He shows that prostate cancer is a constant threat in his mind when he told me that “now I live with the disorder in my head all the time”, and he blames the urologist for not being able to alleviate his anxiety thus:

What I hate are surprises and uncertainties. I would rather, I would be more comfortable if they could tell me you have two years to go, you have one year to go, but nobody can do that.

Given the inherent uncertainties, described in the literature review, that are involved in prostate cancer disease (Madjar & Tingle, 2008), and also the controversial aspects pointed out in different opinions regarding treatments choice (New Zealand Ministry of Health, 2008), these uncertainties can be an issue for patients, especially for Joe.

Talking about his anger he tells:

You go on and on, you get different advice from experts contradicting advice, that leaves you in doubt, that makes me angry. Why don't professional people who study the same subject, why they give you different advice?... I'm angry because people didn't do their job and then afterwards I feel I'm out of the dark, there's no support really. That is basically where I am at the moment. That makes, the counter effect of that is that I am constantly depressed.

In this account Joe clearly attributes his depression to the urologist's lack of support rather than his own difficulties in dealing with the uncertainties. However, what can be noted here is that the depression reported by him was triggered by a combination of both doctor and patient, due to a lack of dialogue. For instance, Joe has a strong need for security, which explains why uncertainty is unbearable for him and makes me wonder if sharing his anxiety with the doctor would help him to deal with disease in a more tolerable way. The following quote exemplifies Joe's need for security:

When I was younger honestly I considered myself bullet proof. Illness and dying was not part of my plan. It was no part, and this may sound stupid, everyone should think about these things. I am insured, I have life insurance, I have money in the bank to take care of my wife. So I've made provision, just in case. But I didn't make provision for prostate cancer at the age of 60.

Throughout Joe's interviews I noted embedded in his experience a strong fear of dying triggered by the disease, although he is not fully aware of this feeling. This will be

described in more details in the themes: sense of control and life-threatening disease.

Although all participants expressed some degree of disappointment with the urologist's attitude regarding communication and time spent with them, I noticed their reluctance in talking about it. Most of them enhanced the urologist's skills in a way that seemed they do not have the right to complain against him. For example, one participant commented that the urologist "could have a bit more bedside manner" and immediately after his comment he looked at me and said:

It's just between you (researcher) and me alright? I don't want to get off side with anybody, I don't want you (researcher) going back to him...

This is a significant example which clearly shows the participant's apprehension of disclosing his feelings. This can be understood in the participants' gratitude to the urologist at being alive. Mac also gives an explanation of this attitude towards the urologist thus:

Nobody wants to suffer. That's why the medical professionals have such a hold on people because they're the only group who can ease your suffering.

Another possible explanation that can be inferred in their unspoken words is a fear that they might need the urologist again.

Being-a-man

One significant aspect that I was interested in exploring in men's life is related to how they see themselves as a man and whether their perception of themselves can be altered when living with prostate cancer. Therefore, I started most of the first interviews by asking: "how has the diagnosis of prostate cancer affected your life?" Most participants responded to this question by telling me about the disease itself although interestingly,

Nor made a connection between manhood and prostate cancer straightaway. He says:

Because quite often you are considered invincible, nothing's going to happen and then along comes a little old cancer. Oh I think it's probably the male, maleness of it that does affect you. Because you can't father children, which you don't want of course. So part of it is your male virility is gone.

Although he makes a connection between maleness with the possibility fathering

children, my reflections raised more questions on how his manhood has been affected.

For example, he considered himself invincible, meaning nothing can beat him, and then

he got beaten by prostate cancer. How does he cope with this? When I asked him 'what

does it mean to you to be a man?' He answered:

Well in my case I see myself as an engineer; I can make things, support the family, and all those things. I feel like I'm a warrior and if I had to I'm a fighter.

This statement makes me wonder of what kind of impact prostate cancer can cause in a

warrior or a fighter? Even though he also said, "You do feel less of a male through the

fact that you can't father children", deepening my reflective analysis on the word

virility, it shows its manhood meaning is related to sexuality. According to the Reader's

Digest Universal Dictionary (1988), the word virile means "Having qualities

traditionally associated with men, such as strength, vigour, or, force. Of or pertaining to

male sexual functions" (p.1676). Taken in this sense, Nor's statement discloses his

maleness has also been affected by the cancer due to the fact that he is facing sexual

impotence.

Sexual Identity

After prostatectomy, Nor reports his sexual life is in transition, where some

contradictions can be seen. For example, he is the only participant that reported sexual

desire altered after the operation. He says:

You don't seemed so interested in sex as you were before which could be a good thing in some ways, you've got so many other things to occupy your mind.

It is because he has a strong belief in spirituality where he draws his inspiration as a mystic. Therefore, he believes that “too much testosterone puts you on other paths, other interests, but not spirituality”. He explains that, according to his beliefs, if he is unable to have sex anymore he can dedicate more to his spiritual life because:

That allows you probably be clearer in your meditation because you're not thinking of other things.

He is inferring that sexuality is linked to the hormones produced by the prostate gland which is considered as a mere chemistry mechanism view point of sexuality, rather than an expression of the body as lived experience. On the other hand, he stresses many times how important sex is, and how he always enjoys his sexual life as an expression of affection, as seen in this quotation:

Sex is really a very, very good bonding between man and woman and it's the glue that holds everything together. And it's a very nice feeling and you're slapping up to someone and just enjoying being there.

These two contradictory statements where he puts sexuality as chemistry and sexuality as bonding shows his conflict in dealing with impotence. On one hand he says that prostate cancer “takes your mind off sex”, on the other hand, he comments:

When you can't get an erection after that (operation) and you think oh my God, it doesn't worry me, it doesn't worry me but, I'm not as randy jumping all over the place, there's all these questions. Um, give me the Viagra's two, three so um I'll do that.

Here we can see his oscillation between two extreme situations: the denial of sexuality (it does take away the sexual urge), and a sense of despair facing impotence (give me the Viagra). The ambivalence shown in his approach to impotence, makes me wonder whether the altered libido reported by him is due to the diminished masculine hormones or due to his inability to bear frustration which will be described in the theme: Sense of Control.

Reflecting on my initial question about the possible impact the prostate cancer caused to his maleness, which has the potential to frustrate his identity as a sexual being, makes me ponder whether he is using denial as self defence to protect himself from considering impotence as a long-term consequence of prostate cancer. Facing sexual impotence as a side effect of treatments, all participants to a certain extent, expressed changes in the way they see themselves as men. Although they knew about sexual dysfunction after prostatectomy and brachytherapy, once they started dealing with impotence, a different scenario appeared.

Similarly to Nor's experience, in Mac's interviews, the theme of sex is predominant as well as contradictory. Mac told me about how he enjoys an active sexual life, and before the operation he was quite happy having sex twice a week or even more. Despite the fact that sex has been a very important and enjoyable part of his life, he repeatedly states that being impotent does not bother him. Urinary incontinence was his main worry and being able to carry on with his busy lifestyle is his priority. He says:

It doesn't bother me the fact that I cannot have sex at the moment because it's not on my list of priorities. It's more important that my lifestyle continues.

When asked about sexual desire Mac says that nothing has changed "the visual stimulus is still there, just means there is no reaction, you don't get an erection". Then I asked if he gets frustrated and he commented:

No too bad. I've only just had the last blood test and find that I'm clear and everything. So at this stage I'm just pleased to be healthy, continent and I have a fairly busy life so I don't waste much time bothering about it.

Here it is important to note that five participants in this study had prostatectomy in the last six months which means survival is their main concern and sexual impotence is still seen by them with a hope of improvement, which explains why they reported not being

much worried about it. However, the aim of my study is to disclose and describe the means by which they deal with impotence as a possibility.

The participants were told by the urologist that it would be something like 18 months before they could get an erection spontaneously, but three months after the initial intervention they could start trying different treatments for impotence. Thus, Mac has tried the pills (Viagra, Cialis) which did not work for him and he is now going to try the penile injection. If the injection does not work, he will have an operation to have a penile prosthesis.

At this stage of interpretation I found myself intrigued by the contradictory statements made by Mac such as “I might have had a high sex drive”; yet, when asked if sexuality is related to male identity he answered;

Maybe more for younger men than 70 years olds. I don't have any problem with that area because I'm already fitter and busier and doing some interesting things than most men my age. So I don't need the sexuality thing for my ego.

I interviewed Mac just three months after of the operation and the question I wanted to clarify was: how in just three months time has his sex drive changed? The explanation is

in this statement:

I could manage the way I am (impotent) for the rest of my life, it doesn't bother me (Mac).

Wondering how Mac could manage such a dramatic change, I understand the reason he is considering different treatments to recover potency, including a penile prosthesis which is usually the last medical treatment to be tried. The possibility of recovering his potency by mechanical devices creates a feeling of control of the situation as he states:

Basically life is back to normal. The only area it impacts on now is sex, and that's a small part and we (he and his partner) have that under control, so it doesn't bother me.

This sense of control will be explored in another theme.

Aging and sex

The participants in this study mentioned the possibility of sex diminishing with age, but when questioned about their sexual desire, and talking about the possibility of sex after the operation, they reveal altered rather than diminished sex activity. To exemplify this, Shamus, who is in the early 70s, reported being able to have an erection before the operation, and then he tells what happened:

Before the operation I thought, and my mate told me too, there is no sex after that... I built up in my mind that that's it! But then again now it was amazing when (urologist) said to me 'you can have sexual life' and I said I thought that's all finished.

The urologist told him about the treatments available to recover potency, which gave him some hope but also triggered a conflict between denial and acceptance of his sexuality. This conflict started many years ago when his wife decided to finish their sexual life without any apparent reason. It is remarkable how he kept the marriage and dealt with his sexuality, as he told me that he felt denied as a man because they were not old at the time. When we talked about a possibility for him to be with a woman he said:

I'll stop and think, look at some of these old guys that are fussing around a nice young bird and I think oh you dirty old man! Get over it, sort of! I enjoy life so the thing is, as far as I am concerned, I've had myself. That's all you've got to think of nowadays. I enjoy life!

Here we can understand why it is difficult to him to accept that his sexuality has not changed, because if he discloses his sexual desire he can be considered “an old dirty man”, which he cannot handle as he also told me that he has always been “a bit of fanatic with cleaners”. The conflict is very clear because his wife refuses sex and for him to go looking for a woman, in his own words:

You'd be classed as a dirty old man.

This explains his need to hide his sex desire, which can infer that it has not yet finished.

When asked how impotence affected him as a man, he explained:

I think to get to an age I am now, it (impotence) used to worry me, the action, everything like that, when it wasn't there. But now I've got over that, it doesn't worry me one little bit.

In other words, now he can accept the possible link between impotence and aging, but when asked if he has an opportunity to have sex again using medication or mechanical devices he says:

That's exactly right! I'm a man!

Shamus's statement illustrates the link between sex and being-a-man. It sounds like a natural connection embedded in their concept of being-a-man.

Being impotent

As described above, sex plays an important role in the men's lives in terms of how they see themselves as men. Thus impotence can be an issue, as it has the potential to affect the self because it goes beyond the physical impairment. For instance, dealing with the possibility of having their potency recovered within 18 months, as mentioned before, causes them anxiety. Tom tells of his experience about the expectation caused by such information:

At the start it was never said that it (impotence) would take 18 months. They say after 3 months you might find this happen and I thought well, I will come right. Same with the water works. When they said that you're going to have problems having an erection I thought well, I was fit and healthy and it will come right but, yeah it's starting to drag now.

From here I wanted to explore the depth of the anxiety disclosed in his words "it's starting to drag now", where he is referring to something that needs time to occur, i. e., the lived time. According to Van Manen (1990) lived time is "our temporal way of being in the world" (p. 104) which means it is related to our inner perception of time in contrast to chronologic time. Within this concept of lived time, Tom's expectations in

recovering his potency leads him to experience anxiety. This becomes clear when, following his statement above, I added this comment “which means you have to be more patient. Are you patient?” And he answered:

Ah no, no, not really, no, no. If I want to do something I like do it then when I think about it that's it. But yeah.

The purpose of my question was to elucidate the word “patient” in its ontological meaning, as the Reader’s Digest Universal Dictionary (1988) explains “capable of bearing affliction with calmness” (p.1134). Thus, Tom’s answer reveals his difficulties in understanding his current experience with impotence as embodiment (see p.50) and temporality. This can be seen in his following statement:

The sexual problems going on for so long, I thought well, as I said, I thought I'm fit that won't to be a problem, just shrugged it off, oh well we'll get through all of that. But now it's starting to catch up with me.

To give a better idea of how he is dealing with time, I interviewed him just three months after the operation, when the recovery processes of urinary incontinence and sexual dysfunction have just started. At this time, Tom is already experiencing a sense of being impotent in its existential meaning. This I noted when Tom told me that he has tried to stimulate himself and nothing happened. I then asked: “How does it feel?”:

I'm disappointed. I feel there's something missing. I feel that it's not right that you can't have it.

This account (something missing) exposes a feeling of being lost where his male identity is affected to a certain degree where somewhat of self pity is disclosed (it’s not right). Here is the point where the sense of impotence transcends the physical act as he says “I would like to have a bit of action” and his inability to act, leads him to despair.

The despair was revealed when the sex therapist explained the medical treatments for impotence, which scared him. It is because Tom considers himself and his wife ‘old

fashioned', as they never talked about sex and, regarding mechanical devices, he calls himself naïve as he never heard about them before. He explains what sex means to him:

To me having sex is something that you do with your partner and you just do it, sort of thing. It's just a natural thing to do but to have artificial things to do, no I don't. But I don't know, I mean what is going to happen in twelve months if I can't. I mean, I might be desperate.

Facing impotence as the end of sex life leads him to despair, but at the same time, pushes him towards other possibilities to recover potency such as trying the pills and having a prosthesis implant. This is because of the meaning he attaches to sex:

Got to have it! It's not the end of the world if you can't but it's still very important. I still think I'm young enough to be able to have sex. I mean when do you stop? I mean that! I get told all the time I've got to grow up because I'm out doing things all the time, I like to be active. Yeah, that's choice of life, pleasure in life. I'd still like to enjoy that.

To him sex is a natural component of being-a-man (got to have it) and he makes an interesting link between sex and active life where pleasure and enjoyment come together and must be lived regardless aging (when do you stop?).

Redefining sexual life

As we live in a highly sexualized society, driven by explicit or implicit social rules, there is an assumption that males have to perform penile-vaginal intercourse as a 'real' sexual activity. Thus, after prostatectomy and brachytherapy, facing sexual dysfunction, men have to redefine their notion of sexual activity. In this study, two participants were able to put forward the possibility of continuing their sexual life without sex as penetration. For example, answering how the operation has affected his sexual life Ray says:

I suppose to a certain degree, there's no actual physical sex if you like, there's always the cuddles and everything else that goes with it so, we've had a good life at it so, we're not going to spoil it now by saying I can't do it and she's not going to say well I'm desperate.

Ray refuses to try any kind of pills or devices to recover potency because it does not bother him or his wife. Before the surgery when the urologist suggested treatments for

impotence he said:

I have no need for tablets. I'm quite able to supply everything I need to supply, even at 70. My wife has understood I've never had that problem and I never did.

In this statement, Ray shows a sense of pride of being able to count on his own resources to provide him and his wife with a sexual life. This is further noted in his response to the question about the meaning of being a man:

Um, not really thought about it. I'd say... I had improved at the skills I've got so, I've got my own back. I've not got somebody else's back. I'm not a product of somebody else's training. I'm a product of my own training.

This can explain his refusal of treatments for impotence. On the other hand, he has been married for 45 years and he reported have a good sexual life with his wife. Therefore impotence is not a problem because it does not finish their sex life. Moreover, the libido has not changed after the operation, as he tells:

Libido is still there. That doesn't change. Not when you have a good wife. When you have a good wife these things don't bother. You do things you've done for years. There's only one thing you can't do and that's penetrate. That's only what 5%, 10%? There's a 90% ex, 90% there still available, still gets pleasure.

In this account, he stresses the important role the wife plays in redefining sex and also the way they approach sex as loving making rather than a mechanical act where penetration is a sine qua non condition.

Mac is another participant that reported a possibility of continuing to enjoy sex without penetration. The difference between the two participants is that, as mentioned before, Mac is eager to try all sorts of devices to recover potency, whereas Ray shows no interest in these devices. However, a similarity between them is that both are in a good relationships where the wife/partner gives them important support and they take their wife/partner into consideration when deciding about sex. Mac says:

I'm very keen for it (potency) work again, but perhaps, if my partner was not handling it well, well then that would worry me too, but at the moment I'm keeping her so busy that we're not too worried.

Mac relies on his partner for support, and this can be seen in this description he made of sex life:

In my experience sex is not just all about the actual sex act. A lot of it is the company, if you like. So the focus shifts more to the companionship if you like, rather than how many times you can have sex in a night or something like that.

Then he exemplifies touch as a means that gives pleasure and makes him happy as well.

The ability to redefine sexual life can create different meanings in their relationships which gives them more possibilities to deal with sexual dysfunction.

Sense of control

Due to the fact that some prostate tumours grow very slowly and are asymptomatic (American Cancer Society, 2008) most participants found out that they have the disease, by 'accident'. Three participants reported some kind of clinical symptoms. For example, Tom was in treatment for an enlarged prostate when the doctor made a diagnosis of cancer. Likewise, Joe and Shamus had presented urinary symptoms of the tumour, although none of them connected such symptoms to cancer. Thus, when they found out about the cancer, they experienced shock, surprise and disappointment (see p.48) and a sense of loss of control over their lives permeates their discourses.

The unknown

By not getting enough information about the disease from the urologist and an opportunity to discuss their own concerns, the participants experienced being in an unknown situation where they had no control. Thus, the first step they all took to try and regain a sense of control of their new situation, was to inform themselves as much as

possible regarding prostate cancer. This was done mainly through searching on the Internet and talking to other men who have or have had prostate cancer. Even for Ray, who says that the urologist was very good because he explained ‘pretty well’ what happens and what was likely to happen, searching for information was very important:

As soon as I got the thing that I had cancer, the obvious thing is to go to your computer. I went to Europe, I went to the States, went to Australia and different people, different countries, different stories on how it was done. You know, generally they (the doctors) say it (the operation) is pretty safe but, there is always a but.

According to Ray, everything in life is just a matter of education, as he says:

If you go looking for information yourself then you’re prepared for what you’re going to get.

In this statement he indicates that to be prepared for something entails a sense of control in contrast to being in a vulnerable situation facing the unknown. Then Ray said that he has accepted what happened to him because:

Fear of the unknown is lack of education. If you educate yourself on what has actually happened, or what will happen, or what would happen, then the fear disappears.

Here Ray expresses that education is the means whereby he gets a sense of control over the situations he might confront. The knowledge gained from that education is fundamental because, as he states, “education teaches you everything”.

Ray uses the word “everything” very often in describing any singular situation, which makes me wonder why he needs to attach such sense of control to education. There is a linear view of cause and effect in the way he explains the process of the treatment. For example he says:

Because they are educating me on what this result (the PSA test) was, what could happen, what needed to be done and made a decision on what had to be done.

Ray shows a pragmatic approach to the disease where the final results of the operation (the PSA test came back zero) justifies everything, so “problem solved, simple as that!”

Thus he says frequently that he does not worry about anything, because based on the final test results, the doctors have “proved” everything they said about the procedure. Ray’s view point is in accordance with the scientific approach to the body as a material thing distinguished from the body, rather than as a phenomenon of lived experience. In his words:

The final test is the answer you want. So if you can work that out in that way, then the rest is immaterial.

He stands in this approach because it gives him a sense of “total control” of the situation; otherwise he will need to confront the ‘immaterial’ phenomenon that he is trying to avoid: fear of dying. This will be understood in the theme of Life-threatening disease.

Nor is another participant who cannot handle the unknown involved in a situation and this can be seen in his searching for answers. Although he gathered information from different sources and joined the prostate cancer support group, he continues saying that “my beef is that there’s not enough information”. Nor also wants something to help him “to handle the frame of mind”, which seemed to indicate a need for sense of control.

This can be observed in this example where he explains how the information has helped him:

I know the incontinence is improving all the time. It wasn’t when I first started off, oh my God what did he cut out? Whereas now I understand how things heal and what is healing and what he’s done, you know, makes more sense. But it’s the unknowing that creates some problems.

It can be understood that the “unknown” is seen as a threat by them in the sense that they cannot control what happens in an “unknown” situation. Therefore, the cause and effect linear approach suits them because it creates a sense of control.

Loss of control

Due to the described need for control embedded in the men's stories, when experiencing loss of control, feelings such as frustration, despair, and embarrassment were all reported. For example, one characteristic that stands out in Nor's interviews is how he deals with frustration related to a sense of losing control. He mentioned a strong feeling of anger he used to experience when things went "out of control", and through meditation he is learning how to manage feeling this way:

I think anger becomes a habit. Something goes wrong, you explode or you get grumpy. But if you then start thinking okay well something's gone wrong what can I do about it, and sit back and then decide what you're going to do. Eventually the anger seems not to come anymore. Although occasionally it does rise.

Thus, Nor shows how difficult it is for him to deal with frustration ("something goes wrong"), which means that something goes differently than he expected and leads him to get angry. Therefore, he tends to deny what he cannot control because he is aware of his inability to have total control of his feelings (occasionally it does rise). To exemplify this, he mentioned a fear of never again having an erection and to avoid this possibility he is reluctant to start treatment for impotence because:

You don't want to push the boundaries in case it doesn't work.

It is clear that he is reluctant to take the risk of trying something that might not work because he cannot bear the possibility of failure. The same has appeared in his conflict of dealing with sexual dysfunction (see p. 57). This can be inferred as avoidance, to prevent himself from being in a situation where he has no control.

Similar to Nor's experience, Joe is another participant who is finding it very difficult to take risks and try different things to improve the depression he is experiencing. This arises from the disappointments (already described, see p. 53) have which led him to feel a sense of losing control. Regarding seeking help for depression he says:

I don't really feel like taking any further risks to be honest, you know repeating the same experience.

Furthermore, Joe, reports losing control of his emotions or his normal behaviour.

Talking about the changes in his body and mood swings due to hormone therapy, he says:

It's a matter of losing control. Control of your normal behaviour. I need to be in control of my life, I know I can't control the illness, that I can't do but what I would like to do is control. Control my life.

To be in control of a specific situation, one must deny the possibilities involved there, otherwise control is not possible. In this sense, if one cannot count on the possibilities of, the unknown, the unexpected, or the unpredictable that can be encountered in the world, a breakdown is likely to occur. Joe's experience is an example of how this can happen. Being unable to deal with the changes that occurred in his life due to prostate cancer, he is depressed. This is clearly linked to his need to be in control, as he says:

I always had a lot of self confidence. But you lose a lot of that because the moment you learn that you have prostate cancer because being a confident person, I'm in control mostly, you cannot control everything, but I am mostly in control and all of the sudden you find yourself not in control.

Although Joe is aware that "you cannot control everything", a sense of being lost can be assumed here due to his inability to adapt to a situation which requires openness to the new, as he says:

Should I now change over to live for today and be grateful that I have this day and forget about tomorrow. Ah that is not easy, because this a lifestyle that I've applied all my life and now all of the sudden change over is not easy and I'm not sure that I am able to do that.

Understanding Joe's conflicts triggered by prostate cancer where a sense of losing control is evident, makes me look at the ultimate situation which human beings must confront without any control: the possibility of dying. As mentioned before, this is Joe's main driver from the disease, i.e., fighting against the possibility of dying. As he says:

My biggest problem is that my mental process in terms of dying, ah, how to go about it I don't

know, I don't know.

In spite of his comment above, Joe is not in a terminal phase of the disease, and as far as brachytherapy is concerned he is responding very well to the treatment. Therefore, his fear of dying is not related to the morbid concept of death, but it must be understood in its existential meanings, which will be explored in the next chapter.

Embarrassment

Reading and re-reading the interviews, I noticed very often a common feeling of embarrassment emerging from all participants when reporting dealing with urinary incontinence. According to the men, incontinence is considered the main issue to be dealt with, as they classify it a nuisance, inconvenient and an uncanny situation to be in. Furthermore, all of them stated that it is worse than impotence which makes me intrigued as to try and understand their rationale behind such statements because, at the same time, they put sex as an inherent part of being-a-man.

Deepening my reflections on their unspoken words regarding incontinence, the meaning embedded becomes clear: this is a side effect where they do not have any control over whereas dealing with impotence, at least they have mechanical devices whereby a sense of control is possible. Therefore, a feeling of exposure is a constant threat they have to cope with. I could easily find an example of these feelings in all participants' interviews (except Joe's because he did not have this side effect from brachytherapy), however, I chose an example from Ray's interview because his words sounded like a summary of a common feeling reported by the men. Ray states:

I think it's an embarrassment thing more than anything else... That's an embarrassment thing on my part, that I would hate to be walking down the street and something happens. You wear a pair of light trousers and suddenly... that would be embarrassed as hell to do that... if someone young

thinks silly old man or something like that.

The perception of threat associated with the risk of exposure by incontinence, led participants to make arrangements which gives them at least a slight sense of control; such as making sure they wear black trousers, having spare pads at hand and making sure they know where the nearest toilet is located. On the other hand, incontinence is a physical condition that requires a certain level of bodily awareness to be dealt with. This is because there are pelvic exercises that strengthen the muscles and help to improve them. However, most of the men mentioned that is difficult to remember to do the exercises, which I maintain, is related to their difficulties in recognising the body as embodiment. Shamus explains why it is difficult to him to remember to do the exercises:

They've (men) got to be told and it's got to sink into them.

Shamus is referring to their dependency on the other in helping them to be aware of their bodies. Tom expresses the same and although he stresses not worrying about the disease, he admits to being conscious of incontinence all the time. But, once again, he is referring to the arrangements already described rather than bodily awareness of incontinence, as he explains the reason he forgets to do the pelvic exercises:

Just always in a hurry or always got something to do and sort of, my wife tells me exactly the same. Have you been doing them? (the pelvic exercises).

Similarly, Nor reported 'forgetfulness' as a reason of not doing the exercises and also being busy doing something else. It becomes visible that "being busy" is a justification used by them for not paying much attention to their body as embodiment.

By contrast, Mac, who said "my biggest worry was being incontinent", regularly did the pelvic exercises and became continent in just six weeks time. It was amazing the

willpower Mac demonstrates that drove him to deal with incontinence, as he tells what he did:

They (health professionals) assured me that if I worked hard on my pelvic floor exercises I would be continent very quickly and I was because I wanted to be continent.

From Mac's experience we can assume that the pelvic exercises combined with his determination worked for him to become continent quickly. This was achieved by not denying his concerns about incontinence which awaken his body awareness. He knew that incontinence would be very difficult to tolerate, which opened the possibility of experiencing his body as a kinaesthetic phenomenon doing the exercise and also adapting his lifestyle accordingly to his condition. Thereby, he and his partner spent lots of time doing activities such as swimming and diving, where the risk of leakage was not a problem.

Another interesting phenomenon I could observe in Mac's story is that, although he has shown need of a sense of control, especially regarding his sex life (see p.59), this does not appear while he was dealing with incontinence. It seems that dealing with impotence he counts on an artificial mechanism to create a sense of control, rather than relying on his body perception. On the other hand, dealing with incontinence, Mac counts on his body perception which can be pursued naturally without need for control. Urinary incontinence is a health condition that can affect men's sense of masculinity due to the possibility of leakage while having sex. This concern has been reported by two participants who are postponing starting treatment for impotence until they become continent again. This is because shame can be a difficult emotion to bear, especially in a sexual situation.

Life-threatening disease

In response to my question about participants' rationale for the treatment chosen, two main reasons were given: to stop the tumour spreading to other organs, and to live longer. Although the men were able to logically articulate the advantages of having the prostate removed in order to stop possible metastasis, they did not speak much about cancer as a life-threatening disease.

The denial of mortality in the decision-making process

Considering mortality as an inexorable possibility for us as human beings, and prostate cancer as a potentially life-threatening disease, I asked the participants whether they thought about their mortality around the time of diagnosis. All of the men reported not taking it much into consideration when making a treatment decision. The reasons given for not considering the tumour as a threat to life, were all based on the scientific approach where the focus is on the disease itself. For instance, was the tumour operable, if it was discovered in an early stage and had not yet spread? These reasons also explain why most participants expressed a similar view of the disease: get rid of it, problem solved! Therefore, the procedure was justified, regardless of the possible concerns they might have, and they do not need to think about it anymore.

However, many contradictions were found in their discourses whereby their hidden concerns were revealed. For example, Mac says that mortality has not bothered him because "my quality of life however long it lasted was very important". Therefore, he did not think much about his mortality. Then Mac admits that the diagnosis was a shock but that mortality did not bother him because "this one (tumour) is not life threatening one". Afterwards given details found in his biopsy results he says:

You're not going to die if you do something. If you do nothing there's also quite a chance you'll get 10 years and it won't get any worse. But there's also a chance that in another two years you have secondary and then it's all downhill, it's horrible stuff.

Here Mac was indirectly talking about the possibility of having the so-called Watchful Waiting procedure where no treatment is conducted, instead of a close monitoring for progression of symptoms (Chapple et al., 2002). However, he did not want to take the risks involved in watchful waiting. At the same time, Mac is disclosing his concerns about mortality as the motivation behind his decision was “you’re not going die if you do something”.

In the same way, Nor also pondered the possibility of this procedure because there was only 5% of the cancer in his prostate and it was still confined to the gland. He explains his thoughts about this:

If I had my way I would have gone for the watch and wait but trouble is if it (tumour) jumps the barrier it would be into the bones... if it have spread I would have to rethink my mortality again.

By saying that he had to ‘rethink’ his mortality, Nor is stating that he has already thought about it and he is also referring to the implicit risk of dying embedded in such a process. However, Nor does not dwell on such thoughts as he states that his main drive regarding have a prostatectomy was to avoid pain and suffering from cancer, as he says:

It wasn't the aspect of dying so much, it was how.

Another situation where Nor mentioned that the diagnosis of prostate cancer led him to think about his possibility of dying, was in the beginning of the first interview, when he stated:

You probably realise that you've got a use by date.

Although Nor seemed to be aware of the possibility of prostate cancer as a threat, he does not address the possibility of dying while making a treatment decision and his

rationale is well supported by the scientific approach. He tells how he made a decision:

The suffering has been awhile. So that's why I decided to have the prostate removed completely and to be done with robotics because that's little less invasive and apparently they can see better because of the magnification of the lenses, and all that...

Nor stressed all the advantages of the procedure in a logical way, which gave him a sense of safety and justified the chosen treatment.

Ray is another participant who says that the decision-making process was entirely based on the test results and when questioned regarding how he felt about having cancer, he says:

Philosophical, philosophical is all the answer I can give you. These things happen. If not to me, to somebody else....so I made the decision to take it away.

For him, to get cancer is something that can happen to everyone, and to think about it is “philosophical”. By saying that, he is referring to a branch of philosophy called stoicism, meaning that he is not affected by the diagnosis because he considers cancer a natural event. However, denial can be noted in his words when answering what made him decide to have prostatectomy:

I said (to the urologist) how long if I don't get operated on. How long I got and he said it could take up to 10 years, it could be less. I said well, I've just had a new granddaughter I'd like to see her a bit more than 10 years if possible, I'd like to get rid of it.

Another relevant aspect where the denial can be seen is that Ray does not consider the tumour as life-threatening because it is just a problem to be solved. He says:

When you (the researcher) talk about dying and things like that, but, that's immaterial to the problem I did have you know, so it's just a case of that's it, deal with.

In this statement he says that the researcher is talking about dying, although I did not mention a word about dying. In fact, I asked him how he felt when diagnosed with prostate cancer and he made a connection with dying, which made me wonder how

aware he is of this link. Furthermore, his rationale to have the prostate removed based on 'live longer' can be seen in this account:

The decision is simple, do you live with it or do you die with it? I prefer living.

Considering cancer as a life-threatening disease

Although some participants do not deny cancer as a deadly threat, they cannot clearly articulate their feelings in this regard. For instance, when asked, if he thinks of cancer as a life-threatening stated:

Yes, I've always been concerned about getting cancer.

Although Tom discloses being concerned about getting cancer and his desire to 'get rid of it', his concerns were denied. He has been assisted by his daughter who is a nurse and specialises in cancer, and he passes the responsibility on to her to understand and explain to him almost everything about the disease; but not to address his concerns.

To exemplify this, Tom says that he did not consider the tumour as a threatening one because it was operable. However, when explaining what worries him about getting cancer, he reported that his father died with stomach problems. Then he told me that his father also had his prostate removed and his uncle died of prostate cancer, which can explain his concerns from a genetic point of view. Moreover, during our interviews Tom asked me questions such as "why does it (cancer) attack the prostate first?" and "if you have cancer in other parts of your body, they would still detect it in the PSA?" Here I can understand his difficulties in dwelling on his thoughts, because there is no room in the treatment process for his unspoken questions.

Similarly, in Shamus' experience, it can be noted that although he expressed feelings

like shock, disappointment, and being scared of being diagnosed with cancer, these concerns could not be addressed in treatment. His words reveal how this happened:

Cancer I think is a deadly thing and there was when I got the phone call from a doctor to say it was a cancerous and they had to cut it deeper and wider, that's when I've got a bit of shock. I felt, well I was a little bit scared, I think.

Here he was referring to melanomas he had removed from his back, before the diagnosis of prostate cancer. Then Shamus tells:

When this came up, the prostate, I don't think men like to talk about things like that, but I think myself the more the men talk about it, the picture, it is brought out.

In this particular instance, Shamus is showing the need for men to voice their concerns, but when diagnosed with prostate cancer he was disappointed by the way he was treated by the urologist who considered his cancer as just “an everyday occurrence” (see p.52). Therefore, the rational approach seemed to be the only one possibility to be taken into consideration in the decision-making process, as he says:

I think is more or less disappointed because you know you got it, so get on with that, Get it fix out.

When I noted that he was not denying prostate cancer as life-threatening, I tried to talk about the meaning of having such disease, but he could not verbalise it:

Well, it was so short from when I had it diagnosed, I didn't worry about it.

Then Shamus carried on telling me about the procedure, the biopsies and operation but said nothing about his feelings, even though he states that “it (cancer) was there but it didn't worry (me) at all”.

That is the similarity between Tom and Shamus' stories, albeit the threat was not denied by them, both did not have space or opportunity to express their concerns. What amazes me in the participants' words is the obvious thing that they seemed not to be aware of: the inseparability of life and death. One cannot be conceived without the other, but their avoidance in recognizing this inherent relationship, can be inferred as a fear of dying

which will be explored in the next sub-theme.

Fear of dying

The intellectual interpretation of the disease shown by men in this study seemed to indicate that they cannot incorporate their emotional reactions into their experiences, especially relating to their possibility of dying. It is due to the fact that the perception of the living body is impervious to a rational approach, therefore their feelings are not clearly disclosed. But an implicit fear of dying permeates their stories. To exemplify this, when I asked Ray whether the diagnosis of prostate cancer made him think about the possibility of dying, which he denied, he introduced the word 'fear' like this:

As I say it was a question of what had to be done. And after it (the operation) was done, what the end result was, both cases at the moment, the end result was excellent so there was no fear involved in that, no fear of dying.

Although he makes a clear connection between the possibility of dying, with fear of dying, he seemed not fully aware of this link. This can be assumed because deepening my question, I asked him if he had fear of dying and he answered:

No. It's probably the one thing you're guaranteed in life, dying and one's paying taxes. Only two things guaranteed in this life nothing else.

In my understanding, these contradictory statements are due to Ray's view of fear (see p. 59) which he relates to the unknown and it is likely to disappear once one gets educated on a specific matter. In this sense, a question emerged in my mind: how can a human being educate him/herself about dying? This goes beyond to the scientific approach Ray uses to prostate cancer. On the other hand, dying can be approached from a religious view, but he has no religious beliefs. Therefore, what parameters does he have to face the possibility of dying within the pragmatic view showed by him throughout his interviews? This probably explains why he cannot put dying into

perspective and his attempt to deny prostate cancer as a life-threatening disease.

Fear of dying and meaning of life

Considering prostate cancer as a potentially life-threatening disease compelled men to rethink their existence and the meaning of life (Abel, 2002). As Joe is the only participant who is consciously facing prostate cancer as a deadly threat, the fear of dying is the most prevalent conflict in his story. Although he is not fully aware of this conflict, such feeling leads him to search for the meaning in the new situation.

However, by not being able to handle dying as a possibility, the realisation of such inescapable reality makes him depressed. The avoidance in addressing such possibility in treatments aggravates his fear to a certain extent where he cannot see many possibilities in living as well. This can be observed in his answer to my question about why he cannot continue with his life as per normal:

Because in the back of my mind I know what is waiting for me... eventually it (prostate cancer) will kill me... the other thing that I realised the other day, even depression may kill me if I don't do something about it.

The impact of dealing with cancer as a life-threatening disease expands one's awareness of mortality and lack of emotional support and in such a situation leads people to experience life as meaningless. That is exactly what Joe feels:

Now all of the sudden yes you become aware of mortality... yes prostate cancer is a definitive possibility... I would like to regain the motivation to get up in the morning and do some work, some meaningful work and yes certainly to start believing in the future again.

Despite the fact that illness and death are inherent in human beings' lives, the men in this study showed a denial in thinking of such events because of the way they see themselves as "invincible" or "bullet proof". As a result, life loses its meaning when death must be put into perspective. This happened to Joe:

When I was younger honestly, I must have considered myself bullet proof. Illness and dying was not part of my plan. No, it was not part, and this may sound stupid, everyone should think about

these things.

Telling me that life is leading nowhere and he is not achieving anything, he states:

It (prostate cancer) sucked the meaning out of life.

As Joe became aware of his own mortality but, at the same time, being unable to find meaning in why he is living, makes him very scared of dying. This can be understood in the following example when he was telling me about a member of the Prostate Cancer Support Group he is attending:

One of the gentlemen since died and that is scary. Sit around the table, there may be 12 people there, next month you turn up there's an empty seat, that is scary. And you think about those things at 3 o'clock in the morning.

The question "who is the next?" can be assumed as part of his thoughts and fears.

Furthermore he gave two examples of men who died of prostate cancer, one of them committing suicide. He told me this when talking of being depressed and being unable to look at the future because of the uncertainties involved. Joe says:

Nobody can tell you how can you go, that's the uncertainty of course. There may be in and out of fear. I have seen people die of prostate cancer and a friend of mine, took a firearm, blew his brains out. And that was ugly to see. I wasn't present but because he could no longer stand the pain. So yes this is serious business. I am, I still consider myself a lucky one.

In this account his underlying fear is disclosed: the possibility of suicide if he gets to a stage where he is no longer is able to deal with the cancer. In other words, his fear is related to himself; he is scared of this possibility which can include suicide.

In this chapter I have described the four themes to emerge from the interviews:

Disappointment, Being-a-man, Control, and Life-threatening disease. In the process of interpretive phenomenological analysis, my stance as a hermeneutic interpreter of participants' stories, has meant that I performed a reinterpretation of their spoken words. In the next chapter I will interpret the emerged themes in more detail.

CHAPTER FIVE: DISCUSSION OF FINDINGS

Language is the house of Being. In its home man dwells. Those who think and those who create with words are the guardians of this house. (Heidegger, 1972, p. 217)

In this chapter I discuss in more detail the themes found in Chapter Four that represent the men's experiences and are pertinent to this study. These themes will be related to the ones in the Chapter Two, the literature review and I will also introduce further literature in order to enrich the understanding of the meaning embedded in the lived experience. I will use pieces of literature and poetry to allow Dasein shows itself, because, as Heidegger (1972) states:

The liberation of language from grammar into a more original essential framework is reserved for thought and poetic creation. (p. 218)

The aim of my study is to explore men's experiences with prostate cancer. Within Heidegger's interpretive phenomenology, my role as a researcher is to reinterpret the men's words and shed light to its meaning. Heidegger (1996) explaining Dasein, meaning being-in-the-world, states that "Dasein as discoursing being-in has already expressed itself" (p. 154); therefore, an interpretation based on the spoken words reveals 'who' and 'how' a human being is. In this sense, the interpretation of the men's stories is an existential analysis of Dasein.

Disappointment

In the major theme Disappointment, the men expressed how they understand themselves as men and how a feeling of disappointment permeated their descriptions in different circumstances. This data suggested that the disappointment expressed by the

participants was mainly with themselves, due to their inability to acknowledge their body as embodiment.

Although in general, the findings of my research echoed those findings of similar qualitative studies, I could not locate this finding in the literature, because research into men's health and masculinity in prostate cancer is more focused on masculinity as a product of social construction (e.g. Arrington, 2000; Chapple and Ziebland, 2002; Oliffe, 2005) and cultural construction (e.g. Broom, 2004). Even in phenomenological studies where the meaning of the body and lived experience were explored (e.g. Abel, 2002; Hagen, Grant-Kalischuk, & Sanders, 2007; Kelly, 2009; Ng, Kristjanson, & Medigovich, 2006), this finding has not been reported.

However, there are similarities between my data and data that I found in the literature. For example, in my study the men demonstrated a taken-for-granted approach to their bodies to overcome the operation and the side effects of treatments. Thus, they seemed not to be conscious of the changes occurring in their bodies which is considered by them solely in its bio-mechanical function. This finding mirrored a study of men's health (Cameron & Bernardes, 1998) where drawing on evidence from a prostate cancer group, the authors suggest "men tend to see the body as a machine... rather than emotions and feelings" (p. 682). Likewise, in my study, the participants compared their bodies with a broken car or machinery to be fixed.

The same finding has appeared in a phenomenological study by Hagen et al. (2007) where men, especially the older ones, denied that prostate cancer has changed them

because they considered the disease as “merely something to be fixed” (p. 214). As a result, they could not find meaning in their experience with prostate cancer. In my study, the data suggests that this denial led the men to experience a feeling of disappointment with themselves due to their inability to see themselves as embodied beings.

I was very surprised when interviewing the participants and I noticed that all of them expressed, a number of times, not being worried about anything regarding prostate cancer. Such statements intrigued me to an extent that drove me deeply into my journey trying to understand how a man can experiencing a disease like prostate cancer and yet state that he is not concerned with his body in such illness. At this point, I was very aware of my own prejudices as I believe that there is meaning in how we live. Further, experiencing our body in illness, requires us to expand our body awareness in order to situate us in what occurs within us, in a particular organ or part of our body. Van Manen (1998) gives a brilliant explanation of this by stating that “the conspicuous disturbance always possesses the character of an encumbrance, something that confronts us... when we sense something conspicuous then we tend to worry” (p. 11).

Therefore, I started to explore deeply the men’s feelings in a fashion where I could put my beliefs aside and listen carefully to their words. As Van Manen (1998), in an article about body experience in illness, superbly asserts that to understand what a person feels, sometimes “...we may need to suspend our belief in favour of the person’s experience” (p. 8). Thus, as the interviews progressed, the avoidance in thinking about the changes in their lives and bodies explained the reasons for their statements. At the same time,

through the contradictory accounts, the disappointment with themselves became clear. Gadamer (1996) states “the absolute inseparability of the living body and life itself” (p. 71), as an evident link, the denial of the body as embodiment revealed by the participants in this study, makes me wonder to what extent it can explain their rational approach to the disease. It is because men have shown an objectified view of their bodies instead of an experiential body being-in-the-world. The problem of the body viewed as an object is described by Merleau-Ponty (1962):

I cannot understand the function of the living body except by enacting it myself, and except in so far as I am a body which rises towards the world. (p. 87)

Since the men’s approach to the prostate cancer was primarily to get rid of the tumour, the perception of their own bodies as living body was denied; thereby, the objectification of the body took place. Merleau-Ponty (2002) explains, when one detaches himself from his experience one becomes an object in the world, because “I regard my body, which is my point of view upon the world, as one of the objects of that world” (p. 82). The risk in taking the body as an object, as Merleau-Ponty describes, is the denial of the human beings’ perception of their own body because such attitude “...causes us to lose contact with perceptual experience” (p. 82).

Listening to our bodies provides us with the answers of how we are in the world, and this includes our health. It is through our bodies that we conceive the world, not in a Cartesian notion of cause and effect, but where all our possibilities as human beings can be encountered. It is through our bodies that we can conceptualize our existence in terms of possibilities rather than a narrow view of casual relationships where the possibilities are denied and the body is seen as a mere machine, and human beings’ perceptions of the world is seen as relational between subject and object (Heidegger,

1996).

By not paying attention to their bodies as embodiment, the men's attitude regarding their body is in accordance to the scientific method of investigation which is basically concerned with measurements, and a phenomenon is studied in its cause-and-effect relationship. This causal relationship is based on Cartesian dualism where body and soul are split, and a distinction between subject and object derived from the famous Descartes' position in considering mind or soul as *res cogitans* (a thinking thing) and the body as a *res extensa* (an extended thing), allows the scientific method to not take any consideration of mind or subjects (Crotty, 1998).

The scientific method is the main approach used in medicine and one must recognise the remarkable development of medicine in the last century. But although the high technology employed in its procedure has dramatically improved medical treatment, the gap between its tools and the human being has increased accordingly. Gadamer (1996) explains how this gap occurs, stating that "Instead of learning to look for illness in the eyes of the patient or to listen for it in the patient's voice, we try to read it off the data provided by technological sophisticated measuring instruments" (p. 98). The same situation has appeared in my study where the participants reported that the urologist's focus was in the test results rather than in their stories. It is because most participants had a da Vinci Prostatectomy which is considered one the most advanced surgical procedures at the moment. Thus, the participants could point out the benefits of this procedure which gave them a sense of safety, although they complained of a lack of caring of their own concerns. It is because the urologist's scientific approach focused on

the disease itself, and a man as bodily being is not considered. Heidegger (2001) states “the phenomenon of the body as such (embodiment) is especially concealed to physicians because they are concerned merely with body as corporeal thing. They reinterpret (the body) as corporeal function” (p. 186).

In the literature review, Arrington (2000) points out the same issue in his study on sexuality among prostate cancer patients, where men were open to discussing their sexuality with the urologist, while the urologist’s focus remained on curing the disease. Although data revealed that both doctor and patient have the same attitude towards the disease, paradoxically, patients complained of lack of communication with their doctor, which may imply a need to have a more friendly relationship with the urologist. This finding supports the work of Hedestig et al. (2003) where participants described the importance of a close relationship with the physician.

This is supported by Gadamer (1996) who raises the question about our own responsibility, as human beings, to be able to address our concerns in a thoughtful manner in order to reconcile our being-in-the-world with the modern sciences that reigns in our contemporaneous world. This is a particular issue suggested by data where the participants were unable to discuss their concerns with the urologist, leading to a feeling of disappointment with the urologist.

The relationship between doctor and patient is broadly described in the literature review chapter which indicates a need to rethink the assumption that men do not talk about their feelings and concerns. In my research, in the sub-theme “Disappointment with the urologist”, the data suggests that identifying suitable interventions, such as open

communication about patients' needs and possibility for patients' concerns to be addressed in decision-making processes, can be very effective in promoting care delivery.

To make ontological care in medicine, employing the Heideggerian concept of facticity is fundamental, because it means that "Human life is always immersed in a specific situation and is involved with its surroundings in a very particular way" (Harman, 2007, p. 25). According to Svenaeus (2006), the concept is relevant to bear in mind, to avoid the scientific reductionism within the empirical science, because a human being must be approached in his/her wholeness. In fact, everything in everyday life has a implicit meaning and the clarification of its meanings allows the health professionals to elucidate the individual needs to be cared for in a specific situation.

Furthermore, the logical scientific approach cannot reach the depth of human being, as Nietzsche (1980) states:

Only people who are all too naive can believe that human nature could be transformed into something purely logical; but if there were degrees of approximation to this goal, how very much would have to be lost along the way!
(p. 39)

Being-a-man

As described in the literature review, there are few studies on the impact of prostate cancer on men as sexual beings: most researchers are focused on the quality of life. On the other hand, sexuality is also mostly described in the literature in its social and cultural meanings (e.g. Arrington, 2000; Broom, 2004; Chapple & Ziebland, 2002; Oliffe, 2006); rather than in its existential meanings. In my study the meaning of being impotent was explored, and the findings suggest the men's perception of themselves as men is somewhat altered due to the side effects of treatments, especially sexual

impotence and urinary incontinence.

Studies in the literature review suggest that a man's identity is linked to sexuality (Berterö, 2001; Hagen et al., 2007; Westman et al., 2006). My findings also show that the meaning of being-a-man has an inherent connection with sexuality. The altered view of themselves as men appeared in a number of other studies in the literature review, and data in my study add to phenomenological studies investigating how manhood and prostate cancer are connected. For example, due to the objectification of their bodies and the difficulties in accepting impotence which affects profoundly men's sense of masculinity, some men in this study showed a denial of their sexuality being affected by prostate cancer. This is because they reported hope of improvement from impotence, relying on what they have been told by the urologist, that potency can be recovered in the 18 months after the operation. In this sense, the men tend not think much about the possibility of being impotent and I interpreted such avoidance as a self defence against their difficulties in dealing with conflicts imposed by prostate cancer.

On the other hand, the denial of the living body makes it more difficult for them to position themselves in this new situation and find meaning. This can be explained because they had the surgery recently. Berterö (2001), however, reported in a study of altered sexual patterns after treatments, that the same hope of improvement existed in men who had had the surgery several years ago. Therefore, my data suggests that, embedded in this hope, there is an avoidance in putting impotence into perspective, and the avoidance can be explained in the way men deal with time.

While exploring how men deal with time in the recovery process of incontinence and impotence, the data reveals that the problem in recognizing their body as embodiment leads them to experience anxiety. This can be understood in the Heideggerian concept of temporality where “Being is comprehensible only on the basis of the consideration of time” (Heidegger, 1996, p. 62). Here time is understood in terms of temporality as a fundamental aspect where Dasein show itself in the world as a whole and where caring is possible. In other words, here time means the individual perceived time of lived experience in contrast to time measured by clocks or calendars.

Here, time implies the notion of the embodiment as a *sine qua non* condition of awareness of how we are and what needs to be cared for. Since participants in this study did not pay much attention to their bodies and approached the side effects of treatments as ‘something to be cured’. They projected the recovery of impotence, in particular, to the future meaning that they do not need to do anything, but wait until it comes right again. As a result, Waksler (2001) states “The promise of a cure urges waiting rather than acting to bring ‘normality’ to the on-going day-to-day process of living” (p. 81). This author suggests that embedded in a search for “a cure”, is taken for granted what is expected “to be cured”, which leads one to deny the possibilities involved in the process of cure to such an extent that one denies his/her own role in the process. Thus, in my study, data suggests that the participants are not aware of the roles they play in the recovery process as they do not show any action. Moreover, as they keep their focus on the future, evidence shows that they do not seemed to be attuned to the disease. Therefore, they do not count on themselves to find possibilities accessible to them, especially when dealing with sexual impotence.

This attitude is well explained by Waksler (2001) in a phenomenological approach to the disabilities' so-called 'medical conditions', where the focus on cure leads to the denial of the present where all the possibilities may be encountered. Waksler states that "It (cure) directs attention to the future and away from the present, away from the construction of lives out of the resources that people do have available" (p. 81).

The participants show the same attitude regarding the ongoing physical decline that naturally occurs with aging because of their attempts to keep themselves active and busy without considering possible changes in their body.

The men's attitude where the denial of the body as embodiment occurs, is to avoid anxiety and reveals a paradoxical attitude because data suggests that such avoidance is what leads them to experience anxiety. The anxiety revealed by data is understood in its phenomenological existential meaning rather than a psychological one.

In a psychological sense, anxiety is seen from mild anxious feelings in everyday situations to a large number of disorders such as panic disorders, phobias, and obsessive-compulsive disorders (American Psychological Association, 2007). Whereas Heidegger draws on Kierkegaard for the concept of anxiety where, as free human beings, we can make choices based on all possibilities we may encounter in the world rather than in the narrow cause and reason deterministic approach. Thus, the future holds all possibilities and as Martin (2006) explains "the intense awareness of possibilities creates anxiety. We can make almost anything happen" (p. 195).

Although the question of the body was not explored in Heidegger's work, as much as

the existential themes, the experience of the body can be understood in his concept of 'being not separated to the world'. In response to this relationship, Heidegger (2001) states: "...we would not be bodily in the way we are unless our being-in-the-world always already fundamentally consisted of a receptive/perceptive relatedness to something which address us from out of the openness as which we exist" (p. 231). Heidegger posits that the body is an ineradicable part of human life, thus the body awareness is related to openness to a given set of existence which allows one to open possibilities in any situation.

Merleau-Ponty (2002) also explores the manner in which the body is understood in its relationship to the world, particularly relating to sexuality. He states that sexual life is:

...what causes a man to have a history. In so far as a man's sexual history provides a key to his life, it is because in his sexuality is projected his manner of being towards the world, that is, towards time and other men. (p. 183)

Dealing with impotence, men demonstrated their sexual lives were in transition, and for the ones who are focused on sex as penetration and the possibility of having an erection, they are facing more conflicts related to their sexuality than the ones who consider sex as a whole expression of sexuality and love.

For instance, one participant who is avoiding treatment for impotence due to his difficulties in dealing with frustration, gave me an example of one man who had the same surgery as he did:

He's dead set on getting his machinery working again because he thinks he can't sort of get over this woman unless he's got his machinery going. (Nor)

In this account the objectification of sex is conspicuous as he describes it just as a machine, giving rise to feelings such as frustration, disappointment, anxiety, despair, and denial emerging from their experiences. On the other hand, the men who consider

sexuality in its totality, not just the mechanic act of penetration, could continue enjoying their sex lives. As Fernando Pessoa (1935) illustrates talking about love and sex:

Love is essential.
Sex, mere accident.
Or different.
A man's not an animal:
Is a flesh intelligent,
Although sometimes ill.

The poem points to the meaning of being ill, or feeling ill, in contrast to having a disease. Illness has an intrinsic connection to health as it is understood as something that disturbs health, thus, Heidegger (2001) explains illness as a phenomenon of privation where “each privation implies the essential belonging to something that is lacking something, which is needed of something” (p. 46). Furthermore, in a study of the phenomenology of health, Svenaeus (2000) makes a distinction between disease and illness by describing “... disease as a state or process causing biological malfunction and illness as the lived experience of the person” (p. 79). Taking illness as a phenomenon of lived experience, the poem above indicates the need to be aware of one's condition in order to situate oneself in a specific experience which encompasses distinctive possibilities for action. It is because “no illness manifests itself in exactly the same way in every individual” (Gadamer, 1996, p. 111).

Although the men in this study did not show an awareness of the meaning of being ill, the data suggests that the role that their wives/partners play, is very significant in helping them to overcome possible conflicts triggered by sexual dysfunction and continuing their sex lives. However, in this study the role played by their wives is not explored in more detail because the emphasis is on the men's experiences as a man with prostate cancer. Nevertheless, this theme is well described in the literature review (e.g.

Banthia et al., 2003; Berterö, 2001; Harden et al., 2006; Maliski et al., 2002).

Another interesting aspect revealed by the data is related to the altered libido due to hormone treatments. The only man who had this treatment, in my study, reported a lack of interest in sex because of depression, even though, he is aware of the changes in his body triggered by the hormones. In relation to another participant, who refers to an altered sexual desire due to the altered hormones in his body, data suggest that the alteration is more related to his denial and avoidance in facing impotence than the altered hormones. This finding differs from those reported by Chapple and Ziebland (2002) and Oliffe (2006) who explored sexuality among men who had hormone treatments and show altered libido due to treatments.

Furthermore, in my study the data suggests the altered sexuality is due to problems of communication in the men's marriages, although the libido is preserved.

Acknowledging and addressing sexual problems in a relationship can be an issue for men as all participants to some degree expressed avoidance in talking to their partners and wives about their sexual dysfunction. This lack of communication between the men and their partners can be understood in Seidler's (1989) words which explains why men have difficulty in expressing their sexual concerns in a relationship because "the difficulties in our sexual relationship reflect issues in our ongoing relationships" (p. 59).

Another sub-theme that emerged from the study participants is related to sex and aging. Here the data suggests that men's view of their sex life is altered not because of aging but due to conflicts in accepting an altered sexuality or sexual dysfunction as a side

effect of treatments. This finding is also reported in Arrington's (2003) study where old men do not accept the fact that sex diminishes or disappear with age.

Describing how men deal with impotence as a possibility, my findings revealed participants trying to have a sense of control of the situation. For example, some participants are considering trying treatment to recover potency, and the evidence from the data suggests that it is because trying treatments gives them a sense of control.

Sense of control

In the major theme "Sense of control", the data reveals that men need to have, at least, some kind of control in their lives in order to position themselves positively in the uncomfortable situation they are living in. On the other hand, this need of being in control may imply a condition that prevents them from confronting the unknown, embedded in such a disease as prostate cancer. Moreover, facing the unknown, they have to take the risks involved, which have the potential to trigger existential and psychological anxiety. Thus, the pragmatic, stoic, and rational approach to the disease the men show in this study, justifies their need for control in order to avoid anxiety.

This phenomenon appears to demonstrate that the participants needed a sense of control in almost all situations in the process of the disease. This ranged from the beginning, where all of them gathered as much information about prostate cancer to help them in the decision-making process, to dealing with the side effects of treatments and prognosis. This finding concurs with Kelly's (2009) study of the embodied impact of prostate cancer, where the author reported men trying to regain a degree of personal control through the information obtained in medical studies of the disease. Likewise, as

mentioned in the literature review, Hedestig et al. (2005a) reported participants in their study striving for control since diagnosed with prostate cancer and sharing their concerns with another man was described as a coping strategy to deal with the burden of being a patient. The same finding appears in my study where the men expressed a need to talk to other prostate cancer patients in order to have a sense of control in the new situation.

This theme 'sense of control' I located in the literature in different studies but it was mainly described in its social situations. For example, Chapple and Ziebland (2002) in a study of prostate cancer and perceptions of masculinity, reported lack of control of bodily functions as embarrassment and inconvenient, in terms of arrangements such as buying pads and personal hygiene while dealing with urinary incontinence. As described in the literature review, embarrassment is the most common theme in studies about urinary incontinence. However, only one study, conducted by Berterö (2001), explores the effects of embarrassment in men's sense of masculinity, because it can be an obstacle for their sex lives. The same data appears in my study where participants show some concern about incontinence as an impediment for sex. The main finding in my study, however, is that incontinence is considered worse than impotence.

Fergus et al. (2002) reveal the same finding in their study of sexual dysfunction, where participants also consider incontinence as being worse than impotence. This attitude did help them to adjust to sexual dysfunction. However, in my study, the data suggests that urinary incontinence is worse than impotence because it is a physical condition where a sense of control is not possible; whereas for sexual dysfunction, there are mechanical

devices which can give men a sense of control over their situation. Interestingly, the only concern men did not deny in this study is the one of being incontinent. However, focussing on their words, denial of the living body once again appears in their experiences and although they report being worried about incontinence, they do not dwell on their concerns. Moreover, the participants know that there are pelvic exercises that can help them to improve the muscle recovery, but they do not do much exercise and their rationale is that they are always busy. Thus, by not paying attention to the body they forget to do the exercises.

On the other hand, one man who did not deny his concerns of being incontinent, was able to expand his body awareness and did the pelvic exercises diligently. As a result, he became continent again in six weeks. The importance of this finding in my research is based on my assumption that the body, as embodiment, plays a fundamental role in treatment and recovery, in contrast to the mechanical view of the body where concerns are denied.

Exploring historically the need for self-control as part of men's identities, Seidler (1989) points to sense of control as "a form of domination over our (men's) emotions, feelings and desires" (p. 44). According to this author, it is control as domination that leads men to see their bodies as machines and as a result, a split between male sexuality and emotions occurred, because emotions represent a threat to the self-control.

Phenomenologically, Gadamer (1996) explores the paradox of humans' need for security being increased by modern science which claims that knowledge is based on

facts; therefore, mastery and control can be promised. In such an approach, an element of certainty is implicit. Even though medical professionals are aware of the limits of knowledge, sometimes they do not address the possibilities involved in a phenomenon which goes beyond the cause and effect embedded in 'facts'. Furthermore, as Gadamer (1996) suggests, it can be assumed that this increasing need for security in our contemporaneous society is in order to avoid anxiety. On the other hand, anxiety is a phenomenon that cannot be denied. Gadamer (1996) acknowledges the attempts of modern science in mastering the neurological phenomenon of anxiety and states "it still remains beyond doubt that anxiety concerning existence is something which belongs inseparably to the life and nature of human beings" (p. 158).

Taking anxiety inseparably from existence, it is through openness to the possibilities human beings may encounter in every lived experience, that care for one's concerns is plausible. If from a male point of view, as shown in my study that acknowledging needs and desires can be seen as a threat to their sense of control (Seidler, 1989), then, as Yalom (1980) brilliantly states:

The confrontation with the givens of existence is painful but ultimately healing.
(p. 14)

Life threatening disease

Although my study is not focused on dying, prostate cancer is considered a potentially life-threatening disease. Consequently, I explored the meaning of having this diagnosis in terms of whether it leads men to think about their own mortality. As mentioned in Chapter One, one of my purposes in this study is to understand men's experiences of having a potentially life-threatening disease within the Heideggerian concept of being-

towards-death which is related to the awareness of one's death.

In a study of phenomenological understanding of health and illness, Svenaeus (2000) explains that, although Heidegger never wrote anything directly about such subjects, his existential interpretation of death can be used in medical investigations to explore the meaning-structure of human existence.

Talking about death is almost banned in modern societies as this theme is seen as morbid or sinister, but in Heidegger's philosophy, death does not mean an event that will occur to us someday in the future, but is something that is a constant possibility we have with us that can happen at every moment in our lives (Harman, 2007).

Even though it is a common sense to say that everyone will die one day, or death is the only thing that we as human beings can take for granted will happen, the possibility of dying is about the other but not myself. Heidegger (1996) states "Dying, which is essentially and irreplaceably mine, is distorted into a publicly occurring event which they encounters" (p. 234). Heidegger explains that the avoidance in talking about one's own death makes death seem like an occurrence that does not belong to anybody in particular. He points out that talking about death can be considered as a 'social inconvenience' or 'tactlessness', thus, the implicit avoidance is justified. However, such avoidance is the denial of the inevitable angst about death. To be able to face one's own possibility of dying, one must be able to endure the anxiety involved. At the same time, an individual will be able to make choices according to his or her own needs.

Thus the avoidance of contemplating one's own death as a possibility, is a denial of being in a specific situation where one might not choose to be. Also one must find him

or herself in a vulnerable position where any kind of control is not possible. However, to be able to situate oneself in a specific situation is a condition to understand one's interpretation and evaluation of his situation, which includes the possibility of dying.

This can be verified in Rilke's (2005) poem:

Why, when this span of life might be fledged away
as laurel, a little darker than all
the surrounding green, with tiny waves on the border
of every leaf (like the smile of a wind): -oh, why
have to be human, and, shunning Destiny,
long for Destiny?... (p. 12)

For a person to be familiar with his own world, there must be an admission that there are many unknown things in his world that cannot be controlled. For instance, an illness can be seen as an alien in one's life that represents a threat which has the potential to take control over one's existence; therefore, anxiety becomes inherent for a human being in such situation.

In this sense, the already described men's need of control revealed by the data gives a coherent sequence to the denial of own mortality expressed by them in this study.

Furthermore, data revealed the way men see themselves as 'bullet proof' and 'invincible', meaning that they live their lives putting death almost completely out of the context. On the other hand, using the scientific method as an absolute standard of treatment, inexorably leads to rejection of concerns about death as a possibility to be considered. This was revealed in data where participants who elucidated their concerns or even fear of dying, could not address such feelings in the decision-making process around diagnosis, because of lack of opportunity or room for them to voice their inner feelings. This finding supports a study by Westman et al. (2006) where the authors described participants' reluctance in sharing their existential issues with medical

professionals, due to lack of time to build trust.

In the literature review, studies suggest that a cancer diagnosis has a strict link with death for most patients. Therefore, scientific knowledge and metaphysical beliefs, which can be individual's values and principles, are important to patients in coping with the disease (Maliski et al., 2002; Westman et al., 2006). My findings suggest that the scientific approach to the disease itself, where the focus is to get rid of the tumour, does not allow men to consider the possibility of having a deadly disease. In other words, as the urologist and the men's focus remained on a problem to be fixed, men's possible concerns of cancer as a deadly disease were denied. However, data shed light on such concerns in the men's experiences, especially around time of diagnosis, because all of them expressed thoughts of the possibility of their dying from prostate cancer. This finding is particularly important to my study because my primary purpose was to explore the meaning men attach to prostate cancer in their everyday lives. My rationale can be read in Frankl (1977) words:

For the meaning of life differs from man to man, from day to day, and from hour to hour. What matters, therefore, is not the meaning of life in general but rather the specific meaning of a person's life at a given moment. (p. 110)

But by not being able to see their body as embodiment, to consider the living time in the recovery processes, and to express their own concerns especially related to the possibility of dying, men in this study were unable to describe meaning in this disease. When questioning the participants as to whether there is a meaning or not for them having prostate cancer, none of them were able to verbalise a meaning. This can be understood by the rational view the men demonstrated in this study which makes it almost impossible to capture and express their inner feelings, in contrast to Frankl (1977) suggestions:

I think the meaning of our existence is not invented by ourselves, but rather detected. (p. 101)

To be able to find meaning in a disease, one must incorporate himself with the disease in the everyday life in order to be able to open up possibilities in living accordingly with the side effects and/or dysfunctions imposed by the disease. This implies understanding the scientific explanations of the disease not only in a rational way, but one must combine the explanation with his own feeling and perception, then a meaning can be found in the experience. Heidegger (1977), in an essay concerning technology, points out the importance of man's essence to be put first to the essence of technology; thereby, it is through the combination of both man and technology that "...modern man must first and above all find his way back into the full breadth of the space proper to his essence" (p. 39).

Another crucial point to be considered is that the awareness of one's death is an essential condition to live an authentic existence. Heidegger (1996) explains that Dasein is always essentially its possibilities, which encompass two different modes to reveal itself: authentic and inauthentic. The concept of authenticity is related to a human being's ability to live his/her own life according to his/her perception and feelings. In this sense, human beings are the creators of their own lives as the world is conceived through the relationships one establishes with the world and the others. In this process, one's identity as singular being can be revealed, in contrast to living like everyone else, where the differences are minimised or even obscured in an inauthentic way.

Understanding Dasein in its everyday activities implies an ability to recognise its unique identity where the lived body is not disconnected. Facing the givens of existence

without denial opens possibilities to a certain extent where that can be understood in this Hölderlin' poem Patmos (as cited in Heidegger, 1977):

But where danger is, grows
The saving power also. (p. 42)

In order to understand the importance of addressing concerns about one's possibility of dying during treatment, one participant in my study who is aware of prostate cancer as a deadly disease, did not have any kind of emotional and psychological support for his feelings, and, as a result, he is facing severe depression. Understanding his experience enhances my assumption that to be able to disclose such concerns in treatments can be fundamental to the integration of human beings and modern science, which has the potential to improve communication between health professionals and patients. This finding is echoed in the literature review where some authors reported understanding that the patient's concerns goes beyond just clinical care of the patient, because it leads to a sense of satisfaction and meaning for both patient and professional (Albaugh, 2003; Block, 2001). Moreover, in a phenomenological investigation carried out by Tamura et al. (2006), the authors described how facing death can create lived experience in the context of care, when health professionals are able to interpret how patients draw meaning from the disease, which compels both to rethink their values in this new situation.

In conclusion, to be able to include the possibility of dying in treatment of a disease like prostate cancer, is fundamental to understanding human beings. It is because, as mentioned in the literature review, prostate cancer is a kind of disease pervaded by uncertainties, and for a man being-in-the-world with such diagnosis, the scientific

approach is not enough to understand and provide him with psychological, emotional and existential support needed in helping him in the making-decision treatments and living with the side effects of treatments.

The need for such support is well recognised by the American Cancer Society (2008), which recommends men choose a treatment for prostate cancer according to what he is emotionally able to put up with. As Heidegger (1996) says “The problem of the possible wholeness of the being which we ourselves actually are exists justifiably if care, as the fundamental constitution of Da-sein, “is connected” with the death as the most extreme possibility of this being” (p. 239).

CHAPTER SIX: CONCLUSIONS AND IMPLICATIONS

Prostate cancer is an important public issue around the world, therefore a deeper understanding of the meaning men connect to this experience could illuminate the effects of this diagnosis and treatments in a man being-in-the-world.

In this study I wanted to understand men's experiences with prostate cancer in order to understand how such a disease affects men in everyday life, in terms of their identities.

By being aware that sexuality plays an important role in men's lives, I explored how men cope with the side effects of prostate cancer treatments. Evidence from the data suggests that a man's identity has an inherent connection with sexuality. Therefore, there is a need for a man to be well informed about the possible side effects of prostate cancer treatments, which include sexual dysfunction.

Another crucial aspect explored in my study was how men situate themselves in the light of the diagnosis of a potentially life-threatening disease. This is the strength of my study, because it opens up possibilities of exploring how men face a diagnosis of a potentially life-threatening disease within the Heideggerian concept of "being-towards-death". I could find no articles in my literature review that explore men's experiences within this concept, therefore my study clarifies the importance of encouraging men to address concerns about the possibility of dying, around the time of diagnosis.

In my opinion, the meaning of exploring men's experience within this concept is because Heidegger goes beyond the morbid approach to death, clarifying that to be able to put death into perspective leads to a human being living an authentic existence.

Findings from the study suggest that all participants have, to a degree, such thoughts when diagnosed, even though they were not fully aware of their feelings. Although the participants stated they did not take mortality much into account around time of diagnosis, the data revealed that due to a scientific approach in curing the disease, there was no room for them to disclose feelings or concerns they may have about dying. Even though some participants did not deny prostate cancer as a deadly threat, my findings shed light on their concerns because the data revealed their difficulties in articulating their inner feelings.

The importance of giving men the opportunity to voice their concerns, especially about dying, is supported by one participant's story where the data showed him suffering depression due to the lack of psychological support for his conflicts triggered by prostate cancer. I have observed that the way in which men experienced the diagnosis of prostate cancer affected how they dealt with the side effects of treatments in their everyday lives. For example, the objectification of the body led them to face disappointment with themselves and also in their relationships with the urologist. It is because they were unable to recognise through their bodies their own needs and the role they could play in the recovery processes.

I believe that to promote health care one must be able to place greater emphasis on the patients' stories. Although this might demand more time professionals spend with the patients, the discussion of the possible outcomes of treatments can contribute to a man feeling more engaged in the recovery process and finding resources to cope with the inherent anxiety involved.

Another essential aspect revealed by the data, is that men need to have a sense of control in how they live. Thus, if men are able to integrate their own being with the scientific explanation of the disease, it might open possibilities for them to cope with side effects and also finding meaning in the experience. I have mentioned that prostate cancer is a kind of disease permeated by uncertainties. Therefore, there is a critical need in providing psychological, emotional, and existential support for a man being-in-the-world with the disease. I believe that findings from the study should assist health professionals, doctors, psychologists, the patients and their families in the treatment decision making process and also in the recovery process from surgical procedures.

Possibilities for further research

As a phenomenological study, the richness of the data in the material collected can never exhaust the possibility for more interpretations but always leaves open doors to be explored. Moreover, an existential interpretation of a human being is a process of becoming; thus, further research needs to be done in this area where complementary studies could enlighten different meanings in the living experience. Due to the complexity of phenomena involved in prostate cancer, there are many open areas in different stages of the disease to be explored in further studies. For example, I was unable to investigate in great depth participants' accounts about the possibility of having a procedure so-called "Watching Waiting" where no treatment is administered; rather there is a close monitoring of the symptoms. Some participants mentioned the possibility of having such procedure, thus it might be a possibility for further studies to explore men's concerns in such a situation within the Heideggerian concept of "being-

towards-death”.

It would be important to investigate how men cope with anxiety in such procedures, where there are no guarantees and to compare with outcomes from surgical procedures. As the focus of this study was on disclosing meaning attached to prostate cancer as a continuous process, it will be interesting to investigate the participants after 18 months of the surgical procedure, as a longitudinal study.

Limitations of the study

The limitation of this study is that I had to keep my focus on men’s inner feelings in the experience and I could not explore and analyse the role played by their wives/partners in the process of the disease, even though they accompanied men in almost all stages of the disease. Another limitation is lack of time and space to interpret the abundant material provided by the men’s stories. I am aware that these are inherent conditions to the study, because human’s experiences cannot be confined in final answers to the phenomena.

One crucial limitation to point out in the study, is that there are no Maori participants included. In view of the statistics on prostate cancer morbidity for Maori in New Zealand, a study that includes them would be very useful to enrich the understanding of the meaning of the disease for men from different backgrounds.

Summary

To conclude, I hope the findings of this study stimulate health professionals to open their minds and hearts to the importance of allowing men to express themselves and to

be understood in their own words. To promote health care one must be able to place more emphasis on listening to patient's stories whereby the meanings can be revealed.

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Appendix A: Northern Y Ethics Approval



Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

27 November 2008

Rosana Eteia de Vasconcelos
75A Christopher Street
Tauranga 3112

Dear Rosana

NTY/08/08/075

A Heideggerian hermeneutic study of the meaning of living with prostate cancer

Lead Investigator: Rosana Eteia de Vasconcelos

Supervisor: Margot Solomon

Sites: ProMed Urology

The above study has been given ethical approval by the **Northern Y Regional Ethics Committee**.

Approved Documents

- Information Sheet and Consent Form dated 3 July 2008.
- Confidentiality agreement dated 13 October 2008.
- Presentation.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until **30 December 2009**. A final report is required at the end of the study and a form to assist with this is available at <http://www.ethicscommittees.health.govt.nz>. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Amrita Kuruvilla'.

Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Email: amrita_kuruvilla@moh.govt.nz

Appendix B: Copy of AUTECH Approval



MEMORANDUM

Auckland University of Technology Ethics Committee (AUTECH)

To: Margot Solomon
From: **Madeline Banda** Executive Secretary, AUTECH
Date: 3 March 2009
Subject: Ethics Application Number 09/11 A Heideggerian hermeneutic study of the meaning of living with prostate cancer.

Dear Margot

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTECH) at their meeting on 19 January 2009 and that I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTECH's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTECH's meeting on 20 April 2009.

Your ethics application is approved for a period of three years until 3 March 2012.

I advise that as part of the ethics approval process, you are required to submit the following to AUTECH:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/about/ethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 3 March 2012;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/about/ethics>. This report is to be submitted either when the approval expires on 3 March 2012 or on completion of the project, whichever comes sooner;

It is a condition of approval that AUTECH is notified of any adverse events or if the research does not commence. AUTECH approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are reminded that, as applicant, you are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

Please note that AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this. Also, if your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within that jurisdiction.

When communicating with us about this application, we ask that you use the application number and study title to enable us to provide you with prompt service. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the AUTECH and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Rosana Eleia Vasconcelos vasconcelos@xtra.co.nz, amrita_kuruvilla@moh.govt.nz

From the desk of
Madeline Banda
Executive Secretary

Private Bag 52006, Auckland 1142
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Appendix C: Participant Information Sheet

Participant Information Sheet



Date Information Sheet Produced:

03 July 2008

Project Title

A study of the meaning of living with prostate cancer

An Invitation

My name is Rosana Vasconcelos. You are invited to participate in my study. I am a psychotherapist and this project is part of the Master Health Science qualification within Auckland University of Technology. I am interested in interviewing men who have been in treatment for prostate cancer in the last year. It is voluntary participation and you can withdraw at any time without giving reasons.

What is the purpose of this research?

This study aims to understand men's experiences of having a potentially life-threatening disease and also the effects on their sexuality. I plan to communicate my thesis findings at professional conferences, and, in research journal article. I also seek the opportunity to present the study's findings to the Prostate Cancer Foundation of New Zealand, Tauranga Hospital, and Urology Clinic as I am also interested in running group psychotherapy for these patients and local workshops sharing the outcomes with other health professionals.

How was I chosen for this invitation?

You have been referred by your urologist as a possible participant.

What will happen in this research?

A one-on-one interview time will be arranged at place that is convenient to you or if you prefer at the Venturo Clinical Administration rooms. We will have 1 or 2 interviews which will last 60 to 90 minutes each. All the interviews will be tape recorded and then will be transcribed and you will receive a copy of the transcription. You will also be sent a copy of my analysis and interpretation of your interview that you can comment on and give me your opinion. About 8 to 10 men will be involved in total.

What are the discomforts and risks?

Due to the sensitive personal nature of this study it is possible it might uncover some emotional distress. You may feel discomfort talking about your experience with the diseases.

How will these discomforts and risks be alleviated?

If you feel discomfort talking about your experience, I will assist you in obtaining emotional support from AUT Health Counselling and Wellbeing which will provide free confidential counselling support. This is an online counselling service available for the participants who live in the Tauranga area.

What are the benefits?

Taking part of this research is an opportunity for men to disclose their concerns, fears, anxiety, and/or psychological disturbances that can be triggered by this disease. The clarification of the meaning they attach to their experiences may empower them to create a sense of control of the disease.

How will my privacy be protected?

All participants will be protected by confidentiality. You will choose a pseudonym and I will not use any identifying details in my study or presentations.

What are the costs of participating in this research?

There is no cost to the participants. If you do incur any expenses as a result of the interview I will ensure you will be reimbursed appropriately.

What opportunity do I have to consider this invitation?

Thank you for reading this information sheet and considering being a participant in my study. If you would like to be part of the study or have any questions that may help your decision, please contact me on the numbers or email listed below within two weeks (fourteen days).

How do I agree to participate in this research?

You need to complete a Consent Form that will be provided.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, *Margot Solomon*, margot.solomon@aut.ac.nz, 09 921 9999 ext 7191.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, madeline.banda@aut.ac.nz, 921 9999 ext 8044.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health Disability Commissioner Act.

Telephone (NZ wide): 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

Whom do I contact for further information about this research?

Researcher Contact Details:

Rosana Vasconcelos – phone number : 07 5771837
email: rvasconcelos@xtra.co.nz

Project Supervisor Contact Details:

Margot Solomon – phone number: 09 921 9999 ext 7191
email: margot.solomon@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on : 03 March 2009

Approved by the Northern Y Regional Ethics Committee on: 27 November 2008

AUTEC Reference number: 09/11

Appendix D: Consent Form



Consent Form

Project title: ***A Heideggerian hermeneutic study of the meaning of living with prostate cancer***

Project Supervisor: ***Margot Solomon***

Researcher: ***Rosana Vasconcelos***

- I have read and understood the information provided about this research project in the Information Sheet dated 16/06/2007
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data analysis, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes No

Participant's signature:.....

Participant's name:.....

Participant's Contact Details (if appropriate):

.....
.....
.....
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 03 March 2009

Approved by the Northern Y Regional Ethics Committee on 27 November 2008

Note: The Participant should retain a copy of this form.

Appendix E: Transcriptionist Confidentiality Form

05 May 2009

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Confidentiality Agreement



Project title: A Heideggerian hermeneutic study of the meaning of living with Prostate cancer

Project Supervisor: Margot Solomon

Researcher: Rosana Vasconcelos

- I understand that all the material I will be asked to transcribe is confidential.
- I understand that the contents of the tapes or recordings can only be discussed with the researchers.
- I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: *[Handwritten Signature]*

Transcriber's name: SITOSA C. NAYAR

Transcriber's Contact Details (if appropriate):

Email: scn@clear.net.nz

Mobile: 021 520 465

Date: 06/05/2009

Project Supervisor's Contact Details (if appropriate):

Approved by the Auckland University of Technology Ethics Committee on: 03 March 2009

Approved by the Northern Y Regional Ethics Committee on: 27 November 2008

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