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The page features a decorative header at the top consisting of three horizontal lines in blue, yellow, and blue. A vertical border on the left side consists of two parallel lines, one blue and one yellow, with blue segments at the top and bottom.

**THE EXPERIENCE OF SEXUALITY  
OF MALE CANCER PATIENTS UNDER PALLIATIVE CARE  
AT HOSPICE WITS HOUGHTON**

**MPhil in Palliative Medicine**

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## **ABSTRACT**

The experience of advanced cancer leaves in its wake devastating effects, which are both complex and multi-dimensional for the patient, their family and society. The consequences are far-reaching and span psychological, physical and sexual dimensions. Unfortunately sexual dimensions are least addressed by researchers and healthcare professionals, even though most patients wish to have this area dealt with.

Sexuality is a complex phenomenon that is influenced and shaped by physical, social, cultural and religious factors. The research that has been conducted on sexuality on the male cancer patient under palliative care has largely focussed on the physical aspects of sexuality such as erection, ejaculation and fertility. Studies conducted on the patients' actual experience of sexuality are few and no studies of this nature have been found to exist within the South African context.

This study has utilised a phenomenological approach to capture a rich and detailed description of the experience. Six participants were included using open-ended interviews. Themes that commonly arose from the interviews were elicited by the principal researcher and corroborated by a second independent researcher.

Central themes emerging from this study included reduced independence and self-perceptions of masculinity, a diminished body-image and concerns about being a burden to their partner. Participants were also found likely to withdraw socially and to experience anxiety related to the physical sexual relationship. Often the focus of sexuality became more emotional rather than physical for the participants of this study.

An integration of the results sought commonalities in themes that would provide the essence of the phenomenon. The discussion of these themes was further integrated with the findings of the literature review to consolidate their validity.

The findings led to specific recommendations relating to further research and training and education of healthcare workers regarding their approach and how to manage a palliative patient on a sexual dimension; to encourage independence for as long as possible and to nurture supportive relationships by facilitating open and honest communication.

In summary, this study was conducted to produce such research within the South African context, to bridge the gap between male palliative patients' needs and healthcare workers' knowledge, and to encourage the active assessment and management of patients' difficulties with their sexuality whilst under palliative care.

# **CHAPTER I**

## **INTRODUCTION**

In providing palliative care to cancer patients, a holistic approach is imperative. This must include sexual dimensions of care.

A diagnosis of cancer is a devastating experience. The patient may turn their full focus on issues related to survival (Katz, 2005). Often healthcare professionals will do the same – the focus turns to potential cure (Hordern et al., 2003). Amidst this emotional experience many other questions begin to arise for the patient including: ‘How will my sexuality be affected by my cancer?’

Males who have cancer may suffer a variety of losses in relation to their experience of sexuality. These relate broadly to feelings of masculinity, loss of gender roles and concerns around both physical and emotional intimacy (Hordern et al., 2007).

A patient with cancer may be too ill to work and to sustain his family; he may feel he cannot be an effective father. He may fear that he is unattractive to his partner and even being able to hug or to have gentle intimate discussions may become a problem (Penson, 2000).

Sexuality is a complex issue. It is imperative to remember that sexuality does not only involve physical intimacy but includes psychological, social and spiritual aspects. It is related to gender roles, perceptions of masculinity, emotional and physical intimacy. What is evident from the literature is the importance of sexuality to palliative care patients, their need to discuss this and the reticence of healthcare providers, for various reasons, to address the issue of sexuality. To date, no known studies have been conducted on this topic within the South African context. It follows that such a study must be performed for palliative care providers to be more aware of the difficulties and to receive training to provide holistic care to palliative patients.

When faced with the task of defining sexuality, one is left with a plethora of physical, social and psychological dimensions that may become key. As sexuality covers so many areas, the impact of cancer requiring palliative care for a male patient, becomes extremely diverse and complex. Each patient will have a different perspective on what sexuality is and how his cancer has affected it.

It becomes imperative for the palliative care team to address issues of sexuality with their patients but often this area is ignored due to various reasons. In treating a patient's total pain, pain related to sexuality must be addressed.

Qualitative research and thus phenomenology is dedicated to revealing and describing context or life worlds from which meaning can be illuminated (Lindegger, 1996). A diagnosis of cancer is a complex phenomenon, as is sexuality. To capture this complexity a phenomenological investigation was used in this study. In regard to chronic illness or disability and phenomenology Lindegger (1996) states: '...many of the issues that confront these patients and their caregivers are psychological or philosophical in nature, rather than organic. I would therefore suggest that many of these questions and issues are best investigated using a qualitative rather than a quantitative framework and methodology.' (p.60).

In conclusion, it is evident that patients are distressed by the impact of their disease on their experience of sexuality. The scarcity of literature, especially current literature reflects the gap in knowledge for the healthcare professionals in their approach to these patients. The few studies that have been performed have been in the United Kingdom and Australia. Thus it becomes imperative that such a study is conducted within the South African context.

## **CHAPTER 2**

### **LITERATURE REVIEW**

A search of the relevant literature using Google Scholar and the search words ‘palliative care’ and ‘male sexuality’ and ‘cancer’ elicited 3120 articles. On surveying these articles, it becomes apparent that most focus on physical aspects of sexuality and fertility. Relatively few articles address psycho-social aspects of sexuality. Furthermore, none of these studies have been conducted within the South African context and thus may not have relevance to our setting. On conducting a broader search in the African Journal Archive using the terms ‘sexuality’ ‘palliation’, ‘male’ and ‘advanced cancer’, no articles were identified.

What is apparent in all the articles found on this topic is how important sexuality is to patients (Hordern, 2007; Hordern et al., 2003; Jonker-Pool, 2002, Katz, 2005; Lemieux et al., 2006; Rice, 2000).

It is evident from the literature that patients may feel too embarrassed to ask healthcare professionals about issues related to sexuality and intimacy in the light of their life-limiting disease (Rice, 2000; Hordern et al., 2007; Penson et al., 2000).

In contrast, literature claims that many healthcare professionals are reticent to initiate this conversation with their patients as the topic may create discomfort and embarrassment. Unfortunately this results in a very large part of the patients’ experiences and concerns about their illness simply being ignored (Katz, 2005; Lemieux, 2006).

It has been found by various studies that most patients wished to discuss their concerns around intimacy and that this should form a part of the holistic assessment offered by palliative care professionals (Katz, 2005; Rice, 2000).

It is well written in the literature that many healthcare professionals do not address issues pertaining to sexuality. The reasons for this are not clear although ignorance, embarrassment, lack of time and lack of experience have been cited as possible reasons (Hordern, 2007).

Hordern (2007) found that many patients expect their sexuality to be addressed by their healthcare professionals. She states that ‘there were mismatched expectations between patients and health professionals and unmet patient needs in communication about sexuality and intimacy’ (pg. 224).

Indeed, healthcare professionals providing palliative care may fall victim to all the social myths discussed earlier: ‘My patient is dying and elderly – they are not concerned with sexuality.’ It is essential that palliative care providers are aware of their own definitions and perceptions of sexuality and are given tools to equip them to deal with these issues with their patients (Hordern, 2007; Hughes, 2000).

Sexuality does not just involve physical sex. It includes perceptions related to body-image, self-esteem, gender roles, perceptions of masculinity, psychological and physical intimacy (Hordern, 2003).

Society also has profound effects on sexuality as it prescribes norms, values and beliefs about sexuality. When society’s views are skewed or incorrect, social myths result. These become a huge hindrance to the patient’s experience of sexuality post-diagnosis (Althof & Levine, 1993).

## **2.1 The physical sexual encounter**

Physical sex for the terminal cancer patient will be different to physical sex for the non-cancer male. The patient and partner may have to engage in preparation prior to physical sexual encounters and may also need to reach decisions regarding the various options available to him in order to enhance physical sexual satisfaction. These may include bowel and bladder preparation, the use of prosthetic devices, penile injections, vacuum erection devices and medication. This preparation may hinder spontaneity and may be unsatisfactory to the patient and his partner.

The following studies were found regarding the use of prosthetic devices, penile injections and vacuum erection devices. Most of the studies found related to patients with spinal cord injury. This may be useful for those patients with central nervous system malignancies, or spinal cord compression. A study by Nikas et al., (1990) of 40 World War Two spinal cord injured veterans, found that none of the subjects had had a prosthetic device at any time after their injury and only 40 % had indicated that they would have wanted one, while 60 % reported that they would never have even considered having a penile implant.

A study of 17 spinal cord injured male patients using penile injections was carried out by Richards et al., (1992). They assessed marital, social, personality and sexual

dimensions via a pre- and post-intervention. It was found that scores on all four dimensions improved significantly with the use of intercavernous injections. The greatest improvements were found in measures of self-acceptance and sexual pleasure. The assessment tools were not defined in the article and therefore it is difficult to ascertain precisely what aspects within each dimension were assessed.

Smith & Bodner (1993) reported a study in which seven out of 36 spinal cancer patients who had utilised the vacuum erection device, discontinued it after six months due to dissatisfaction because of the blocking of ejaculation, bruising and insufficient erections.

Denil et al., (1996) assessed patient and partner satisfaction using the vacuum erection device. Nearly half of the couples included in the study reported increased sexual activity and increased sexual satisfaction using the vacuum erection device. With a significant result being shown, vacuum erection devices may be a useful suggestion to palliative care patients who still wish to engage in physical sexual activity.

## **2.2 Psychosocial aspects of sexuality**

### **Social myths regarding sexuality**

Perhaps one of the largest hindrances of sexual functioning for the advanced cancer patient is the destructive societal and individual held stereotypes/misconceptions about sexuality. It follows that if these myths constitute a large hindrance to sexual functioning, it may be an area that requires the most adaptation on the part of the patient and society around him for his effective sexual adjustment post-diagnosis (Althof & Levine, 1993; Lemon, 1993).

It is perhaps difficult for individuals who are healthy and active to think of terminally ill individuals as sexual beings (Althof & Levine, 1993; Rabin, 1980). Furthermore many terminally ill patients may be elderly. Lemon (1993) briefly sums this up by stating that the biggest social myth of all for patients to overcome is our society held belief that, "Only the young and able-bodied are considered to be sexual beings." (p.75).

Below is a list compiled by a search of relevant literature (Lemon, 1993; McCammon et al., 1998; Persaud, 1986; Pervin-Dixon, 1988; Rabin, 1980), of

pervasive myths which are held by patients, their significant others, healthcare workers and society at large:

- i) Terminal patients are not sexual beings.
- ii) Sick or elderly persons are not interested in sex and sexuality.
- iii) Sex means achieving intercourse.
- iv) The male must initiate sexual activity and encounters.
- v) The male must be the active partner in sexual activity.
- vi) Love and intimacy is expressed through sexual activity.
- vii) Masturbation is considered sinful or dirty
- viii) Terminally ill patients should not be sexually active as it is draining on their energies and therefore harmful.
- ix) Sexual activity weakens the effects of medication.
- x) Partners may contract cancer if they are physically intimate

Singh & Magner (1975) emphasise the destructiveness of these myths. They state that it has been established that sex and sexuality for the patient is just as important as it is for the healthy. Farrow (1990) remarks that disability and disease do not eliminate sexual feelings and that patients still continue to be sexual beings and to have the same sexual desires as found in any other individual (Stein, 1992).

### **Specific concerns of the patient regarding sexual encounters**

Additional psychological concerns regarding sexuality may include fears of not being able to be open and honest in communication with the partner, fears of exploring new methods and techniques, the cooperation of the partner, role changes, fears of rejection and fears in establishing new relationships (Persaud, 1986; Rieve 1989).

Concerns regarding sexuality need to be addressed early during care in order to facilitate appropriate sexual adaptation. Often, the patient has these concerns early on in his diagnosis but is too embarrassed to address them with the medical staff or social workers (Ide & Ogata, 1995; Lemon, 1993; Reeve, 1998).

Intervention techniques, such as the PLISSIT model, are useful in dispelling many of these myths and concerns regarding sexuality post-diagnosis (Griffith & Lemberg, 1993).

Closely associated with physical and psychosocial aspects regarding sexuality for the patient are the various psychological consequences that need to be addressed post-diagnosis.

In a study by White et al., (1992), specific physical sexual concerns were ranked in the following order by male patients with life-threatening illness:

- Not satisfying a partner
- Not feeling sexually attractive
- Urinary control
- Bowel control
- Damaging oneself
- Loss of interest or desire
- Moral or religious concerns and beliefs
- Having to plan for sexual activities
- Feelings of embarrassment if having to use prostheses, penile injections or vacuum erection devices.

The article does not state how the ranking was elicited, whether open-ended questions or closed ranking scales were utilised. If a predefined list was used to rank numerically, it is difficult to ascertain whether some concerns may not have been included.

A qualitative study of 145 spinal cord injured veterans, using informal interviews, (Rabin 1980) found that sexual satisfaction was positively correlated to increased feelings of self-esteem. They also found that sexual satisfaction was not related to the level of spinal cord lesion but was significantly related to the spinal cord injured veteran's degree of independence. This was a very significant finding that would support encouragement of maintenance of some level of independence in palliative care patients.

In a study of 142 spinal cord injured individuals regarding the ranking of their most important areas of their lives, spiritual life was ranked as more important than sexual life. In this case, it may follow that spiritual life may have some dictatorship over sexual life (Ide & Ogata, 1995). White et al., (1992) found the opposite to be true: sex life was rated as more important than spiritual life. The differences could be accounted for by the large discrepancy in sample size as White et al., (1992) only used 79 spinal cord individuals as compared to 142 spinal cord individuals in the Ide & Ogata (1995) study. Differences may also be attributed to regional distribution

of religion or culture as corresponds to the representative sample drawn for the two studies.

White et al., (1992) also studied the areas of concern about sexual activity for the spinal cord injured male. Concerns regarding sexual activity that centred around religious or moral beliefs were ranked as a specific concern even though it was ranked the least area of concern. For these individuals, sexual experience may be hindered by these religious or moral beliefs.

### **2.3 Psychological consequences that need to be addressed regarding sexuality for a male cancer patient under palliative care**

The patient under palliative care may require assistance with his perceptions of his sexuality. Cancer may negatively affect his body-image and self-esteem as he may feel unattractive or may no longer be able to work or to fulfil other masculine roles. Furthermore, depression and anxiety may negatively affect his experience of sexuality. Other factors such as social myths, personal definitions of sexuality and communication problems may require attention.

To exacerbate this problem, both patients themselves and healthcare workers are often reticent to address sexuality due to embarrassment, ignorance or feeling that such discussions may seem frivolous in the face of death (Rice, 2000; Hordern et al., 2007; Katz, 2005).

#### **Body-image**

Body-image is a psychological experience of one's body, body parts and body function (Rabin, 1980). When cancer strikes, this psychological experience is shattered as the body, its parts and its ability to function are severely affected. Bowel and bladder control may be lost, the individual may lack mobility, the ability to attain and sustain erection and ejaculation diminishes and alternative techniques and/or devices must be utilised for sexual encounters. Because of this many patients prefer to avoid sexual encounters for fear of humiliation (Althof & Levine, 1993; Lemon, 1993; Rieve, 1989).

An altered body-image due to cancer may result in concern about how the patient is viewed and perceived by others (Pervin-Dixon, 1988). In the study by White et al., (1992), areas of concern regarding sexuality were ranked from highest to lowest.

From a total of 17 ranked concerns, concerns over body-image, for instance 'feeling sexually unattractive' (p.228) were ranked as number five. Urinary accidents, which may also be related to body-image, were ranked at number three.

The altered body-image needs to be addressed by reorganising the individual's view of his body so that the affected parts are reintegrated into his body-image. The cancer patient who cannot achieve this reintegrative process, may show poor sexual adjustment as he cannot place the affected parts of his body into his image of himself. This individual may display symptoms of depersonalisation and refusal to utilise sexual devices and options as a defence to his ego in order to maintain his body-image integrity (Althof & Levine, 1993; Singh & Magner, 1975).

Important in reconceptualising the patient's body-image is the partner's attitude towards his body. The patient may be feeling, 'How can my partner possibly feel attracted to me now?' and the partner may also be feeling hesitant or repulsed. Together, the couple needs to reintegrate each other's bodies into their sexual activities. This is achieved mainly through communication and encouragement. Developing a good or acceptable body-image fosters a feeling of self-acceptance (Althof & Levine, 1993; Solomon, 1982).

### **Self-esteem**

As disease progresses, the patient's vocational and social roles may be no longer possible. In this way their social value is altered and this affects their self-esteem. In cancer patients, altered self-esteem is often experienced as feeling less masculine as they are possibly no longer the bread-winners and they have even become dependent on their families. Feeling less masculine may have an effect on sexual relationships as the patient may feel incapable, unworthy and clumsy (Althof & Levine, 1993; Lemon, 1993; Persaud, 1986).

The key to addressing problems in self-esteem is to promote patient autonomy. This can be facilitated in the medical setting soon after diagnosis by allowing the patient to participate in decision-making processes. The patient should be encouraged to maintain his interests as far as possible and to remain independent for as long as possible (Grundy & Swain, 1986; Lemon, 1993; Persaud, 1986).

## **Mood disorders**

For the cancer patient, a mood disorder may constitute a premorbid disorder or may have been precipitated by his diagnosis and/or his acquired learned helplessness. In either case, the mood disorder needs to be addressed. Treatment of depression often takes the form of antidepressant drugs. Antidepressants fall into one of three categories: the tricyclics, the monoamine oxidase inhibitors or the selective serotonin re-uptake inhibitors (Frude, 1998). Depression in itself fosters symptoms of decreased libido, inhibited orgasm and ejaculation. A side effect of antidepressants may also constitute sexual dysfunction (Banov, 1999). Other symptoms of depression that may hinder sexual functioning include loneliness, social isolation, guilt, feelings of helplessness and hopelessness, neglect of personal hygiene and appearance, pessimism and a loss of interest and motivation (Banov, 1999; Hirschfield, 1999; McIntyre, 1999; Rieve, 1989; Siösteen, A., Lundqvist, C., Blomstrand, C., Sullivan, L. & Sullivan, M. 1990).

## **Anxiety disorders**

Because it is common for the cancer patient to become socially isolated (Rabin, 1980), he may be vulnerable to developing anxiety disorders such as social phobias, panic attacks or agoraphobia. Phobias specific to sexual encounters may also develop. Anxiety in itself may manifest problems pertaining to sexual encounters for example the patient may deliberately avoid sexual encounters or may avoid approaching members of the opposite sex. Anxiety disorders may too be treated with antidepressants which may further debilitate sexual functioning (Banov, 1999; McIntyre, 1999).

Perhaps the cancer patient, who is already experiencing sexual dysfunction, can be treated for anxiety and depression in alternative ways such as psychotherapy, as in this case antidepressants may further debilitate sexual dysfunction which may result in greater anxiety and depression. This point should be borne in mind for the treating practitioner.

## **Social myths and personal definitions of sexuality**

In addressing sexuality in the male cancer patient under palliative care, it may be necessary to dispel certain erroneous beliefs and sexual attitudes which serve to define what sexuality is to the patient. Premorbid sexual attitudes and definitions need to be

ascertained as these may have caused a premorbid sexual dysfunction which may be exacerbated by the cancer or the premorbid attitudes may so vastly contrast the patient's current reality, that he develops a sexual dysfunction (Lemon, 1993).

To facilitate sexual adjustment, the patient may need to expand his definition of sexuality and alter his sexual attitudes and beliefs. Often, the patient will have to modify his traditional societal roles about who is active and who is passive in the sexual encounter. He may also have to dispel his personal definition and attitude that sex is equal to intercourse and broaden these definitions and attitudes so as to include psychological aspects of sexuality, in other words, sensuousness, intimacy and communication (Althof & Levine, 1993; Donahue & Gebhard, 1995; Farrow, 1990).

### **Communication**

Many couples may struggle with open and honest communication post-diagnosis and may become dishonest, critical or incongruent in their communicative messages to each other. Other couples may not communicate at all. Communication post-diagnosis may be largely dependent on the quality of communication that the couple engaged in pre-diagnosis. Couples who always managed to communicate well pre-diagnosis may be at an advantage over couples who lacked communication, post-diagnosis (Althof & Levine, 1993; Lemon, 1993).

It has been recommended that patients and their partners address the issue of communication as early as possible after diagnosis. Partners may need to address taboos and learn how to communicate in a functional way, for example, partner criticism, especially if it is harsh or sharp, may result in that partner severely limiting his sexual participation in future (Althof & Levine, 1993; McCammon et al., 1998).

## **2.4 Premorbid personality and other factors that may serve to facilitate or hinder sexual experiences post-diagnosis**

This section has been divided into two separate sections. The first deals with premorbid personality factors that may facilitate or hinder sexual adjustment; and the second with other factors.

### **Premorbid personality factors**

Premorbid personality may refer to the individual's personality prior to his cancer diagnosis. Premorbid personality aspects such as the developmental level of the male, his coping or defence mechanisms, his locus of control, attributional style, self-efficacy, introversion or extraversion and frame of reference may greatly hinder or facilitate sexual adjustment post-diagnosis. These premorbid personality factors are addressed in the following sections.

### **Developmental level of the patient**

A 65 year old patient may possess better abilities to communicate with his partner about sexual matters than a 25 year old. This may be due to his advanced psychosocial developmental stage as indicated by Erickson's stages of psychosocial development (Louw, 1991). The 25 year old patient who is in Erickson's stage termed intimacy versus isolation may be especially prone to isolation. Having cancer may decrease self-image and body-image and may result in exaggerated social withdrawal as compared to a healthy individual (Rabin, 1980).

On the other hand, the 65 year old patient in Erickson's stage of integrity versus despair, may or may not have successfully resolved the previous developmental crises. If his resolution of the previous crises were successful he may have achieved ego-integrity and wisdom, which may facilitate communication about sexual matters with his partner (Donahue & Gebhard; 1995, Louw, 1991).

### **Coping/defence mechanisms**

The particular defence mechanisms that a cancer patient engages in may affect his sexual adjustment to his diagnosis and his sexuality. Ineffective defence mechanisms that are utilised by the patient, in other words repression, projection, reaction formation, rationalisation, fixation/regression, identification, conversation, denial, negation, isolation, undoing and compromising may hinder the patient's sexual experiences post-diagnosis (Meyer et al., 1989).

Coping mechanisms entail conscious, rational ways of dealing with anxiety and may include such strategies as intellectualisation, generalisations and humour (Reber, 1995). Intellectualisation focuses on the analysis of problems rather than the emotive content of them. Generalisations serve to make judgements about entire

classes of people rather than individuals thus depersonalising the problem. Humour may also be utilised to make light of the gravity of a problem (Reber, 1995). These coping mechanisms may be employed by the patient to deal with his sexuality.

### **Locus of control and attributional style**

A male cancer patient under palliative care may have an external locus of control and may believe that he has no control over the happenings and course of his life. This individual will remain passive in his approach to his sexual adjustment (Mayer & Sutton, 1996).

On the other hand, the patient with an internal locus of control (he believes that he has an influence on his behaviour and life course) may be more pro-active in his sexual adjustment (Louw, 1991).

Attributional style may also influence the male cancer patient's sexual adjustment. Attributional style is the extent to which individuals attribute negative outcomes to internal, stable and global causes or external, unstable and specific causes. Attributional styles that are internal, stable and global in relation to negative events may foster in that individual a learned helplessness. Learned helplessness is the conditioning of an individual from being exposed to uncontrollable negative events which eventually result in the individual feeling that he is powerless and he literally gives up (Baron & Byrne, 1994).

The male cancer patient under palliative care with a good attributional style will evaluate positive events in an internal, stable and global way and negative events in an external, specific and unstable way. An example of this would be the patient who has made a successful attempt at being intimate with his partner. He would reason as follows: 'I am a good person (internal), I could do this any time (stable), I succeed because of who I am (global)'. If the patient with a good attributional style failed at initiating intimacy he may reason: 'I failed because she has a bad attitude (external), I only failed this time (unstable) and maybe it's because her soap opera was about to start (specific)' (Mayer & Sutton, 1996).

The patient with a poor attributional style will show the opposite pattern and may develop a learned helplessness towards sexuality. He may believe that sexual adjustment is beyond his control and may give up trying (Louw, 1991).

### **Self-efficacy regarding sexuality**

Self-efficacy is the expectancies and beliefs of an individual about whether or not he can perform a specific behaviour. In the male cancer patient under palliative care, self-efficacy regarding sexuality may encompass his beliefs regarding his capabilities of being a sexual being, both physically and psychologically and all that it entails, for example sustaining his relationship with his partner, communicating openly and honestly, ability to attain and achieve erection and ejaculation, ability to satisfy his partner, et cetera (McCammon et al., 1998; Sue et al., 1994).

### **Introversion/extraversion**

Because the extravert has been identified with characteristics such as being sociable, active, assertive, lively, carefree, dominant, sensation-seeking, venturesome and showing greater interest in the opposite sex; it may follow that the extraverted male cancer patient may show greater sexual adjustment post-diagnosis (Mayer & Sutton, 1996; Rabin, 1980).

The introvert on the other hand is found to be preoccupied with his/her own thoughts, feelings and imagination, shows less interest in the opposite sex, prefers to engage in activities alone, for example reading, appears aloof and sometimes asocial (Meyer, Moore & Viljoen, 1989). Mayer & Sutton (1996) state that introverts tend to experience more loneliness and are less experimental and less frivolous in their sexual activities than extraverts. Thus the introverted patient may encounter more frustrations and limitations in his sexuality.

### **Frame of reference**

For some individuals, sexual behaviour and values may be based on their philosophy and its associated beliefs. Some fundamentalist religions place acute restrictions on sexuality and prescribe severe punishments for those individuals who practice these restrictions which are regarded as sinful (Castillo, 1997; McCammon et al., 1998).

For the cancer patient who engages in such a sexually restrictive philosophical stance, sexual adjustment may be hindered (Castillo, 1997). It may also be true, however, that this individual had never been sexually 'healthy' pre-diagnosis because of his philosophy and its severe beliefs regarding sexuality. Any individual adopting such rigid beliefs may be crippled with anxiety and conflict regarding sexuality regardless.

The patient who adopts a philosophical stance that is more liberal and open regarding sexuality may facilitate sexual adjustment (Donahue & Gebhard, 1995).

### **Other factors**

Other factors influencing sexual experience may include the age of the male, the amount of time elapsed since diagnosis, his degree of dependency and the quality of his interpersonal relationships.

### **Age**

The age and developmental level at which the patient may facilitate or incapacitate his sexual experiences (Lemon, 1993). This is also dependent on his previous successful or unsuccessful resolutions of developmental stages (Meyer, et al., 1989).

### **Time elapsed since diagnosis**

Depending on how much time has passed since his diagnosis and depending on the individual, he may be in any of the stages of adaptation/grief according to Kübler-Ross (Lemon, 1993; Louw, 1991; Reeve, 1998).

Whether the patient and the partner are in the denial, anger, bargaining, depression or acceptance stage may facilitate or hinder sexual experiences. Possibly, the best stage for sexual adjustment is the acceptance stage as the individual has now come to accept his diagnosis and prognosis (Donahue & Gebhard, 1995; Gilliland & James, 1997). The patient and his partner may be in different stages, which render sexual adjustment difficult.

### **Degree of dependence/independence**

The progressive nature of cancer, especially in the terminal stages, renders the patient more dependent on others. This is so, as the male may no longer be capable of working and as such must rely on others financially. This dependency often filtrates many other areas of the patient's life such as feeding, bathing, dressing, toilet functions, mobility and preparation for sexual activity. Often, this shift from independence to dependence leaves the patient with a shattered body-image, self-esteem and confidence.

Siösteen et al., (1990) stated that 'independence in activities of daily living and a good mental condition, free of anxiety and depression, are likely to increase self-esteem and feelings of attractiveness as a partner, both of which are essential in sexual relations. An active and fulfilling sex life will also improve overall adjustment and quality of life. Thus, alterations in quality of life and sexuality seem to be interwoven and reinforce one another' (p.294).

### **Interpersonal relations and support**

The partner of the male cancer patient under palliative care may be the most important significant other in either facilitating or hindering his sexual experiences (Persaud, 1977). Partners of patients may react with a sense of resignation, entrapment and/or isolation. The partner may be fearful of the massive responsibilities he/she may have to endure. Fear may also include sexual and fertility concerns and this may give way to anger, anxiety, depression, fear, guilt, loneliness and frustration. The partner may too experience a feeling of disinterest in sexual activity and may view the patient as unattractive, distasteful or asexual. Fear of hurting the patient, dislodging catheters or colostomy bags, or tiring the patient, may become issues. Also caregiver burnout and fatigue may render the partner depressed and distressed.

In the case of the male cancer patient under palliative care, the healthy partner becomes just as vulnerable to sexual dysfunction as the patient. Reactions of this kind may make the patient feel less attractive and less competent and as such will further hinder his sexual adjustment (Griffith & Lemberg, 1993).

Lemon (1993) and Rabin (1980) have emphasised the importance of interpersonal support between partners in the facilitation of sexual adjustment. The key component to this is open and honest communication. It has also been recommended that the couple undergo sexual therapy.

## **2.5 Homosexuality**

Homosexual individuals may face many challenges regarding their sexual orientation. These include issues of disclosure to both family and healthcare providers, discrimination and misconceptions which may lead to social isolation and stigmatisation.

A search for studies that have looked specifically at the homosexual male's experience of sexuality whilst under palliative care rendered a response of 'no results'. The only studies found relating to palliation and gay or lesbian patients included studies on the patients' preferences to be treated at home or within a hospital or hospice.

The terminal experience of homosexual men may be negatively affected by the difficulties described above; it is not clear how these would affect the sexual experience.

Smolinski and Cohen (2006) have written an article in which they state: 'the needs and desires of lesbians and gay men with cancer at the end of their lives are not fundamentally different from any other dying individual's needs' (p. 51). Furthermore, Stein and Banuck (2001) completed a 64-item survey to ascertain the preferences in homosexual individuals regarding end-of-life care. It was found that this community requested stronger and more intensive palliative care than the heterosexual community in that they wanted holistic care, not just medical support and that they requested that their healthcare providers are equipped with superb communication skills.

## **2.6 Treatment and programmes addressing sexuality**

This section will give attention to the interdisciplinary care that is required addressing sexuality in the male cancer patient with specific reference to the PLISSIT model.

### **Interdisciplinary care**

The patient is often left with many questions, most of which he is too embarrassed to ask the medical staff providing palliative care. These concerns appear mainly to revolve around sexual ability and sexual satisfaction in terms of both the patient and the partner (Ide & Ogata, 1995; Lemon, 1993; Reeve, 1998).

Medical staff often cannot answer, or avoid questions on sexuality. Rabin (1980) has suggested the reason for this is largely based on fear and ignorance on the part of the medical staff.

Griffith & Lemberg (1993) suggest that addressing sexuality should not await questioning by the patient but should begin soon after diagnosis. The responsibility of

addressing sexual issues is shared among many professionals: doctors, nurses, social workers, psychiatrists, psychologists, occupational therapists and physiotherapists. These professionals together can offer the patient medical, supportive and functional (educational and practical) advice towards aspects of sexuality (McAlonan, 1995; Rieve, 1989).

### **The PLISSIT model**

The PLISSIT model, proposed by Annon in 1976, is a widely used sexual intervention programme used for individuals with severe injuries, disease or sexual dysfunction (Griffith & Lemberg, 1993; Stausmire, 2008). The PLISSIT model proposes four stages of intervention that can be utilised by the healthcare professional team members according to their knowledge and comfort (Lemon, 1993). PLISSIT is an acronym for the following stages of sexual rehabilitation:

- P - this is the permission stage in which the individual and his partner are encouraged to discuss their sexual concerns and problems. The therapist may assure clients that their feelings, thoughts and concerns are not uncommon.
- LI - in this stage limited information is given to the individual and his partner that may dispel myths, clear up misconceptions, give anatomical and statistical information and educate the client on effects of medication, drugs and alcohol on sexual functioning. Giving the client and his partner such information may help to alleviate some of their anxieties.
- SS - in this stage of the PLISSIT model, specific suggestions are made to the client and his partner. A specific course of action is proposed and may include joining support groups, experimenting with various sexual aids and techniques/or doing certain exercises.
- IT - the last phase in the PLISSIT model of intervention is intensive therapy. This phase is utilised when the previous three phases have not had any or very little effect on the client and his partner. This includes highly specialised therapy with a psychologist or sex therapist (Griffith & Lemberg, 1993; Lemon, 1993; McCammon et al., 1998).

Hughes (2000) proposes that healthcare professionals providing palliative care to cancer patients become well versed in using the PLISSIT model to assess patients' sexual concerns.

## **2.7 The role of palliative care and healthcare professionals in addressing sexuality**

A qualitative study by Hordern and Street (2007) sought to explore the ways that both patients and healthcare workers communicate about sexuality in cancer. This study used a reflexive inquiry approach with semi-structured participant interviews with cancer patients and healthcare professionals. The study was based in Australia and included 50 patients diagnosed with cancer and 32 healthcare professionals who had worked in palliation for a minimum of 12 months. All participants had to speak English.

It was found that most patients wanted information, support and practical suggestions about how to cope with their sexuality after a diagnosis of cancer. In contrast, many healthcare professionals assumed that the patient would not be interested in this type of communication as they believed that the disease should be the focus. In addition, most healthcare professionals were found to have very limited understanding of patient sexuality and many stereotypical assumptions were made about patient sexuality based on age, sex, diagnosis, culture, and partnership status.

The conclusion of this study was that healthcare professionals needed to address their own understanding of sexuality in order to comprehend how this may affect patients with cancer, particularly on an emotional level.

The research by Hordern and Street (2007) has elicited valuable information regarding patients' needs and healthcare professionals' limited knowledge and understanding of sexual issues for the cancer patients. However, care must be taken in generalising the findings to a South African context. Also only English speaking participants were used and the findings may not be relevant to a population with diverse cultures. In addition this study did not indicate the stage of cancer, and thus a similar study performed only on patients with end stage cancer may elicit different results.

In contrast to the findings of Hordern and Street (2007) that healthcare professionals do not address sexuality in palliative patients, a study conducted by Cort (1998) at the Guy's Hospital in London, surveyed the attitudes of Hospice nurses towards sexuality in cancer patients. It was found that: 'Sexuality was acknowledged to be both important and

relevant in Hospice nursing. A high level of awareness of sexual and relationship issues were apparent, reflecting broadly liberal attitudes' (pg.54). This finding is encouraging but it is certainly not reflected in other papers. Cort's study does not state whether or not these nurses had received specific training or education in addressing sexuality with their patients.

## **2.8 Phenomenology as a research method and its application to male palliative care cancer patients and their sexual experiences**

From the outset of conducting research, the researcher needs to select not only a topic but most essentially a paradigm or a research method that is most likely to address the research question. Paradigms are frames of references from which we attempt to understand social and human phenomena. As such paradigms include theories and methods as utilised by the researcher. These theories and methods hold implicit and explicit assumptions, which allow research results to be easily communicated to other professionals (Creswell, 1994).

Broadly speaking, there are two main paradigms within the field of human and social research. These include the quantitative methodologies and the qualitative methodologies of inquiry. The assumptions of these two paradigms are often diametrically opposed and as such their relative advantages and disadvantages show the same pattern (Neuman, 1997).

### **Phenomenology as a research method**

Giorgi (1983) defines phenomenology as 'the study of the phenomena of the world as experienced by conscious beings and it is a method for studying such phenomena. When a phenomenologist uses the term "phenomena" he means that whatever is given in experience is to be understood simply as the correlate of an act of consciousness and it should be described precisely as it presents itself. In other words, the existential claim of what is presented is withheld and this frees the phenomenologist to examine what is given more closely. Thus a "phenomenon" in phenomenological parlance, shortly speaking, is precisely what is given to consciousness as a person experiences it' (p.144-145).

Thus phenomenological studies are concerned with human experiences which may also be referred to as phenomena but as they occur from the individual's perception or frame of reference (Becker, 1987; Meyer, Moore & Viljoen, 1989; Reber, 1995). These

phenomena are examined through detailed descriptions as given by the individual being studied (Beck, 1994). The phenomenologist should approach these descriptions without imposition of personal theories, values, ideas or specific system as the aim is to comprehend the phenomenon in its full reality as they manifest themselves. This process is known as **bracketing**, as the researcher needs to 'bracket' his/her own experiences, theories and beliefs to understand those of the informants as they truly are (Beck, 1994; Creswell, 1994). To achieve this bracketing, the phenomenology researcher has to be open-minded and prepared to enter into the world of the individual who is being studied (Ablamowicz, 1992; Guglietti-Kelly & Westcott, 1990).

Briefly, the method of phenomenological studies involves extensive and prolonged interaction with a limited number of individuals to ascertain patterns and themes and relationships of meaning (Beck, 1994; Creswell, 1994).

Because phenomenology is a qualitative method of research, it is frequently criticised as lacking method and as such as being unscientific. Giorgi (1983), however, responds to this criticism by stating that even within the quantitative methods of research, the data obtained must pass through the researcher's consciousness and as such is experienced by that researcher. In this way all observations must have subjectivity and if 'subjectivity' entails that which is apprehended and not what something really is, then the term 'objectivity' may be considered erroneous as it has no reference to a human object. However, according to phenomenology all objective realities or phenomena are constituted by and for human subjects (Du Preez, 1985; Quail & Peavy, 1994).

The phenomenon that is being studied in a phenomenological study may be referred to as the object. It is the object of consciousness (Angus, Osborne & Koziey, 1991). This object may be a perception or an experience of an individual eg: the experience of sexuality in the male cancer patient undergoing palliative care.

To further clarify the field of phenomenology as a research method, specific phenomenological concepts will now be addressed.

### **Phenomenological concepts**

The phenomenological concepts addressed below are not exhaustive as only those concepts relevant to the study of cancer and sexuality have been included.

## **Being-in-the-world**

This concept has three broad categories: Umwelt, Mitwelt and Eigenwelt.

**Umwelt** refers to the physical and biological world around the individual but it is not objective, rather the Umwelt is the individual's perception of his/her relationship to the physical and biological world around him (Maddi, 1996).

**Mitwelt** refers to the individual's social world, ie: the people around him/her and with whom he/she interacts. Again, Mitwelt is not objective but rather the individual's perception and orientation towards others and his/her interaction with others (Maddi, 1996).

**Eigenwelt** literally means one's own world and refers to internal processes and dialogues and one's relationship with oneself. In short, it refers to the operation of self-consciousness (Maddi, 1996).

These three modes of being-in-the-world may represent a frame of reference for the individual from which he/she perceives and experiences the biological, social and personal world around him/her.

## **Lebenswelt**

Lebenswelt is what Husserl defined as those experiences that an individual experiences directly each day (Thévenaz, 1962). Lebenswelt literally means life-world. This everyday direct experience of the world by the individual serves as the starting point of existential-phenomenology and is the foundation for all conceptual philosophy and knowledge. Lebenswelt constitutes a pre-reflective life world from which scientific knowledge can be based using reflective thought processes.

## **Intentionality**

The existential-phenomenological position holds that every situation that an individual faces in his/her life requires a decision (Maddi, 1996). Even if an individual chooses to ignore a situation, this is still a decision. These series of everyday decisions is what phenomenologists believe to be the basis to understanding the individual's core tendency in striving toward becoming an authentic being.

This directional relationship between the individual and his/her decision and the world, implies that every moment and situation in the individual's life expresses what phenomenologists refer to as intentionality (Maddi, 1996). Intentionality is closely related to our consciousness and indeed refers to the ongoing nature of our consciousness. We are never merely conscious but must be conscious of something. This something is the object of our consciousness. This object may be concrete or abstract (Giorgi, 1983). Consciousness is therefore characterised by intentionality as when one refers to consciousness, one is implicitly or explicitly also referring to its intended object (Du Preez, 1985). Freud also believes that all behaviour is motivated or has intention but where he believes this intention to be largely unconscious, existential-phenomenologists believe it to be conscious (Maddi, 1996).

### **Phenomenological reflection**

The term 'reflection' as utilised in a phenomenological orientation was initially used by Sartre when he distinguished a reflecting consciousness and a pre-reflexive consciousness (Thévenaz, 1962).

Reflection of consciousness or phenomenological reflection refers to the individual making that which was implicit in a certain experience, explicit (Brockelman, 1980). To do this, the individual has to raise the particular experience to his/her consciousness and express the object of his/her consciousness at that moment. In this way the experience is relived within the consciousness and expressed, and thus made explicit through phenomenological reflection (Du Preez, 1985).

Brockelman (1980) has mobilised three stages which he termed 'moments' within this type of phenomenological reflection. These will be briefly addressed below.

- i. Attempting to gain access or contact with the experience constitutes the first moment. The individual needs to confront and relive the experience as it is present in the consciousness.
- ii. This moment necessitates that the individual 'steps back' from the experience in order to be reflective about it. In this way the individual attempts to distance himself/herself from the experience and to make sense of it. This moment entails the disjunction between the expression of the experience and the actual experience, ie: the period between the first and third moments.
- iii. The final moment of phenomenological reflection according to Brockelman (1980) entails insight into the experience. This insight is implicit or explicit in

the individual's essential description of his/her experience. For the listener to gain insight or meaning of the experience, he/she needs to eliminate personal theories and insignificant events in order to obtain the essence of the phenomenon under examination as experienced by the speaker.

### **Ontological anxiety and guilt**

As was stated above, phenomenologists view individuals as living within a world that requires a series of decisions and choices. Any decision entails a certain amount of overriding emotion which may influence the ultimate decision that is made within the realm of existential decision making. Phenomenologists speak essentially of two influencing emotions: anxiety and guilt (Maddi, 1996). Any decision involves either thrusting the individual forward into the unknown or unpredictable future; alternatively, the individual may decide to remain with the familiar and the predictable. An individual who chooses to remain in status quo may forgo challenges and opportunities that may await him/her in the future and as such experiences anxiety; however, pushing forward into the future may foster a considerable amount of anxiety. This anxiety and guilt is referred to as ontological as they constitute inevitable parts of being human.

Phenomenologists emphasise that ontological anxiety should be optimised and ontological guilt minimised. In this way, the individual may reach his/her full potential through persisting in the face of anxiety (Maddi, 1996).

### **Thrownness**

Existential-phenomenologists believe that through mental activity, one can achieve freedom and create one's world (Maddi, 1996). However, limitations are frequently imposed on this ability to create freedom and one's world. These limitations may be biological or social and must be accepted by the individual as necessities or givens in life. These limitations or necessities are referred to as facticity or thrownness of existence (Spiegelberg, 1965).

Necessities and possibilities are differentiated in the phenomenological view. Necessities entail those limitations (usually biological in nature, eg: disease) excluding life situations and other personal commitments. Often the individual may confuse possibilities with necessities and as such hinder their tendency to become an authentic being by blaming others, denying their plight or ignoring their ontological guilt. These individuals may lack the courage to face ontological anxiety (Maddi, 1996).

## **Human bodiliness**

Perhaps, of all the phenomenological concepts described above the concept of bodiliness may constitute one of the most important concepts for the male cancer patient.

According to Kruger (1979), individuals are mostly in a pre-reflective state concerning their bodies. Individuals are largely unaware of their bodies and simply take them for granted until something happens to their bodies and infringes on this pre-reflective state. This may occur, especially after a cancer diagnosis as the body steadily loses its functioning and instead of being an instrument to fulfilling the male's potential, it is suddenly a huge barrier and hindrance to this fulfilment. The individual then becomes reflective about his body and what it used to do and the body becomes an object of consciousness.

Kruger (1979) emphasised three aspects pertaining to the concept of human bodiliness.

- i) The individual exists in the world as a body. The individual may take his/her body for granted although it is instrumental in everyday tasks.
- ii) Everyday tasks make certain demands on the body and the body must accommodate these demands in order to successfully achieve the goal of the task.
- iii) The human is characterised by an upright posture, which in itself constitutes a task that needs to be maintained throughout the individual's lifespan. This upright posture signifies awakens and distances individuals from the ground and thus the world. Furthermore, the individual first begins to use the pronoun 'I' when he/she has acquired this upright posture. By using the pronoun 'I' the individual distinguishes himself/herself as a separate entity to others and the world.

Bodiliness encompasses not only the object of the body but may also be viewed as central to one's existence. Citing examples: spirituality may be expressed through bodily position eg: the position of prayer. Communication may be facilitated by the sitting and upright posture position but hindered by completely a supine, prone or erect standing posture. Thus the body is fundamental to the very experiences of being human (Du Preez, 1985).

The phenomenological concepts described above will be related to this study later in this chapter and to the research findings.

### **Methodological assumptions of phenomenology**

Phenomenology is not concerned with the 'why?' of certain phenomena but rather asks the question 'what?' In this way phenomenology constitutes descriptive research (Rosnow & Rosenthal, 1996). The researcher is attempting to describe a particular phenomenon, not to render causal explanations. Phenomenological research attempts to gain a deeper understanding of individual experience which may lead other researchers to ask the question 'why?' or 'how?' Thus, descriptive research may be a necessary first step to later research and as such phenomenology should not be considered superior to positivistic research but rather as complementary.

The phenomenological researcher needs to approach the descriptions of the phenomenon under study in an empathic way, ie: he/she needs to attempt to view the descriptions from the individual's frame of reference. The individual's frame of reference refers to the meaning he/she has attributed to the experience/phenomenon which has emerged through a series of interpretations, perceptions and decisions made by the individual (Bogdan & Taylor, 1975). This meaning that is attributed to the phenomenon constitutes the individual's truth. Truth in a phenomenological sense is created according to an individual's own perception of events and may vary over time (Spiegelberg, 1965).

Although phenomenological research can never be purely phenomenological (due to the researcher's own preconceived beliefs which will always be present despite stringent attempts at bracketing), phenomenologists believe there to exist an underlying structure common to the phenomenon under investigation. This common underlying structure is believed to emerge across numerous situations though repeated investigations of the phenomenon over time (Valle, King & Halling, 1989).

In the previous sections, phenomenology has been discussed as a research method. The following section supplies a justification for the use of phenomenology in researching the male cancer patient under palliative care and his sexual experiences. The concepts described above will be integrated into this justification.

### **The choice of a phenomenological research method in the arena of the male cancer patient under palliative care and his sexual experiences**

In attempting to gain deeper insight and understanding into the experience of sexuality for the male cancer patient, a phenomenological study would be best suited to this

cause as it is a descriptive study, which has this very purpose (Rosnow & Rosenthal, 1996). This study is not attempting to establish causality or linear relationships between variables, nor is it concerned with establishing relationships between variables and as such does not require a quantitative method of inquiry (Neuman, 1997).

On reviewing previous studies on cancer and sexuality, many have focused on the physiological aspects of sexuality, which by its very nature demands a quantitative approach as physiological data is measurable. No phenomenological studies on this topic have been found.

In justifying the utilisation of a phenomenological approach in this study, one can return to the fact that human sexuality constitutes a complex phenomenon in that social, cultural, psychological, physical, personal and spiritual dimensions are all intertwined. To attempt to quantify the human sexual experience would be to do it a great injustice. As Daniluk (1993) who conducted a phenomenological study on the experience of female sexuality states, 'Phenomenological methods are particularly appropriate for the examination of meanings and experiences about which little is known or that are fraught with erroneous assumptions and misinformation' (p.55). Sexuality regarding cancer patients is surrounded by numerous myths and stereotypes. Similarly the phenomenological researcher, Halling (1994), emphasises that 'in order to advance as a science, we must return to accurate observations of inner experience. We must fit to inner states words that remain grounded in phenomenology' (p.76).

In order to allow the participants of this study to describe their sexual experiences and to avoid the reduction of these experiences to the researcher's preconceptions, the researcher used the open-ended interview which is consistent with phenomenological methodology (Becker, 1987). Open-ended interviews, also called unstructured interviews are defined by Rosnow & Rosenthal (1996) as '...questions that offer the respondent an opportunity to express feelings, motives, or behaviour spontaneously' (p.416-417).

In Daniluk's (1993) phenomenological study on the meaning and experience of female sexuality, she states that the open-ended interview empowers the individuals to express their experiences in their own words and without sanction. This she felt, was particularly important to such a sensitive and intimate topic such as sexuality. Similarly, Helgeson (1992) explains that the aim of phenomenological investigation is to allow a phenomenon to reveal itself in its full intensity and that the most common

and appropriate method that succeeds in allowing the phenomenon to show itself is the open-ended interview, which is taped and transcribed.

The phenomenological interview can be likened to a conversation. It is an interaction which takes place in the context of a relationship. This interaction seems to provide a rich data source of human structures of experience. To facilitate openness and generosity in divulging information, the participant needs to feel comfortable and trusting toward the researcher. The researcher is not interested in responses that are believed to be socially appropriate but is interested in the truth of the phenomenon as experienced by the individual (Bowling, 2002; Polkinghorne, 1985).

Issues concerning validity and reliability in phenomenological research are addressed in a different manner to traditional quantitative scientific inquiry (Quail & Peavy, 1994). The aim of phenomenological research is to access essential meaning rather than facts and statistics. Phenomenology deals with structures and totalities of experience, not with discrete units of data. As such validity and reliability is an unfolding process that reveals meanings as they are experienced by individuals. Quail and Peavy (1994) also state that trustworthiness on the part of the researcher is essential to the validity and reliability of the study. This trustworthiness is established by the researcher's ability to be entirely convincing and thorough in his/her presentation of the research in terms of the original aims of the study.

In approaching the question of validity and reliability of a phenomenological study, Register & Henley (1992) state: 'The best measure of generalisability, reliability and validity in (phenomenological) research, however, is ultimately in the correspondence between the results obtained and the experiences you, the reader, yourself have had' (p.472). In this study the transcriptions and the results have been made transparent so that the reader may scrutinise them and as such pass personal judgement on the credibility of the study. These results are also given to the participants of this study to ascertain validity and reliability through correspondence of actual experience and of results.

Phenomenology accepts the cancer patient, as it does all individuals, as being-in-the-world and as perceiving meaning from all his experiences including his sexual experiences. The trauma of cancer may result in the male being confronted with many of the phenomenological concepts such as phenomenological reflection, ontological anxiety, thrownness and human bodiliness, in a severe form. In order to fully capture the complexity of the male's sexual experience under palliative care, phenomenology as a method of inquiry seems most adept.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1 Aim of the study

To explore how males with advanced cancer under the care of Hospice Wits Houghton experience their sexuality.

#### 3.2 Objectives

Four main objectives of the study:

- 1) To explore how the disease process influenced experiences of masculinity.
- 2) To explore how gender roles have been affected by cancer.
- 3) To explore how physical intimacy with partners has been affected by the disease.
- 4) To explore the effects on the experience of emotional intimacy with partners.

#### 3.3 Methods

##### Study design

This is a qualitative study which utilised phenomenology as its design. In-depth individual interviews were conducted. As data saturation was achieved with low numbers, a small sample size was utilised.

##### Study site

Hospice Wits Houghton in Gauteng currently serves 280 terminally ill patients. It services the greater Johannesburg and Witwatersrand areas. These include urban areas and townships. The male patients included in the study are culturally diverse with approximately 65% white males; 50% English speaking and 15% Afrikaans speaking; 27% black males, including mostly Zulu and SeSotho speaking patients; 6% Indian male patients and 4% coloured male patients. Of these male patients 60% were retired, 26% were employed and 14% were unemployed at time of diagnosis. Services

include home-based care as well as in-patient care. Government as well as private and medical aid patients are included. A letter of permission to conduct the study from the site is included as an appendix.

### **Study population**

Of the 280 patients under the palliative services of Hospice Wits, 152 are male cancer patients.

### **Inclusion and exclusion criteria**

This study focused on male patients with cancer, thus patients with HIV/AIDS or chronic non-malignant conditions are excluded.

Further exclusion criteria to the study included:

- Comatose patients.
- Patients who are deemed frail in terms of the researcher believing that patients are too exhausted or dyspnoeic to participate fully in in-depth interviews.
- Patients with cognitive inabilities rendering them unable to communicate effectively in relating their experiences.

Inclusion criteria included:

- Male
- Diagnosis of cancer
- Under palliative care at Hospice Wits Houghton
- Any language
- Any sexual orientation

### **Sampling**

This was achieved by purposive and convenience sampling. It was purposive in that males with cancer at Hospice Wits Houghton were sampled, in other words, the participants had these predefined characteristics necessary for the study. This sample also sought to include a variety of races, cultures and sexual orientation, thus ensuring a maximum variation sample.

The sampling was also convenient in that male cancer patients who were scheduled for home-visits during the time-frame for data collection were approached to be interviewed.

The sample size was not predetermined and relied on data saturation, ie: once themes and topics became repetitive in that little new information was gleaned from further interviewing. This was achieved after interviewing six participants.

### **Ethical considerations**

The very nature of the aim of a phenomenological study: to access the individual's life world, is obtrusive. In this study, this obtrusiveness is further exacerbated by the sensitivity of the topic of sexuality. First and foremost, the researcher has a responsibility to respect the rights, needs, values and wishes of the participants (Rosnow & Rosenthal, 1996). The researcher was also the treating doctor which may well have constituted a subtle perception of coercion. Patients were assured that their care would not be impacted on should they not wish to participate. Ten patients were approached of which four declined to be participants.

The following safeguards as listed by Creswell (1994) were employed to protect the participant's rights:

- The research topic and objectives were articulated clearly in order to be well understood by the participants.
- Each participant personally provided consent to participating in the study.
- Transcriptions, interpretations and reports were made available to the participants if they wished to see them.
- In the decision-making process in the study, the researcher firstly considered the rights and protection of the participants.
- The researcher honoured participant anonymity and maintained complete confidentiality.

This study employed all five of Creswell's (1994) ethics listed above. Furthermore the ethic of offering the participants a debriefing session if they so required, (Rosnow & Rosenthal, 1996) was employed. The participants were informed of this session prior to the actual interviews and they were contacted telephonically a few

days after the interview to ascertain how they felt after the interview and if they required debriefing.

Ethical approval to conduct this research was obtained from both HPCA's and UCT's research ethical committees. Permission to conduct the study with Hospice Wits patients was obtained by the site.

Informed consent was made a priority in this study in order to ensure that each participant understood the nature of the study and that they were free to discontinue at any stage without any detriment to them. This was imperative due to the sensitive nature of the study as well as the participants being of a vulnerable population by the nature of their advanced disease.

The patient with incurable cancer is recognised as a vulnerable population. The patient and their family are faced with many issues, often very emotional, relating to impending death. It is imperative that participants are mentally capable of providing informed consent. Furthermore, patients may be frail and in pain, and simply too exhausted to participate in research. Patients may also feel that they are expected to participate in order to please the researcher or to avoid disapproval. This study relied on informed consent and the explicit knowledge that participants may withdraw from the interview at any time without any detriment. In addition, when the researcher perceived that a participant was exhausted, the interview was terminated and the patient chose to reschedule or withdrew completely.

When a patient became unduly distressed by the interview, the tape recorder was switched off immediately and counselling offered. It should be noted, however, that the interview in itself served as therapeutically beneficial.

A participant that was distressed was to be recognised by careful observation of both verbal and verbal cues by the researcher. In addition, participants were asked during the interview if they were feeling distressed, or if the interview was making them upset and if they preferred to terminate the interview. This distress protocol was also included in the initial informed consent form that each participant was required to read and sign. Fortunately, none of the participants of this study opted to terminate the interview due to distress.

### **3.4 Data collection and analysis**

#### **Data collection tools**

Two tools were developed for this study: a biographical questionnaire and an unstructured interview.

The biological questionnaire was developed in order to elicit the basic biographical information related to each participant. The items included in this questionnaire were based on the literature review and discussions with the supervisor of this study, as well as with colleagues comprising doctors, nurses, a psychologist and a sexologist. Each gave inputs into what items would be relevant to this study.

The unstructured interview was formed in a similar way; in consultation with colleagues and the literature review. Its development was also based on the phenomenological principle described in the literature review. Questions were designed to be open-ended so as to decrease the potential of biasing answers. Moreover, the design allowed enough freedom for the participants to guide the flow of the interview. However, it also had the capacity to steer the participant back to the topic, should they tangene.

#### **Data methods**

Participants were recruited from Hospice Wits. Male patients who had a scheduled doctor's home-visit during the time-frame of the study were approached. Doctor's home-visits were determined by home-care sisters assessing patient need. Each participant was provided with an informed consent form and given a few days to peruse the form and to decide whether or not they wished to participate. If they decided that they did wish to participate, the consent form was signed and an appointment was set up at a time and place convenient for the patient.

A biographical questionnaire was completed. This was to gather background information such as diagnosis, treatment, religion, age and was constructed according to the literature review. Questions were included to elicit information that may potentially affect sexual experiences post-diagnosis.

In order to supplement information, each participant was required to answer a predetermined structured biographical questionnaire. This covered aspects such as

age, specific diagnosis, treatments received, religious and cultural background and sexual orientation. This was developed based on the literature review and in consultation with the research supervisor as well as an independent clinical psychologist who is experienced in phenomenological research.

At the scheduled interview, the researcher used a tape recorder (with the participant's pre-signed consent) and anonymity and confidentiality was reinforced. Field notes were kept by the researcher in order to note observations made during the interview process. These tapes were sent to a transcriber who transcribed the recordings verbatim.

The interviews conducted in this study lasted between 45 and 80 minutes. After asking the research question, the researcher participated very little, intervening only when the participant began to philosophise about experiences or when they diverged from the topic. This was done by gentle persuasion to return to the topic. Although all participants were interviewed by the principal researcher, a research assistant who is a clinical psychologist trained in research methods and research ethics, and who had experience in phenomenological studies, was familiarised in the study to be conducted. He assisted with the development of the biographical interview as well as in independently generating themes from the transcriptions in order to corroborate the themes generated by the principal investigator. Interviews were conducted by the principle investigator in all cases as all the participants were fluent in English.

The interviews of this study were transcribed verbatim shortly following the event. Whilst the interview was being conducted, the researcher noted as many non-verbal cues as could be perceived. Directly following the interview, the researcher also wrote down her impressions regarding the participant's attitude, approach to the interview and any other information she considered relevant. The auditory tape recordings as well as the transcriptions constitute the raw data of the study from which data analysis was conducted (Bowling, 2002).

### **Data analysis**

In order to achieve this complex task of data analysis, the researcher needed to follow sequential steps that rendered the analysis into more manageable sub-tasks. Numerous steps elucidated by different authors were used (Du Preez, 1985). These steps were given to and followed by an independent researcher who assisted in confirming the

themes that arose from the interviews. The procedure of the data analysis utilised in this study is discussed in the following section.

The very nature of the aim of a phenomenological study: to access the individual's life world, is obtrusive. In this study, this obtrusiveness is further exacerbated by the sensitivity of the topic of sexuality. First and foremost, the researcher has a responsibility to respect the rights, needs, values and wishes of the participants (Rosnow & Rosenthal, 1996).

### **Systematisation of data using consecutive steps of analysis**

In order to conduct a phenomenological study on males with cancer under palliative care and their sexual experiences, a method to analyse participants' descriptions needed to be devised. The proposed steps of data analysis included an integration of the methods proposed and cited by Ablamowicz (1992), Colaizzi (1975), Kruger (1979), Polkinghorne (1985) and Wertz (1983). These steps included the following:

#### **Step 1: An intuitive and holistic grasp of the data**

In this step, the researcher read through the descriptions as objectively and open-mindedly as possible to grasp a holistic meaning and feeling for them. The aim of this step was to warrant a naïve understanding of the experience under study without the application of conscious reasoning or study (Kruger, 1979).

Once a holistic sense of the data was obtained, the descriptions were read again with a more reflective attitude to prepare the researcher for the more exacting nature of the following steps.

#### **Step 2: The utilisation of an 'existential baseline'**

This represents the change brought about in experience due to a life event eg: sexuality as a healthy male versus sexuality of a male with advanced cancer.

Due to the permanency of advanced cancer and the drastic consequences on sexuality for the male patient, this step was included in the process of data analysis.

In this step, the researcher noted the meaning of change due to cancer for the participant pre- and post-diagnosis.

### **Step 3: Spontaneous emergence of Natural Meaning Units**

In this step, the data was broken down into naturally occurring units of meaning which emerged spontaneously in the descriptions. This intuitive approach was done by dividing the transcripts into blocks or units that appeared to express one particular meaning. This division of the transcripts into NMU's was achieved by the researcher's judgement which was made as objectively as possible. The researcher needed to therefore bracket theories, assumptions and expectations to glean NMU's that occurred naturally in the text. As such these NMU's should have expressed the participant's meanings of the experience (Du Preez, 1985).

### **Step 4: Constituent Profile Description and first order profiling**

In this step, the emerging NMU's were examined for redundant or irrelevant units. Redundant units were judged to convey identical meanings and irrelevant units were those units judged not to be applicable to this study. These redundant or irrelevant units were discarded and as such a condensed summary of the original raw data remained. This condensed version is what is labelled a Constituent Profile Description and consisted of non-repetitive and relevant statements.

Once the Constituent Profile Description was completed, the intention conveyed through each NMU was expressed by the researcher as concisely and as accurately as possible. This was the first time that the researcher expressed the participant's descriptions and as such is labelled the First Order Profile. In the researcher's expression, implicit psychological aspects of the NMU's were made explicit (Ablamowicz, 1992).

### **Step 5: Second order profiling**

In this step, each NMU was examined and interrelated to the topic under study, ie: how does a particular NMU relate to the question: 'What is the experience of sexuality for the male cancer patient under palliative care?' If certain NMU's did not relate to the topic they were eliminated, further reducing the data. Once the relationship between the NMU and the research question was established, it was translated into psychological terms. This second expression of the participant's description by the researcher is called the Second Order Profile. This step also integrated the existential baseline (Colaizzi, 1975).

### **Step 6: Synthesis of transformed NMU's**

Following Second Order Profiling, the researcher attempted to synthesise the transformed NMU's into descriptive statements. These statements contain only

relevant and non-repetitive information regarding the phenomenon under study. In this step the transformed NMU's were interrelated with each other and with the original transcription.

### **Step 7: Transferring individual experience to general experience**

The above steps were carried out on each individual transcription. What remained for the researcher was to search for a 'golden thread' that ran through all the interviews. This 'golden thread' elicited commonalities in the phenomenon as experienced by the participants in the study. The golden thread refers to those themes that recur for participants in this study. When themes are repetitive and naturally emerged from the transcriptions, this was seen as the golden thread of the study and is reflected in the results section. Thus, this final step entailed that trans-situational experiences of sexuality in male cancer patients under palliative care were synthesised into a general description of this phenomenon (Polkinghorne, 1985).

It is only possible to transfer individual experiences to the general experiences of the participants in this study. A similar study with different participants may render different results, thus in line with descriptive and qualitative studies, generalisation to broader population groups should not be made.

## CHAPTER 4

### RESULTS

In this chapter, the results of the integration of themes from each participant, are presented. The integration is applied by those themes that appear to typify or characterise the experience under study. Appendix 7.5 demonstrates the biographical profile of each participant.

#### **4.1 Introduction**

In an attempt to access the experience of sexuality of palliative care cancer male patients, the following section focuses on the commonalities of themes arising from the participants' descriptions of their experiences. From the outset, it should be noted that each participant used different descriptions, responses and ways of incorporating their experiences into their life worlds. This is expected as each participant exists within a unique context with his own personality dynamics, coping mechanisms, background and set of circumstances which will all contribute to his experience of being-in-the-world.

Variations did occur between participants in terms of the type of cancer, the age of the patient, sexual orientation, cultural background and whether they had a partner or not. These variations may influence participants' conceptualisation of their sexual experiences and the meanings attributed to them as was discussed in the literature review in Chapter 2. Participants who are in a relationship may certainly conceptualise their experiences quite differently from participants that are single.

Age and consequent maturity, developmental stage, sexual orientation, cultural background and period since diagnosis are also likely to affect the meanings attributed to the experience of sexuality for a palliative patient.

Similarly, the type of cancer and resultant degree of debility and disfigurement may well affect the male's experience of sexuality. A patient with a spinal tumour or metastases may be more dependent and may not be able to achieve erection.

Nevertheless these variations provide richness in accessing the experience under study and as such allow for a fuller and more detailed understanding thereof. Differences in certain descriptions will be addressed; however the focus will be on commonalities of themes in order to grasp the essence of the phenomenon of the experience of sexuality in the male cancer patient under palliative care.

## 4.2 **Central themes in the experience of sexuality for the male cancer patient under palliative care**

Common themes emerging from the participants' transcriptions related to topics such as a decline in independence, altered perceptions of masculinity, changes in relationships with (potential) sexual partners. Other important themes related to sexuality included coping mechanisms, the role of religion and sex, and wisdom arising from their experiences. All participants related how healthcare professionals had negatively affected their experiences.

### **Establishment of an existential baseline**

Although the existential baseline was listed as a step in the phenomenological analysis in Chapter 3, it may also be viewed as a central theme for all participants. Most participants established an existential baseline by reflecting on their sexuality pre-cancer and contrasting this whilst under palliative care. This comparison became a source of loss and resulted in frustration and anger. The loss was experienced in many areas of sexuality: the physical sexual encounter, body-image (bodiliness), feeling attractive to partner or potential partners, changes in independence and masculinity, career paths, and changes in relationships.

- “Before I was ill, as I said, I was well built, you know, so the girls like a guy with a good body so I was quite popular with the ladies. Now I feel like I’m less of a man.” Participant A.
- “I don’t normally love and leave it halfway. I used to love right through to the end of the sexual procedure, now I can’t, I know I’ll go right to the middle, she’ll be disappointed, and then? I don’t know what she’ll do thereafter, in my absence.” Participant B.
- “But now after the chemo and at the moment now, I don’t feel attractive. I feel I look like Ethiopia – all thin and bony, and everybody when they see me for the first time now they – it’s such a shock. I can see the shock on their faces. Now I have to deal with that and it’s very hard dealing with people’s reaction.” Participant C.
- “I’ve had great intimacy with, with wonderful women. And it’s not just a sexual thing, uh it’s a whole encompassing part of the relationship and I enjoy it. I do enjoy an intimate relationship, a close relationship, uh, physical both, not sexual only but to be close to someone; I mean that for me is enormous. Where that’s all

gone since this cancer? My head has done something to me that's chased that all away – it's put away in a shelf somewhere.” Participant D.

- “I had dreams of watching my kids grow up, enjoying spending time with them. Career-wise I was very set in my ways. I had a clear career path, I was working my way up the ladder towards um, upper management. I was um ... doing well – had numerous doors open to me. I was climbing the corporate ladder – plans for the future were further studies, maybe even maturing to Masters and stuff like that. Now I don't plan so far forward. I live more for today.” Participant E.

### **Declining independence**

Most participants described their fears about becoming less and less independent as their cancer progresses.

- “I feel like I'm less of a man because if you meet someone while you're sick you're going to be an extra stress factor for them, they don't want to baby you, you know you don't want to be like a baby for them where they have to push you around, take you to the toilet, all these things.” Participant A.
- “She (wife) looks after me ... when my backside, when my faeces was oozing out, she would come and wipe it. I sympathise with her because I'm afraid of arousing her feelings, for nothing, because I'll arouse her feelings, and do nothing.” Participant B.
- “Now I'm confined to being in bed most of the time and that's very difficult for me. And then I sometimes cry about it because I miss going to the movies, I miss seeing my friends. I miss getting in my car and just going, there's a part of me that wants to buy a plane ticket and fly to Cape Town see ... family, and do the things that I used to do ... but I just don't have the capacity ... I have to rely on others ... and it's very annoying and frustrating. So some nights I will shout and scream and then the people in the house get such a shock because I'm actually quite a subdued ... sensitive person.” Participant C.
- “Unfortunately I have to rely on other people to do things that um, I used to do without thinking – going to the shops, buying some sweets or something. If I want to walk around the garden and work on the pool I have to make sure that I'm feeling strong enough to actually do it. And then there mustn't be anything physical. I have lost a lot of my independence. When it comes to driving the car –

where I used to be the primary driver, now I'm sitting – so I'm a sitting passenger. I'm like – feeling a little child on the left-hand side, sort of thing.” Participant E.

- “Afterwards when it came back like it has now, I'm really dependent on people, I'm like a baby, I mean I wear a nappy!” Participant F.

Participant D is fiercely guarding his independence and not allowing any close relationships.

- “I mean as soon as I knew I had cancer I knew I actually didn't want to get involved with anybody. I wanted to cope with it myself. I've just decided, literally since it started, I'm going to go and I'm going to get rid of this first. I'm going to sort this all out and uh I didn't want someone next to me to help me through the process. I wanted to do it myself.”

### **Feelings of masculinity**

Some participants overtly described an altered perception of their masculinity post-diagnosis.

- “... it's (the cancer) taken a lot of my manlihood, because you know, I feel like I'm less of a man. I think I feel like I'm half a man because I feel that women want someone to be proud of.” Participant A.
- “As I said, then you have to rely on people, taking me to the toilet. You know, me being uncomfortable in meeting girls because, you know, which girl is going to want only half a man?” Participant A.
- “I can express myself as a man, but I'm a bit shy. There is that shyness of not wanting to disappoint the other side, for instance, here at home, they are not aware that I am useless, I have never told them, but the time will come that I will tell them.” Participant B.
- “For her I felt less of a man because I had to go to deposit sperm, just in case she wanted kids.” Participant F.

Decreased feelings of masculinity were closely related to the loss of their previous roles as a man and increasing dependence on others for their care as their cancer progressed. Specific loss of 'male' roles included fears of not providing for and protecting families and loss of careers and social status and this impacted on the need to be respected as a male.

- "... me using a catheter, you know, men going to the toilet being manly all urinating and bragging. You know boys being boys laughing. So me not being able to do that anymore because I've got the catheter in – the toilet gets empty very quickly. From that point of view I do feel like I'm half a man, because you don't do what normal men do." Participant A.
- "Every man feels that they're macho, you know, from being a young boy, you're macho in playing rugby. You know to impress the girls because playing rugby, wrestling, you know. Macho for me is being well built, where a girl can take you into a place, well-built and say, you know what, this is my boyfriend and, you know, no one can look for nonsense with him ... being macho is about the women feeling like you can protect them. I don't want to come across weak to anybody. I don't want people to feel sorry for me." Participant A.
- "I wanted to become a professional bodybuilder. I think that was one of my big dreams for very long. But, you know obviously a successful career was the mind-set. I got work at a company which is every boy's dream job, where I worked with motorsport, racing tyres, racing seats and that sort of thing. So I was in heaven. And then obviously I was looking good from working in the gym and I had a lot of female friends, it was a wonderful life, it was just – I thought I had it all." Participant A.
- "I'm angry at people who want to bully me because I don't have legs. Some of them even think my brain is lower, is a lower level than it used to be. Go to the malls, go with your child, you'll find that person who is dealing with you is talking to the child, he's not talking to you but you are the one carrying the purse, he sees that you are the one, the father of the child but he talks to the child, you are now of a lower brain." Participant B.
- "When he introduces me to a stranger, they'll say this man used to be – he used to do this. He doesn't say this man does this and this, can do this and this, they'll say you used to, as if you are already dead." Participant B.
- "I have not been able to work to provide for them (family), I don't know, I'll be a doormat." Participant B.
- "Oh, I was sobbing because I – my job was – my life. I mean it was everything to me. Being the principal of that school. Everything about the school was just what I've always envisaged and now all that is away. So ja, I felt inadequate. I'm a man, I must be strong, you know but um, I just didn't have the strength. So ja, that was a main part of my life that was just cut away." Participant C.

- “The biggest thing in my life is my sport and my exercise. Work is, work is important. My work’s been terrible. I haven’t done much in a while, um, it really hassled my headspace. Still is to this moment. My kids, my family. Concern for them if something happens to me because I really don’t have any back-fall financially or anything for them. So the support for them has been my biggest thing because I haven’t been able to support them.” Participant D.
- “It is very demeaning and very belittling, because before, having being able to open bottles for people, for my wife, for the children, um, being the strong one – being able to lift a hammer and knock a nail into a wall. Uh, now not being able to do that – having to rely on my wife to do that all – or somebody else to do that for me has impacted rather largely on my role as a man, as the muscle of the house, so to say.” Participant E.
- “It’s been very difficult because I know I can’t get work and I can’t get income.” Participant F.

Participants A and B demonstrated a strong need to try even harder to assert and maintain their feelings of masculinity.

- “... it takes more of a man to talk about your feelings than to hide it, just be positive, get out there, socialise with friends.” Participant A.
- “Also from half a man, it’s not just to say my legs, maybe I’m going to be paralysed, but I can tell you now if it happens that I’m going to be paralysed, I’m going to be picked for the South African basketball team or the South African wheelchair team.” Participant A.
- “I continuously remind them, (his family) look I’m the head of the house, this is my house.” Participant B.
- “... even if she’s (his wife) the breadwinner, she doesn’t provide much bread. I beat her as I’m lying in this bed, in providing for this family.” Participant B.
- “I undermine them, instead of them undermining me, I say to them, ‘look don’t undermine me because I don’t have legs, you know I can think, shut up, let me talk.” Participant B.
- “Physically it will be tricky when I’m under attack, it’s going to be tricky. I’ve got to think – how to move out of a situation. If I fight back, I have to fight very dangerously. If I have to fight, I have to fight to kill, to finish.” Participant B.

Participant D fought to maintain his independence so as to preserve his perceptions of masculinity.

- “I want to do it on my own, I’ve wanted to cope with it myself.”

Participant F tried to maintain his independence for as long as possible.

- “Immediately I became dependent on other people but throughout the treatment, I took myself there to the hospital and I took myself home.” Participant F.

The loss of ability to participate in sport or keep physically fit impacted on both participant A and D’s experiences.

- “We were brought up in a sport crazy family and I think that’s where my love for sport came. Also with the gym training, which if I think about it now, it’s actually stupid but one of the reasons I was in the gym permanently is because, I thought there’s nothing better than wearing a short or tight shirt going out and showing off your muscles. That was a couple of years ago when I was still healthy. That was the mind-set. Looking good just to impress the girls, that was the aim: hunt. You know men are hunters, hunt girls as many as you can and showing off with your muscles, seeing how many girls you can get. I’m not able to train anymore. I’m not able to be in the gym anymore, I’m not active in sport. It does discourage you, because you still see all your friends playing sports and they’re active. You feel unattractive for yourself. So now you, you know, if I don’t feel attractive for myself, how can I expect a spouse or a girl to feel attractive with me?” Participant A.
- “Before I was always out there. Fit! Running! Cycling! Bicycling! Talking to everybody in the pub, having a gas. And then all of a sudden, bang, this arrives. So you – quite difficult to explain, exactly how one feels, but I’ve literally said I’m going to get rid of this (cancer).” Participant D.

### **Relationship with (potential) partner(s)**

This theme was expected to arise whilst discussing sexuality. The participants spoke commonly about their partners or partner in terms of the perception the burden they may be to their partners and the importance of open and honest communication to address this. Themes related to a diminished body-image or feelings of attractiveness as well as a fear of rejection from partner emerged. Although marital and relationship status differed amongst the participants, the following central themes regarding relationships emerged.

### **Concerns about being a burden to the (potential) partner**

Participants A and C overtly expressed their concerns about becoming a burden to their (potential) partner.

- “I don’t want to commit while I’m sick. Now what I’m telling myself all the time is, if you meet someone while you’re sick, you’re going to be an extra stress factor for them. They don’t want someone, they don’t want to baby you.” Participant A.
- “... everything isn’t always the way it was, things have changed now. So, when I went to bath by myself, now I need you to come and help me out of the bath. I need you for a few reasons, that wasn’t there before. Because (partner) for instance, for months on end, he was here every day, every minute. Coming from work he’ll be here. Weekends he will be here. But he’s also had a life and he’s still got his life.” Participant C.

### **Diminished body-image/feelings of attractiveness to a partner**

Participants A, C, D, E and F commented about their body-images of being sick, and how this made them feel less attractive to their current partners or potential partners.

- “I had permanent catheters in me, and with the urine bag and when I met girls I didn’t tell them at first, and obviously what a surprise for them when they saw the bag. And I feel, I felt less of a man, I mean, I know myself if I had to see that I would’ve been put off.” Participant A.
- “But now after the chemo and at the moment now, I don’t feel attractive.” Participant C.
- “It’s a form of weakness because of the illness – because I’m sick. I’m not well. I don’t like to be seen out there to be unwell. I’ve been so healthy.” Participant D.
- “I feel very ugly and I cover up as much as I can, I try not to expose anything, but clothes not fitting, shirts hanging on me that used to fit properly. Um ... belts way too big that the holes used to be one or two from the end and now there aren’t enough holes in the belt. The self-image is really taking a knock.” Participant E.
- “I’m unattractive to girls because women, just like men want a nice body, women want a nice body as well. I wear nappies.” Participant F.
- “I don’t feel as though I deserve it (a physical relationship).” Participant F.

### **Feeling judged/fear of rejection**

Participants A and B both felt anxious about being negatively judged by females because of their illness. This culminated in a fear of rejection.

- “I’ve thrown away all these years not meeting the right person and maybe not giving them a chance so they can decide: do I want be with this person and what’s going to happen with him, or is this too much for me to handle, and you know, cheers? Maybe she can’t look past a urine bag and past a catheter and so. Because how unattractive can that look? That, that can’t be sexy for a girl.” Participant A.
- “When you meet people, their tendency is not to look at you.” Participant B.

### **Social withdrawal**

Following on from the previous theme – a fear of rejection, many of the participants tended to withdraw socially. This was often due to their illness and simply not feeling well enough to socialise. Friends also seemed to peter out. They would see friends less and thus encounter fewer situations in which they could meet potential partners.

- “I had many many friends; since I got ill, I’ve only got a handful of friends now ... Coming from work, buddies picking you up, going to gym, you know, that’s not going to happen anymore again. A possibility of me not finding a spouse, maybe me not becoming a father ever.” Participant A.
- “I’m not moving around a lot, visiting friends. I can’t attend even things like funerals, those are the things I miss. It’s me who isolates myself and I understand the reasons why they don’t come to see me. I switched off my phone; my phone was in off or in silent mode. I wouldn’t listen to it. I would see it buzzing or bumping over the table, in hospital, but I wouldn’t take it.” Participant B.
- “I was very sociable. Got a lot of friends and I used to hang out with friends and go and see everybody and come home at night, have dinner and then go out again. Now I’m confined to being in bed most of the time, and that’s very difficult for me. And then I sometimes cry about it because I, I miss going to the movies. I miss seeing my friends.” Participant C.
- I’ve actually, to be honest, shut down socially. On the relationship front, I don’t know – I haven’t really – it’s quite a difficult one to say. It’s as if I’ve boxed the period.” Participant D.

- “I’ve become a recluse, so to say, not to go out. Try and stay home like a hermit. My friends have lessened. When people come now they feel sorry for you or they’re not sure how to react around you. Not knowing if they’re going to upset you, or if they say something that may be detrimental. So the friend-base has dropped considerably.” Participant E.
- “My speech is slurred so it’s very difficult for me to make new friends.” Participant F.

### **The physical sexual relationship**

The physical sexual relationship had changed for all participants. Although participants missed physical intimacy, most lacked libido due to poor body-image and symptoms related to their cancer. Some participants demonstrated much anxiety around whether or not they could get and maintain an erection. This fear resulted in performance anxiety. Physical barriers such as colostomy bags, nappies or urinary catheters were raised as concerns for some participants. Most believed that physical intimacy needed to become less important than that of emotional intimacy. This was only found to be a possibility if participants could engage in open and honest communication with their (potential) partners.

### **Lacking libido or sexual desire due to poor body-image or symptoms related to cancer**

A central theme that emerged amongst the participants of this study was that of decreased interest in the physical sexual encounter. Decreased desire was related to poor body-image and/or physical symptoms related to the cancer or its treatment.

- “I don’t want to go to her and massage or do those romantic things because it’ll mean I arouse her feelings.” Participant B.
- “With my partner, there’s a lot less intimacy – and you know I was thinking this morning I can’t even remember when last we got steamy or, you know, intimate, or French kissing. Because I’m not feeling well. So, and because I’m you know, I’ve got pains and bloatedness and things, eh – you know, bodily-wise – I’m probably like a dog you know – when dogs really get ill, they go and hide somewhere, away from affection and crawl up.” Participant C.
- “I used to be in the relationship, the more affectionate one, he has become that because I feel ill, sick. I can’t think of it (intimacy) now – because it’s like

something that's been wiped off the board and I'm like, the other night he wanted to put his arms around me and hold me, and I was like – I can't have any pressure around my – waistline, you know. It's too sore, please, you know. He hurt me. I used to pack pillows in the middle of the bed like a mountain." Participant C.

- "It (a sexual encounter) would be a bit of a try out because of all the cortisone. Um – because I have no urge at all." Participant D.
- "I've had no desire for a year now." Participant F.

### **Anxiety around erection and physical sexual performance and resultant avoidance**

Participants seemed to harbour much anxiety about whether or not they would be able to perform sexually, if they could get and maintain an erection and if they could satisfy their partner. Fears of disappointing their partner emerged. This at times resulted in participants avoiding or not initiating sexual contact.

- "Who's going to want to look at me? So I think – I think – half a man – would also be in pleasing your girlfriend if you're intimate. You know if you're not happy with yourself, how would that work? You know it's not going to succeed." Participant A.
- "My fear is that she'll get aroused, and I won't be able to finish her off. If I start this and I'm unable to finish her off." Participant B.
- "I'm afraid of arousing her feelings, for nothing, because I'll arouse her feelings, and do nothing – those are things that are still holding me back. I don't allow myself to openly love her. It's about a penis, it's the only type of love I know, I don't normally love and leave it halfway, I used to love right through to the end of the sexual procedure, now I can't, I know I'll go right to the middle, she'll get disappointed, and then – I don't know what she'll do thereafter in my absence. I know the reasons, although I can't say to her, you are free to go and meet other men, but I know – she is starving." Participant B.
- "But how would I feel if it (erection) didn't work? I think it's quite difficult. I would, one would feel, you wouldn't feel great. When you don't perform you don't feel good – embarrassment ja, I'm sure I could do better than this. Because I've never, I mean I'd never had a problem with that so – maybe I see it as a problem, that's why I'm scared of it." Participant D.

- “I worry about what’s gonna happen. How its (erection) gonna work and uh, if it’s ever gonna work again.” Participant E.
- “I was worried about becoming impotent from the chemotherapy.” Participant F.

### **Physical barriers to the physical sexual encounter**

Perhaps closely related to body-image and fear of rejection, Participants A, B, E and F expressed a lack of spontaneity or fear of rejection related to urinary catheters, colostomy bags or nappies.

- “Maybe you find that special girl, because maybe she can look past that, I mean, maybe she can look past a urine bag and past a catheter and so. But basically I push them (girls), you know, I push them away straight away ... because how unattractive can that look? So ja, look it plays a big role being, having to use a catheter because you can’t concentrate on making her happy. All you think about in your mind is, oh I hope she doesn’t notice this or I hope she doesn’t think, you know, lesser of me.” Participant A.
- “The only thing that is withholding me is thing, thing (colostomy bag), that doesn’t make me stand, and the catheter, you know if I can be without a catheter and this thing (colostomy bag).” Participant B.
- “The impact is incredibly, incredibly large in that um ... to lie at night together and hold your wife, and that is a very difficult situation in that you’ve got things hanging out of your body and so it’s very difficult to cuddle and spoon so to say. Um, got to be careful of pressing the pipe closed and then having your bladder swell up and not being able to release the liquids. Um – the intimacy is ... rather a passion-killer when you’ve got all these pipes and tubes hanging out of you and it’s difficult to feel the person against you because you always aware of the smell. So, on an intimacy level it’s a very hard and very difficult sort of situation. It’s embarrassing, it’s very demeaning.” Participant E.
- “My self-confidence would affect my physical relationship – I wear nappies.” Participant F.

### **A shift towards emotional rather than physical intimacy and satisfaction**

Prior to their diagnosis of cancer, Participants A, B, C and E felt that physical satisfaction was of prime importance within a relationship. As they have become

sicker, this focus has shifted to include more emotional pleasure in intimacy such as talking, feeling close and doing small things together.

- “I know males: to see how many girls you can pick up, how many girls you can sleep with and bragging to your friends about it. I don’t think about it as that anymore. I think you get sexual intimacy and then you get intimacy. I think intimacy for me is being with that special person in your life and doing small things. Taking the dog for a walk, walking to the park, chatting, watching movies, lying in, next to each other, holding each other. If you can’t perform sexually, that’s not the end of the world.” Participant A.
- “What she (wife) does, her performance is far deeper, it exceeds any expectations for sexuality. She looks after me, she cares for me.” Participant B.
- “We’re like comrades. Just two people surviving and helping each other. It’s become a comradeship. It’s like being eighty-nine years old and sleeping in two single beds. We’re there for each other but that romance, it’s not there anymore. But he (partner) is that angel, that light, that force, that one that you know, (is) there to help.” Participant C.
- “Now we need to share the closeness. Um, sitting watching TV together, just sit and watch the sunrise. Although there can’t be intimacy on a sexual level, there can still be intimacy – an emotional connection, which is now as important, if not more, than a sexual connection.” Participant E.

### **The importance of open and honest communication**

Most participants felt that to have a successful relationship, openness and honesty in communication were vital.

- “I’ve got to tell her, that I worry that I don’t touch you, then she’ll tell me to touch her, or not to touch her, but that’s the first approach, I have to ask for permission.” Participant B.
- “You must speak to them – you can say now I’m not feeling well, do you mind lying next to me on the bed. Just open up.” Participant C.
- “If I felt grim – I would explain to her. I mean, I think if the relationship is good and there’s going to be intimacy and then the rest, I think one would be able to explain it and understand each other, in terms of that.” Participant D.

- “You want to be able to speak to this person; you want to know everything about the person.” Participant E.
- “I’m engaged, she knows my condition yet she accepts me and that’s very uncommon.” Participant F.
- “I told her my situation and she understands and so I proposed about a week ago but I don’t even have money for a ring.” Participant F.

### **Religion, sex and cancer**

A very interesting theme arose for many participants and that is of religion and how it impacted, mostly negatively, on their experiences of sexuality.

- “I’ve got a lot of anger at the world, anger towards God because I’m not healthy.” Participant A.
- “Is this really me? Is this really me, is there no mistake? Maybe God wanted to punish someone else, no God must be punishing me for something that I did, there must be something that I did, that I’m being punished for.” Participants B.

Participant D is not particularly religious but he still asks existential questions.

- “ ... you ask so many questions during this period, and uh, sit and ponder in bed and think why, why did this happen? Why did it happen then?”

Participants E questioned why God allowed him to have cancer.

- “I often ask God “why me?” I often see people that are abusive to their family, that are aggressive – that hurt their family, and I think, why, why’s this person healthy? Why’s this person got the strength of an elephant, and here I am? I don’t hurt my family. I love my family. I’ve looked after my family and yet I am now stuck with this. And it’s a lot of why’s and a lot of no answers.” Participant E.

Participant F tried to reason on an existential basis.

- “There’s a reason for everything.” Participant F.

Participant C is religious and homosexual and for him God was punishing his homosexuality by giving him cancer. He had just told his mother that he is gay.

- “And then she said, ‘You know I love you. You’re my son. That’s fine but just remember it’s not in line with God’s word.’ And she started quoting some Bible scriptures.”

Participant C then went on to reason that the reason he got colorectal cancer was because God was punishing him for being homosexual.

- “I’m being punished because I’m gay. And all the old tradition stuff. Sunday school teachings. All the things you’ve read on the other side of the interpretation came back to haunt me and I thought, yes, since you’ve been gay you haven’t been involved with church as much as you used to. Because I used to sing, lead worship, and I thought this is God’s punishment for you.”

### **Coping mechanisms**

Each participant demonstrated in his interview a variety of coping mechanisms he employed to cope with his sexuality. Although the coping mechanisms may have been different, all utilised one or more types of coping mechanisms. These included denial and trying to be positive. Denial and trying to be positive were sometimes intertwined in that participants tried very hard to remain positive despite no hope of cure.

- Macho for me is, is staying positive. Be macho for yourself, saying whatever life throws at me, I’ll beat it – as far as I’m concerned I’m not sick anymore.” Participant A.
- You know if I can be without a catheter, I’ll walk.” Participant B – paraplegic from spinal surgery.
- ‘I just decided that I’m just going to go on and try and be as normal as possible, you know fight the good fight. Chin up my boy. Come on you can do this.’”

Participant C.

- “I’ve literally said I’m going to get rid of this. I think my thing at the moment is GET BETTER, SORT IT OUT AND THEN MOVE TO THE NEXT STEP. Move to normal life again of squash and social ... I don’t believe I’m going to get to that situation where I’m gonna be on the cliff and that’s it, and it’s bad. I’m just so positive. But if we get to the situation where we ... it’s difficult, I don’t ... for me it’s not a possibility.” Participant D with metastatic melanoma to lungs, brain, lymph and bone.

- “As long as I keep positive I should be fine.” Participant E.
- “When is this going to go away?” Participant F.

### **Wisdom**

Most participants seemed to have derived some wisdom out of their experiences which they felt they could share with other men with cancer.

- “ ... it takes more of a man to talk about your feelings then to hide it. So I would say, just be positive – take time out where you feel sorry for yourself or angry at the world, yes you’re allowed to do that. I think it’s very important that you do feel sorry for yourself and angry with the world but it’s important for you then, to pick yourself up and be positive. Hunt girls even if they push you away or laugh at you, you know, so what, find someone else, until you find that confidence in small things again, you know, I think that’s very important.” Participant A.
- “If you are weak and feel discouraged, don’t rush and get discouraged, a person who feels disempowered, by the situation, needs to go slowly, you don’t have to be fast about it, go slowly.” Participant B.
- “One thing I would say is: try and let the people in, your friends, your family, your support. Listen carefully and realise that everything isn’t always the way it was. Also allow your partner some space of his own to recharge. Allow him to do things, you know, don’t feel rejected. Don’t become the victim of oh he doesn’t love me because now he’s going off. It is difficult because you do want somebody around all the time. Maybe because you are scared something will happen to you, nobody’s there to help you. But then so be it then, you know. The partner needs to be able to recharge. Partner needs two or three days, an evening where he’s not at home. Can, maybe come and check-up if everything’s there, but then trust him, let him go.” Participant C.
- “Learn to cherish every moment, enjoy every moment as it comes along – not to skip over the good things. Share more in the pleasure of being with each other. Share more with your family – cherish every moment because you never know what’s gonna happen tomorrow.” Participant E.

## **Healthcare professionals**

A central theme that emerged from the participant interviews on their experience of sexuality was their disappointment in healthcare professionals particularly poor communication and feeling abandoned.

- “Doctors are to blame because they’re not emotional. They see you as a number, I think if doctors just explained to me. They only saw me as another patient. Yeah, this guy’s coming with another back pain. Two patients before it was also a guy with back pain. If they listened better instead of rushing the patients ... Let’s mess him around, send him for X-rays, then I don’t have to deal with him. Most doctors are afraid to get on the emotional side because they don’t want to feel sorry for a patient but it would be nice if they made time to understand you a little bit better. They could have just warned me beforehand: sexually he won’t perform, sexually he won’t get an erection, you know things like that.” Participant A.
- “These doctors run away. They don’t want to give me the correct advice, these doctors.” Participant B.
- “My experience with the doctors have been that ... they might be popular, and they might be considered the best ... but they still don’t have the time to follow up, to do a follow through. I never went for the scan. But he also never phoned to say, how did the scan go? Where’s the scan? I just felt in my experience the past year that I wanted some facts, some phoning, some facts, this is going on. It’s probably because I was born in a Free State town where the doctor used to also come to our house, and where they knew us personally. Now in the big cities it’s very clinical. I mean my oncologist said to me that ‘I’m in this with you. We in this together.’ I thought, ag rubbish! We’re not in this together. I never hear from you and when I get here I have to wait two hours to see you, and then you prescribe the tablets and send me home. I wanted more sympathetic outreaching, caring.” Participant C.
- “I found that doctors – um nobody’s actually sat me down and said, well you know this is what’s gonna happen. They skip over everything quickly and they don’t seem to go deeper. They don’t always divulge what’s going to happen.” Participant E.
- “Well they (doctors) haven’t discussed it (sexuality) so ... it would have made a difference because then I know what I am as a man, it’s important for me.” Participant F.

## **Conclusion**

This chapter has dealt only with the themes that have emerged from the phenomenological interviews. These have related to declining independence, decreased feelings of masculinity, impact on relationship with partners and physical intimacy. Furthermore coping mechanisms and the role of religion on sexual experiences emerged as well as wisdom. Even though not always directly related to the sexual experience, most participants felt disappointed in their healthcare professionals.

In accordance with the literature review, most findings were not unexpected. The impact of the disease of the participants in this study's experience of sexuality was a difficult one.

The following chapter will discuss the findings of this chapter and integrate them where possible with the literature review.

## CHAPTER 5

### DISCUSSION

#### **5.1 Establishment of an existential baseline**

In drawing comparisons between the experience of sexuality pre- and post-diagnosis, an indication of the participants' personal definitions of sexuality was given. Comparisons made on a physical, psychological or social dimension demonstrated which of these or which combination of these dimensions defined sexuality pre-diagnosis. These altered dimensions during palliative care formed the crux of the loss and resultant frustration experienced. All participants compared sexuality pre-diagnosis to post-diagnosis on a physical dimension. Most participants also utilised a social dimension (in their altered ability to attract partners) and all spoke of a psychological dimension (the loss of independence).

In order to integrate their status of sexuality whilst under palliative care, male patients with cancer may need to broaden their definitions of sexuality or alter the relative importance of the various dimensions of sexuality. This was stated by Althof and Levine (1993), Donahue and Gebhard (1995) and Farrow (1993) in Chapter 2.

Perhaps by achieving an appropriate definition of sexuality during palliative care, the feelings of loss and frustration with respect to sexuality will be alleviated. This is so, since an altered definition may revoke the frustration and anxiety around the experience of sexuality whilst under palliative care. This change in dimension emphasis is evident in most participants who speak of a newfound shift toward emotional sexual pleasure rather than physical sexual pleasure.

#### **5.2 Declining independence**

All participants in this study presented with a desire for independence despite their progressive decline in physical health. It appears from the study that levels of independence and masculinity were directly proportional to each other, ie: as the patient became more dependent on others, his perceptions of his masculinity seemed to decline.

In addition, it appeared that the greater the level of independence, the greater the patient's self-esteem, confidence and perceptions of masculinity. This finding is corroborated in the literature review in which Grundy and Swain (1986), Lemon (1993), Persaud (1986), Rabin (1980) and Siösteen et al. (1990) emphasise the importance of independence in facilitating feelings of masculinity and sexuality.

### **5.3 Feelings of masculinity**

Declining feelings of masculinity related to the role of protector, breadwinner and figurehead of the family as well as dominance and assertiveness, come to the fore in this study. These roles and traits of masculinity were also listed by Buran and Byrne (1994) and Lemon (1993).

Following the diagnosis of incurable cancer, all the participants expressed concern over not being able to fulfil the stereotypical roles of a man. Many participants revealed their fear that they may no longer be able to provide for their families. They were also concerned that they would no longer be able to protect their families.

All the participants mentioned two specific components of masculinity – the need to be respected as a male and the loss of social status. All participants felt that their manhood still needs to be respected, but this is not the case. This presented in a variety of situations ranging from being able to urinate with other males in a public toilet to shopping situations in which the male wanted to feel that he could make the decisions and pay the bill, to wanting to perform household roles, to wanting to continue to be respected for his career or sporting accomplishments.

This need to be respected as a male was actively sought by some study participants by becoming more assertive in their attitudes and relationship to others. Another approach was to actively avoid any help in order to maintain his levels of independence and masculinity.

Again, this finding is consistent with the literature review in which Farrow (1990) and Lemon (1993) found that the loss of self-esteem is brought about through role loss, in other words, the loss of being the breadwinner, protector and head of the family. This was found to negatively affect masculinity. Persaud (1986), had found in spinal cord injured males that the promotion of patient autonomy is imperative in improving self-

esteem and masculinity. This too was related to some level of independence and was found to facilitate sexual relations (Althof & Levine, 1993; Rabin, 1980).

Most of the participants spoke of their role of fatherhood, current or potential. Feelings about the role of fatherhood were ambivalent. Some participants expressed the desire to have children but were concerned about not being able to fulfil the role of fatherhood. Other participants were concerned about not being able to provide for and care for their children in their current situation and after their death. The literature review did not specifically cover the influence of fatherhood on masculinity but this study did elicit this as a central theme to the experience of sexuality.

Thus, the masculinity of the male cancer patient under palliative care seems to be influenced by certain expected male roles such as being the breadwinner, protector and father figure and in terms of respect attained from his partner and others as a mate. The nature of terminal cancer may affect many of these dimensions of masculinity and as such become the source of much frustration and psychological pain. In gaining respect from his family and others and by being able to fulfil certain aspects of his male roles, the patient's masculinity may remain more intact. This was strongly related to the degree of independence and the need to become assertive. By the family and others within the patient's social circle avoiding over-protective and over-sympathetic behaviour, the patient's feelings of masculinity may be preserved.

#### **5.4 Relationship with (potential) partners**

Four central themes relating to the patient's relationship with his partner emerged. These included concerns about being a burden, diminished body-image and feelings of attractiveness, feeling judged or feeling rejection and social withdrawal.

Certain participants had overtly expressed their concerns about feeling that they were or would become a burden to their partner or potential partners. Another remark noted was that if the patient were healthy, he would not be attracted to someone who is sick.

Certain participants felt that they would not become close to anyone as they did not wish to be seen as sick or disabled. Married participants felt that they would understand if their partners were to leave for another man because they regarded themselves as "useless". However, there was a great amount of gratitude towards partners for staying with them. This perception of being a burden related closely to all

the physical, psychological and psychosocial consequences of terminal cancer as discussed in the literature review.

Most participants elicited the theme of not feeling attractive due to the physical aspects of their illness, including weight loss, poor mobility, catheters or colostomy bags. This is collaborated with a diminished body-image.

This perception of being unattractive due to being physically ill and often disabled may not only be the perception of the patient but also of society at large. This perception of unattractiveness or poor body-image elicits fear for the single male cancer patient in attracting potential partners. The study cited by White et al. (1992) ranked the concerns of the male patient as “feeling sexually unattractive” as fifth on the list of 17 concerns and “others viewing the individual as unattractive” as seventh. These concerns may be linked to the social myths listed in Chapter 2, such as “disabled persons are not sexual beings”, and “disabled persons are not interested in sex and sexuality”.

In the light of the findings of this research and the literature study, it follows that the male cancer patient under palliative care, particularly those that are single, may feel that they are too unattractive due to their illness, to meet potential partners. This perception may generate from social myths which only serve to exacerbate the patient’s already vulnerable body-image, self-esteem and sexuality. This too was found by Pervin-Dixon (1988) in the literature review. This may lead some patients to become isolated and withdrawn resulting in depression and thus further decreasing the chances of meeting potential partners or engaging in sexual activities. This was also found by Rabin (1980), Althof and Levine (1993), Lemon (1993) and Rieve (1989).

Most participants expressed concerns about being judged to be inadequate by others because of their cancer and this culminated in a fear of rejection. Some participants felt that partners would not want to be with them because of their catheters. Certain participants felt that society rejected them and saw him as someone with little intelligence because of their health condition.

A common theme to all participants in this study was to become socially withdrawn and isolated. This seemed to stem from the factors discussed above including decreased body-image and self-esteem, and a fear of being judged or rejected. Participants also actively sought to avoid social situations in which others demonstrated too much sympathy as this left them feeling disempowered and

emasculated. Many also felt that some of their previous friends had abandoned them now that they were terminal. This social isolation and withdrawal resulted in less social situations in which the patient could meet potential partners and friends.

## **5.5 The physical sexual relationship**

In discussing the physical sexual relationship, all the subjects disclosed certain losses, needs and changes within the encounter. Often the losses and changes were directly related to physical symptoms associated with advanced cancer and effects to medication. Five central themes emerged as significant for the male patient under palliative care with regards to the physical sexual relationship. These included:

- Lacking libido or sexual desire due to poor body-image or symptoms related to cancer;
- Anxiety around erection and physical sexual performance and resultant avoidance;
- Physical barriers to the physical sexual encounter;
- A shift towards emotional rather than physical intimacy and satisfaction;
- The importance of open and honest communication.

Most participants felt that they lacked libido. This was multifactorial and included low self-esteem, poor body-image, pain, immobility, depression and anxiety. This finding was corroborated in the literature review.

Most participants demonstrated concern about whether or not they could physically satisfy their partners, and whether they would be able to attain and maintain an erection. Interestingly and importantly, none had attempted penetration since they knew that their condition was incurable, yet all missed this aspect.

Another important issue arose for those participants with urinary catheters, nappies, or colostomy bags; they were worried that these would hinder the sexual encounter by dislodging and messing or by putting the partner off. This concern was also raised in the study by White et al. (1992).

Many participants felt that prior to their being sick, the focus of sexual satisfaction was on a physical level, whereas now this focus had shifted to include more

psychological or emotional pleasure within a relationship. Acts such as holding hands, just being together or having intimate conversations became very important.

The male patient with cancer under palliative care may be required to re-define or broaden his concept of sexuality. As a result of his illness, he may no longer be able to achieve penetration due to a variety of reasons, as discussed above. In order to reconceptualise sexuality, the patient may need to make a 'mental switch'. As discussed by Donahue and Gebhard (1995) and Farrow (1990), the patient may need to dispel the myth that sex is merely physical and broaden this concept to include psychological aspects. In this way, the patient's psychological/mental sexual needs may be satisfied in his sexual experience where physical satisfaction may not be possible.

In order to facilitate these changes, most participants felt that they had to have open and honest communication with their partners or potential partners. It was felt that with the patients' and the partners' fears, needs and concerns should be discussed prior to attempting a physical sexual encounter.

Open and honest communication is vital to any sexual relationship. This may be exacerbated with the terminally ill cancer patient and his partner's relationship due to the numerous fears, frustrations and limitations imposed on the relationship by the disease. These were discussed in Chapter 2. A study by Kreuter et al. (1994) revealed that approximately half of the relationships of a severely disabled patient and his partner, survived. Those relationships that terminated, demonstrated decreased sexual activity and disinterest, and this was positively correlated with poor communication skills. It is not clear if these sexually disabled patients were terminal and thus caution must be exercised in applying this finding to palliative patients. Nonetheless, the literature by authors such as Althof and Levine (1993), Lemon (1993), McCammon et al. (1998) and Solomon (1982), also consistently stress the importance of communication in the patient's relationship.

## **5.6 Religion, sex and cancer**

A common theme arising in this study was that of religion and how it negatively impacted on the males' sexual experiences whilst under palliative care. Often this provoked existential questions for the patients.

Participants who were very religious felt that God may be punishing them by giving them cancer. These participants tended to engage in bargaining with God.

This study demonstrated that the more active the patient's frame of reference in terms of religion, the more influence it had on his experiences of sexuality whilst under palliative care. This finding is consistent with the literature review in which Castillo (1997) and McCammon et al. (1998) claim that the individual may base their sexual behaviour and values on their religious beliefs. The study by Ide and Ogata (1995) demonstrated that some patients rated their spiritual life as more important than their sexual behaviour. The study by White et al. (1992) also demonstrated that "moral or religious concerns and beliefs" were listed in a list of concerns regarding sex for the male patient. Donahue and Gebhard (1995) found that a more liberal and open approach to religion facilitates sexuality post-diagnosis.

### **5.7 Coping mechanisms**

A variety of coping mechanisms were employed by each participant in his interview. Some coping mechanisms are seen as healthy and protective whereas others are dysfunctional. This was explored in the literature review by Meyer et al. (1989). Two coping mechanisms were found to be common to the participants – denial and trying to remain optimistic. Although the latter could be viewed as healthy, it appeared to merge with denial in that some patients would be determined to be cured even when there was no hope for a cure.

These coping mechanisms were found to be utilised in the patients' general approach to their illness and not only to their sexual experiences.

### **5.8 Wisdom**

Interestingly, most participants felt they had derived much wisdom from their experience of sexuality with terminal cancer. These participants all offered advice to other patients that may be in the same situation. This advice came in the form of telling others to be honest with their partners, not to avoid social situations, to keep trying to meet partners even if you are rejected, and to try to remain positive.

Erikson's last learning task in life is that of attaining wisdom. It seems that the patients in this study, although at a younger age than what Erickson proposes to be end-of-life, have moved to this task by virtue of the terminal nature of their disease.

## **5.9 Healthcare professionals**

Most participants in this study felt immense disappointment towards their doctors. They felt that their doctors had failed to communicate effectively with them and their families and that their doctors had never explained the possible limitations that they may experience in their sexuality, mostly on a physical level.

Many felt abandoned by their doctors and this resulted in anger, isolation and frustration. The need was expressed for doctors to be more or to appear to be more emotionally involved with their patients and to initiate difficult conversations.

Participants felt that their doctors did not have the time to discuss emotional issues or that they (the patients) were viewed as a mere number in the queue.

This finding was also demonstrated by Hordern (2007) and Katz (2005) in the literature review in which patients wanted to discuss issues of sexuality with their doctors but felt that this may appear frivolous to the doctor.

## **5.10 Using a phenomenological framework to assess the sexual experience of the male cancer patient under palliative care**

In order to gain a richness and depth into the understanding of the experience of sexuality for the terminal male cancer patient, it may be useful to apply phenomenological concepts to this study. This may assist in accessing the experience within the dynamic context, which influences and is influenced by the patient. The phenomenological concepts discussed in Chapter 2 are now examined in terms of this study.

### **Male cancer patients under palliative care as beings-in-the-world**

The male cancer patient does not exist in isolation in the world. Indeed, the very concept of sexuality is shaped by physical/biological factors **Umwelt**, social factors

**Mitwelt**, and psychological or individual factors **Eigenwelt**. This is also demonstrated in Chapter 2 in the attempt to define sexuality. These three broad categories of being-in-the-world will shape the experience of sexuality for the patient, and also the manner in which they interpret and respond to the experience.

The experiences of the participants in this study demonstrate the influence of all three categories of being-in-the-world in the descriptions of their sexual experiences. In terms of **Umwelt**, participants spoke about their physical sexual relationships and the extent of their biological sexual functioning. In discussing their frustrations and losses in this regard, their perceptions of the physical sexuality was encountered. All participants related their experiences in terms of their relationships or potential relationships. This is consistent with the category **Mitwelt**. The male cancer patient's family and their reaction to and treatment of him greatly shape his sexual experience and influenced his feelings of masculinity. This was also true of the patient's frustrations, losses and hurts in not being able to fulfil certain roles presented to males by society. The interview, with both verbal and non-verbal communication, the patient's manners of expression and his coping mechanisms and beliefs encompassed his **Eigenwelt** or his internal processes. In terms of this category, the patient is an individual within a relationship with himself. He has an identity and a sense of self-positioned within his family and the broader context of society.

The manner in which the subjects of this study derive meaning and sense of the sexual experiences, requires a depth in understanding from the mutual interplay of all contexts of his existence. It would not do justice to merely interpret this experience from within the context that it was created. There is an on-going dynamic interplay between the patient's **Umwelt**, **Mitwelt** and **Eigenwelt**, which also shape and direct his **Lebenswelt**.

### **Lebenswelt**

The **Lebenswelt** or the life world of the patient is expressed by each relative description of his sexuality. Each participant has disclosed his sexual experiences as experienced subjectively by him. This is directly related to being-in-the-world in which through various contexts and their simultaneous influences on each other and the individual, the patient creates meaning from his experience. These meanings are made explicit in the NMU's of each description. These meanings are also derived via the concept of choice of **intentionality**.

### **Intentionality**

The situation of having incurable cancer and the subsequent experience of sexuality, demands from the patient a decision or choice. The participants of this study are all conscious of their experiences of sexuality as was demonstrated by their descriptions in this regard. As such, each participant actively made choices in the various dimensions of their sexuality based on the broader and ever-changing content within which they experience sexuality. These choices range from physical sexual options, relationship values, children, religion and coping strategies. These choices may be made consciously or unconsciously, the former probably through **phenomenological reflection**.

### **Phenomenological reflection**

The participants of this study were forced into phenomenological reflection by being asked to describe their sexual experiences. It may be true that they had engaged in such reflection prior to the interview as meanings and choices had already been made. This reflection may have facilitated some degree of acceptance of the patients' sexual experiences whilst under palliative care, it may, however, also have served to be a painful reminder of their sexual limitations.

### **Ontological anxiety and guilt**

The nature of incurable cancer and impending death will automatically throw the patient into the unknown and unpredictable within a sexual context. This uncertainty will entail a certain amount of ontological anxiety. The participants of this study expressed this. They stated their fears and concerns regarding masculine roles and sexual limitations.

Whilst under palliative care, the male cancer patient is consistently faced with decisions regarding his sexuality and may immerse him in either ontological anxiety or ontological guilt. Choices that are safe and predictable will not invoke anxiety or guilt, neither will they provide the opportunity, challenge and growth in so far as his sexuality is concerned.

Terminal cancer provides numerous opportunities for growth and challenge within the sexual arena. The male can choose to remain dependent, single and sexually inactive. He may also choose to relinquish his masculine roles completely, thus thrusting him

into ontological guilt. A male may for example choose to continue making family decisions in conjunction with his family until such time that he is non-communicative.

Whatever choices are made, ontological anxiety or guilt needs to be dealt with by assessing and confronting sometimes overwhelming feelings of loss, pain, frustration, anger, lack of control, guilt and resentment. It appears though that by facing the challenge and enduring the process of ontological anxiety, the patient may have richer and fuller sexual experiences. This decision may only be reached once the patient has accepted the **thrownness** of his experience.

### **Thrownness of the sexual experience**

Terminal cancer imposes many limitations on the experience of sexuality (discussed in the literature review). These limitations often impose on the amount of freedom the patient may achieve in terms of his sexuality. This lack of freedom is demonstrated in this study by the limitations imposed on the physical sex due to symptoms, debility or physical barriers, the loss of certain masculine roles and declining independence. These limitations constitute the thrownness of the sexual experience.

The patient under palliative care with these limitations will experience frustration, psychological pain and often helplessness. His limitations are conscious (as demonstrated by the interviews) and most of the participants of this study have attempted to accept some of their limitations. The greater the acceptance of their limitations, the less influence thrownness has in terms of their sexuality. Many participants expressed the importance of being open and honest about their limitations to their partners. A lack of acceptance was also demonstrated in the study as all participants established an existential baseline by comparing their experience of sexuality before and after the diagnosis of cancer. Whilst this comparison is considered to be expected, the ideal would be to experience the here-and-now as its own unique experience. In dwelling on the past or wishing for the impossible, the patient may lack the courage and motivation to face ontological anxiety and may well dwell on his previous **human bodiliness**.

### **The male cancer patient's human bodiliness**

This phenomenological concept was clearly elicited in this study. The participants all established an existential baseline in terms of what their bodies could do to fulfil their various roles of sexuality pre-diagnosis and compared this to their situation post-

diagnosis and under palliative care. Prior to the diagnosis of cancer, the participants were in a pre-reflective or unconscious state, probably taking for granted their sexuality and how their healthy bodies contributed to it. Following diagnosis and physical deterioration, their sexual human bodiliness became reflective and conscious as demonstrated by their comparisons.

The patient that is terminal can no longer utilise his body to accommodate his sexual demands physically, psychologically and socially. In this regard the patient may attempt to adapt by making certain 'mental switches' to redefine his sexuality. Most participants in this study demonstrated this.

### **5.11 A note on the process of interpretation**

Although the above steps seem like discrete entities, their synergistic nature transcends this separation (Ablamowicz, 1992). This synergism is characterised by three reflections: description, reduction and interpretation. In the words of Ablamowicz (1992): '...within empirical phenomenological reflection there is always individual phenomenological reflection; within description there is always reduction; within reduction there is always interpretation.' (p.33).

During the process of data analysis, the researcher is required to elicit categories or NMU's from the text. The researcher must not assume any hierarchical ordering of importance for these categories; they should all be treated as equal. This will necessitate bracketing on the part of the researcher (Ablamowicz, 1992).

Reflection is required for both the eliciting of categories or NMU's from the text and for the first and second order profiling or transformations (Polkinghorne, 1985). These transformations are perhaps the most difficult area of the data analysis process as the participant's dialogue needs to be transformed into psychological text (Du Preez, 1985). To achieve this successfully, the researcher needs to remain objective in describing what is truly meant by each NMU and by deciding which NMUs' are redundant or irrelevant to the topic of research.

In the final step of the process of data analysis the transformed meanings need to be synthesised into a descriptive whole. This process requires reduction of data which is again achieved through reflection (Polkinghorne, 1985). The final description of the phenomenon can be verified by comparing it to the transformation, the transcriptions and the participants. This verification may also serve as a validity test.

This process of data analysis and interpretation resembles that of hermeneutics. Hermeneutics is an interpretative procedure or method of Social Science in which text in the form of a conversation is examined in order to discover embedded meanings within that text (Reber, 1995). To do this, the researcher has to be absorbed into the text to gain a viewpoint of the whole. The researcher then needs to 'step back' from the whole and discover its parts and how many relate to each other and to the whole, ie: the researcher achieves a unitary and valid 'gestalt' (Neuman, 1997).

Because the researcher is an individual and despite rigorous attempts at bracketing presuppositions, researcher subjectivity and bias may still influence the data analysis process. This leads to the possible limitations of this study which include:

- The study may be criticised on the modest sample size. Perhaps a replication of the study with different participants may elicit differing results. This point is, however, consistent within the phenomenological framework and as such the results should be interpreted within the research's perhaps limited context.
- The researcher as a subjective being-in-the-world may well have exerted some influence on the collation of data and the analysis of the results. The researcher attempted to avoid the potential bias and subjectivity by adopting the following strategies.
  - ~ Consistent with the phenomenological method, the researcher attempted to achieve bracketing of all presuppositions and theories;
  - ~ The interviews were transcribed verbatim with non-verbal cues indicated where appropriate;
  - ~ Validation of themes was achieved through justification from raw data by way of direct quotations;
  - ~ A second independent researcher was asked to validate the themes elicited from the raw data;
  - ~ Findings were qualified and supported by the literature review where appropriate, and were integrated into the various phenomenological concepts.
- Participants were Christian or atheist. Other religious persuasions may have impacted differently on the experience of sexuality for the male cancer patient under palliative care.

## 5.12 **Conclusion**

This chapter has provided a discussion of the findings of this study and has correlated the findings to the relevant literature. In addition, the findings were integrated within the phenomenological framework and its relevant concepts.

It is expected that this integrative approach has elicited a comprehensive and rich description of the essence of sexuality for the male cancer patient under palliative care. It is apparent that this phenomenon is fraught with many frustrations, hurts and losses. Sexuality is perceived by these patients as a broader concept encompassing a plethora of dimensions. It appears that these patients need to further broaden these dimensions to include greater emphasis on psychological dimensions and perhaps consciously reduce others such as the importance of physical dimensions.

The description of this phenomenon has elicited numerous relevant hypotheses, which may encourage future research. These potentialities are examined in the final chapter together with various recommendations. The present study is also evaluated in terms of its strengths and limitations.

## CHAPTER 6

### CONCLUSION AND RECOMMENDATIONS

This final chapter presents an overview of the study's findings. The study is evaluated in terms of its strengths and limitations. Within this evaluation lies the validity of the study. Recommendations in terms of addressing the experience of sexuality for males with incurable cancer are given as well as suggestions for future research.

#### 6.1 Overview of the phenomenon of the experience of sexuality for the male cancer patient under palliative care

The study has elicited several central themes of the phenomenological interview. These themes may be viewed as the essence of the phenomenon. The themes have been discussed in detail in Chapter 5 and are summarised below.

- Drawing comparisons between sexuality as it was prior to having cancer and what it is with incurable cancer, is central to the phenomenon of the sexual experience. In this comparison the patient establishes an **existential baseline**. The patient perceives his sexuality with cancer to be frustrated by numerous limitations imposed on him by the nature of his illness.
- The consequences of advanced cancer imposed restrictions on the male's level of **independence**. The experience of decreased independence frequently negatively impacts on the patient's perceptions of his **masculinity**.
- The patient's experience of his sexuality elicited themes related to his **relationship with his partner or potential partners**. In this regard most seemed to be concerned that they would be a burden to their (potential) partner. A **diminished body-image** and **feeling unattractive** to the partner often hindered sexual relationships. In addition, the male was scared of **being judged** or being **rejected** by others and this would lead to **social withdrawal**.
- The **physical sexual relationship** was hampered by **lack of libido**, **anxiety around sexual performance** and **physical barriers** such as urinary catheters and colostomy bags. The patient would often shift focus in the sexual relationship

from what was physical satisfaction to mere **emotional intimacy** and satisfaction. This needed to be facilitated by **open and honest communication** with partners.

- **Religion** played a role in many of the participants' interviews. Most felt that they were being punished by God for previous wrong-doings.
- **Coping mechanisms** that were commonly used by participants included denial and positive thinking. Often the optimism was inappropriate and became merged with denial.
- Many patients had elicited an element of **wisdom** from their sexual experiences and expressed their wish to guide other men with advanced cancer.
- **Healthcare professionals** became a great area of concern to the patients. Doctors did not seem to explain or explore the possible limitations that would be imposed on their everyday life as well as their sexual functioning. Most wanted to discuss these concerns but felt that the doctor did not have the time or emotional involvement to engage in such conversations. Many participants felt abandoned by their doctors.

These central themes of the phenomenon of sexuality for the male cancer patient under palliative care are generated and influenced by broader contexts. The patient is a being-in-the-world with physical, psychological and social dimensions, all which impact on and shape his experience, the meanings he derives from it and the decisions he makes in regard thereof. Despite these individual dimensions, factors and choices, the phenomenon of this experience of sexuality elicited central themes and based on these, recommendations in addressing this phenomenon have come to the fore.

## **6.2 Recommendations to address the experience of sexuality for the male cancer patient under palliative care**

In reviewing the literature and the findings of this study, it would be appropriate to recommend the following.

### **Education of healthcare professionals**

Healthcare professionals need to become aware of the palliative patient's sexual experience. Training programmes must be developed for healthcare professionals to be adequately equipped to initiate and sustain a conversation about sexuality. In

addition, practical advice must be given, eg: how to be intimate with a catheter, what options exist in the case of impotence, to encourage the male to maintain some degree of independence, even if it is a small area.

The patients of this study and of others by Hordern (2007), demonstrate that this is what most patients want from their healthcare professionals.

### **Supporting continued independence**

The degenerating nature of cancer will render the patient less and less independent. He may need to rely on others to bath, change and feed him, to move him around and to assist in his toilet functions. He may no longer be the breadwinner or the family protector. In this way the loss of independence may negatively affect many areas of the patient's sexuality, self-esteem, body-image, confidence and perceptions of masculinity.

It appears that even if independence is retained in small areas, eg: decision-making about his own care, the better his perceptions of masculinity can remain intact. This will also positively influence the areas mentioned above. Autonomy, where appropriate, can also be promoted by familiar support and relationships that are not based on sympathy but on mutual respect.

### **Supportive relationships**

A supportive relationship is also influential in many aspects of the patient's sexuality. A supportive relationship may serve to foster in the male improved self-esteem, body-image and independence.

It may become necessary for the patient and his partner to attend some type of intervention such as psychotherapy or sexual therapy. This may facilitate factors such as mutual respect, understanding and most importantly open and honest communication. Communication is also key to the physical sexual relationship. Partners need to be transparent in terms of their fears, desires, limitations and needs.

### **6.3 Recommendations for future research**

The lack of research on sexuality (including all its dimensions) of the male cancer patient under palliative care is indicative of the dire need of studies in this regard. This is especially true in the South African context where no studies in this area were found. The following serve as recommendations for potential future research:

- Research needs to be conducted on the development of a training / educational aid for healthcare professionals, patients and partners. This may be in the form of either workshops or a Digital Video Disc (DVD) that explores the different areas of sexuality. A measurement tool that assesses the efficacy of the training aid needs to be developed. This tool should be applied both pre-and post-exposure to the training tool.
- Various studies could be conducted to determine the relative impact of age, mental status, culture, religion and sexual orientation on the experience of sexuality for the male cancer patient under palliative care.
- A phenomenological study on the sexual experience of the partner would serve to contextualise the interplay of sexuality between the healthy partner and the terminal male.
- Research conducted to evaluate the effect of myths held by society regarding the patient's sexuality would be recommended. It may be necessary to devise an educational programme directed at family members, healthcare professionals and society in an attempt to dispel these myths, thus eradicating their effects.
- A similar study on female cancer patients under palliative care may be conducted.
- Similar studies including participants of other religious persuasions could be conducted to elicit whether the sexual experience for the male cancer patient is different for patients with a Hindu, Islam, Buddhist or Jewish background.
- The value of creating a support group for these patients and their partners may be examined in future research. Such a group may facilitate areas such as lack of support, isolation and ignorance about sexuality in a palliative patient.
- A study needs to be conducted within the South African context in an attempt to elicit the reasons why healthcare professionals are reticent to discuss sexuality with patients. Based on these findings, training programmes for medical and nursing schools can be developed.

## 6.4 Conclusion

It is believed that this research has managed to access the experience of sexuality for the male cancer patient under palliative care. The rich descriptions of this phenomenon serve to demonstrate the complexities and interplays of sexuality, terminal cancer and individuality and the ultimate uniqueness of this experience. Despite this uniqueness, a golden thread appears to weave its way through the phenomenon. It is hoped that these complexities, contrasts and commonalities have been conveyed to the reader.

The phenomenon for the male cancer patient is one that is pervasive and ever-present. It is one that is always influenced by the individual's broader context. It is a process that the patient has been thrust into, a process that requires continual confrontation, courage and strength. It stands that for the healthy-bodied individual, including healthcare professionals, there is no room to hold myths or judgements regarding the male cancer patient and his sexuality. Indeed, the healthy individual can derive humbleness and motivation in their sexuality and hold great admiration for the male cancer patient's sexual being.

*“When we first set sail, none of us could have imagined what was going to happen. But we weathered every adversity that came our way; the boat proved to be stronger than we ever realized. Whether or not this light up ahead shows the way to our final destination is not so important now. However long the journey, we will survive.”*

(Reeve, 1998; p 299)

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## 8. APPENDICES

### APPENDIX 8.1

#### INTERVIEW GUIDE

Sexuality is a very broad concept. Most people think that it only involves physical sex, but it also involves just being a man, fulfilling your roles as a husband or partner, for example providing for your family, being able to be a father and having open, honest communication with your partner about any problems you both have. Many people with cancer start to struggle with some of these issues. Can you tell me about your experience of sexuality at this time?

#### Prompts

- What has changed since your diagnosis?
- What are your experiences in your role as a husband/partner and as a father?
- How do you feel about your body now?
- Can you tell me about physical intimacy – has it changed in any way?
- What are your feelings about your relationship with your wife/partner? Has anything changed?
- Has anyone from the medical profession spoken to you about sexual issues?
- What are your feelings about this?

## **PARTICIPANT INFORMATION SHEET**

The study you are considering being a part of is a study on the experience of sexuality in male cancer patients under palliative care at Hospice Wits Houghton. It has been found that both psychological and physical problems around sexuality become a great source of concern in cancer patients. This research is an attempt to assess these concerns so that healthcare professionals may be trained in providing optimal care for patients. This will include addressing aspects related to sexuality that are of concern to a patient.

Participants of this study may not directly reap the benefits gained from the study as the results will be used to help future patients. It may, however, be of benefit to you to discuss your areas of concern.

Interviews may cause distress for some participants. Should this happen to you, you are free to end the interview and a counsellor will be made available to help you.

The research will entail a 45–60 minute interview with the researcher scheduled at your convenience. A biographical questionnaire will also be filled in to elicit background information such as diagnosis, treatment, religion, etc. All interviews will be strictly anonymous. Interviews will be transcribed without identifying markers. Transcribed tapes will be destroyed after the research is complete. There are no right or wrong answers in the interview; it is merely a conversation related to your experience of sexuality with a diagnosis of cancer. This will broadly cover perceptions of masculinity, gender roles, and emotional and physical intimacy.

You are entitled at any time of the interview to withdraw from the study. Whether or not you decide to take part, or should you decide to withdraw from the study at any stage, your care will not be affected.

Results of the study will be made available to you and will be used for future training and research purposes.

Thank you for considering becoming a participant in this much needed study.

### **Researcher's name and contact details**

Should you have any questions related to the study, you can contact Dr Sue Walter at Hospice Wits Houghton on 011 483 9100.

***If you have any questions about your human rights or any ethical issues about the study, you may contact:***

***UCT Human Research Ethics Committee:***

***Mrs Lamees Emjedi***

***Research Ethics Committee***

***E52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory***

***Telephone: 021 406 6338***

**C O N S E N T   F O R M**

I, ....., agree to participate in the study conducted by Dr S. Walter on ‘The experience of sexuality of male cancer patients under palliative care at Hospice Wits Houghton’.

I have read and understood the participant information sheet which details the nature of the study and what is expected of me. I have been given an opportunity to ask questions about the study.

I am aware that my participation will remain completely anonymous and that I am able to withdraw from the study at any time.

**SIGNED:** .....

**RESEARCHER:** .....

**LETTERS OF ETHICS APPROVAL**

>>> Liz Gwyther 2012/09/28 10:34 AM >>>

Dear Beryl,

HREC do not send approval in word format only in pdf. we usually scan this document into the dissertation

kind regards

Liz

Dr Liz Gwyther

Palliative Medicine

University of Cape Town

**PROFILE OF PARTICIPANTS**

<b>PARTICIPANTS</b>						
	<b>A</b>	<b>B</b>	<b>C</b>	<b>D</b>	<b>E</b>	<b>F</b>
<b>Age</b>	31	60	44	57	42	30
<b>Diagnosis</b>	Spinal tumour	Prostate cancer with metastases to spine and liver	Colorectal cancer with metastases to liver, lymph and bones	Metastatic melanoma to bones, brain, lymph and lungs	Osteosarcoma with metastases to liver and lung	Breast cancer with metastases to lung, liver and brain
<b>Sexual orientation</b>	Heterosexual	Heterosexual	Homosexual	Heterosexual	Heterosexual	Heterosexual
<b>Religion</b>	Christian	Christian	Christian	Non-Religious	Christian	Catholic
<b>Ethnicity</b>	White South African	Black, South African	White South African	White South African	White South African	White South African
<b>Languages</b>	Afrikaans/English	Zulu / English	Afrikaans /English	English	English / Afrikaans	English
<b>Children</b>	0	3 adult children	0	2 adult children	2 young children	0
<b>Current relationship status</b>	Single	Married	Gay relationship	Divorced	Married	Engaged
<b>Previous occupation</b>	Marketing/sportsman	Civil engineer	School principal	Businessman	Computer technician	Direct marketer
<b>Primary caregiver</b>	Mother	Wife	Partner	Friend	Wife	Mother