Lived experiences post-penectomy surgery for patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study.

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DECLARATION

This is to certify that the work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). The work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

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DEDICATION

I DEDICATE THIS DESERTATION TO MY THREE CHILDREN. DO THE RIGHT THING THE FIRST TIME AND ALWAYS PUT GOD FIRST IN EVERYTHING YOU HOPE TO ACHIEVE IN YOUR LIVES.

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ABSTRACT

Background

Penile cancer is a rare malignancy with prevalence higher in areas of high Human Papilloma Virus (HPV) such as Africa, Asia and South America. In middle- and low-income countries where circumcision is not routinely practiced, the rate of penile cancer could be ten times higher. A penectomy refers to a procedure which all or parts of the penis are surgically removed. Total penectomy involves the removal of the entire penis. During this procedure, a new opening is created in the perineum through which urine can pass. In some cases, the testicles, scrotum and lymph nodes may be removed. A partial penectomy involves the removal of part of the penis and typically leaves the shaft intact. Surgical treatment is inevitably mutilating. Despite its therapeutic effectiveness, total penectomy leads to mutilations that affect the ability of patients to void urine while upright. It also affects the patient's corporal image, genital sensibility, and self-esteem.

Purpose: The purpose of the study was to explore the lived experiences of post-penectomy patients receiving care in a Public Hospital in KwaZulu-Natal.

Methodology

This was a qualitative study based on Edmund Husserl's descriptive phenomenology which is described as the science of the essence of consciousness or inquiry into the consciousness of the patient. Purposeful sampling was used for the study. Data was collected using face-to-face in-depth interviews with patients who had penectomy surgery and were receiving follow-up health care in the selected public hospital. These patients were a year or more post-surgery therefore had sufficient experience to provide rich data. Participants were met and told about the study when they came to the hospital's outpatient department for their follow up visits, and interviews were conducted where they are most comfortable such as at their homes.

Results

The data was analysed by means of content analysis and raw data was coded and sorted into sub-categories and categories. Sub-categories were: feeling severe pain, beliefs about causation of illness, feelings of loss of life, sense of self care, coping

mechanisms, support system, loss of self-esteem, fear of people knowing about the surgery performed, bodily discomfort from disfigurement, being able to have sexual satisfaction, and use of sexual gadgets. The underlying meaning of categories were formulated into themes which were: thought processes before penectomy surgery, psychological effects of penectomy surgery, difficulty in urination, and sexual function post penectomy surgery. All participants had penile cancer. Pain was the main reason for these participants to make a decision to have the penectomy surgery; participants had severe sores around their penile area and these sores were not healing. Other reasons during their thought processes before making a decision for the penectomy surgery was the penile cancer itself, with participants being worried that if they delay or they do not agree to the surgery the cancer would spread to other organs of the body

Conclusion

Even though penectomy surgery is a debilitating procedure and inevitably mutilating despite its therapeutic effectiveness, the pain and the illness that the participants were going through led them to take the decision to have the surgery. Outcomes were the relief of pain and healing from penile cancer. No recurrence of cancer was verbalised by the participants after the surgery.

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GLOSSARY OF TERMS

Term	Meaning
Penectomy	Surgical removal of the penis
Partial penectomy	Surgical removal of a part of the penis
Hygiene	Practices conducive to maintaining health and preventing disease, especially through cleanliness
Circumcision	The action or practice of circumcising a young boy or a man
Urination	The discharge of urine from the body

LIST OF ACRONYMS

CANSA	Cancer Association of South Africa
HIV	Human Immunodeficiency Virus
HPV	Human papilloma virus
KZN	KwaZulu-Natal
MEC	Member of the executive committee
MMC	Medical male circumcision
QoL	Quality of life
TMC	Traditional male circumcision
WHO	World Health Organization

CHAPTER 1: OVERVIEW OF THE STUDY

1.1 Introduction and background to the research

Penectomy is the surgical removal of part of or the entire penis (Slaoui et al., 2015). There are different types of penectomies, namely: partial, total and radical total penectomy.

- A partial penectomy is usually performed when only the cancerous tissue and a 2cm margin of healthy tissue is removed while leaving enough length of the penis for the patient to urinate naturally (CANSA 2018: 6).
- A total penectomy, with perineal urethrostomy, is the removal of the entire penis. With this surgery, the surgeon tunnels the urinary tract underneath the scrotum, resulting in the need for the patient to urinate in a sitting position (CANSA 2018: 6).
- Radical total penectomy, with inguinal lymph nodes dissection, is a total removal of the entire penis including the scrotum and removal of the lymph nodes in the groin and or pelvis.

In clinically lymph-node positive patients, surgical staging by inguinal lymphadenectomy is indicated, but radical inguinal lymphadenectomy carries a significant morbidity related to problems of lymph drainage from the legs and wound healing (Slaoui et al., 2015: 3).

Penectomy is cited as the most common and effective procedure to treat penile cancer (CANSA 2018: 5). Penile cancer is a rare tumour and is more common in the southern hemisphere (50 in 100 000), while it accounts for 20% to 30% of all male cancers in some regions of Asia, Africa and South America (Sansalone *et al.* 2015: 1). The major risk factors for penile cancer are phimosis associated with poor hygiene, which leads to accumulation of smegma, and human papilloma virus infection (CANSA 2018: 2). According to CANSA (2018: 2), the incidence of penile cancer in South Africa in 2014 was 1: 1692 among the black population; 1:1864 in Asians; Coloureds 1:1692; and 1:1775 among Whites. Currently, in a regional Kwazulu-Natal (KZN) specialized urology hospital, 27 patients had penectomy surgery in 2019 while 29 other patients

had penile biopsies which confirmed squamous cell carcinoma (St Aidan's Hospital Theatre register). If men do not seek medical help for proper and early diagnosis, penile cancer complications can result in amputation.

Other conditions that can lead to penectomy are botched circumcision procedures and untreated sexually transmitted diseases. In 2017, it was estimated that approximately 250 traditional circumcision procedures lead to penile amputation every year in South Africa (Moodley and Rennie 2018: 86). Penectomy surgery would also be performed in cases of untreated sexually transmitted infections (STIs) and destructive penile warts. Despite benign histology, these also lead to penectomy surgery, however, these conditions are not as common as cancer is (Pireda-Murillo *et al*. 2019: 2).

While most complications resulting from botched circumcisions, STIs and penile cancer can be remedied if diagnosed and treated in time, what necessitates penectomy in most patients is the delay in seeking health intervention. Nyalela *et al.* (2018: 2) states that men are generally less likely to seek medical help or utilize available health services when experiencing health problems. She further argues that men tend to seek medical help when signs and symptoms were perceived to be severe. Another delay in seeking medical treatment is due to patients preferring traditional healers to modern medicine. These patients believe that traditional medicine can remove the root cause of the illness and that it offers treatment and greater privacy than the public clinics (Nyalela *et al.* 2018). In some instances, this is further exacerbated by the demographics of healthcare practitioners in most healthcare facilities, where some men deem it culturally inappropriate to speak to women about problems of sexual nature. Nursing is predominantly a female profession so a female majority health facility may be perceived by some males as a hostile environment for males (Nzama, 2013). In culturally sensitive societies, such considerations lead to delays in health-seeking resulting in the need for penectomy in cases of penile ill-health.

Penectomy is inevitably mutilating despite its therapeutic effectiveness. Total penectomy leads to mutilations that affect the ability of patients to void urine while upright. It also affects the patient's corporal image, genital sensibility, and self-esteem (Pompeo *et al.* 2015: 2). This study surveyed some of these post-surgery challenges

on a number of patients at a public hospital in KZN in an effort to establish the lived experiences of the affected population.

This was a qualitative study based on Edmund Husserl's descriptive phenomenology, which is the method used in research to explore and describe lived experiences of individuals (Christensen, Welch and Barr 2017: 113). Data was collected using face-to-face in-depth interviews with patients who had penectomy surgery and were receiving follow-up health care in the selected public hospital. The sample included patients who had one year or more post-surgery experience on the assumption that they would have had sufficient experience to provide rich data. Participants were recruited as they came into the hospital's outpatient department for their follow up visits and the interviews were conducted mostly in their homes.

1.2 Problem statement

A penis is a vital part of the reproductive system. Shefer, Kruger and Schepers (2015: 103) state that in South Africa Zulu men have to prove their masculinity and become a man by using sex and becoming a father as a way of avoiding the shame of questions about one's masculinity. According to Reihling (2020: 3), traditional masculinity is commonly defined through risk taking, uncontrollable sex drive, and compulsory heterosexuality, physical and emotional toughness.

According to Onoya *et al.* (2015: 101), South African communities seem more accepting of multiple sexual partners among males than females. This stems from the culturally endorsed dominant gender role and control that men exercise in sexual relationships as well as cultural expectations of men. Furthermore, multiple sexual partners are associated with a higher social status within the community and emphasise manhood so may be a source of power, contributing to men's self-worth. Men's involvement in multiple relationships was considered to help preserve steady relationships (Onoya *et al.* 2015: 103).

Hoai *et al.* (2020:1) state that penis size is a highly sensitive topic and often raises concerns associated with human masculinity and male sexual health. Through the ages, from artists to pornography, the penis has featured as a symbol of masculinity,

virility, fertility, power, and strength. Not only are the genitals often central to one's sexual experiences, gender identity, sexual orientation, and bodily self-image, but they are also commonly regarded as extremely 'private'—not to be touched or even seen without one's explicit consent, which is typically granted only in intimate situations (Earp and Steinfeld 2018: 2).

According to Sansalone *et al.* (2017: 1) penectomy has been associated with sexual and psychological problems regarding orgasm, body image, life interference, and urination Lidner *et al*. (2019: 3) state that radical partial or total penectomy is associated with significant functional, sexual and psychological deficits, despite high oncological control rates. Removing all or part of the penis can have a devastating effects on a man's self-image and ability to have sexual intercourse (CANSA 2020: 6). Furthermore, many man who have undergone a total penectomy must sit to urinate. Having to undergo penectomy surgery can thus affect these men's self-esteem.

Sansalone *et al.* (2017: 9) state that appropriate preoperative education and multidisciplinary follow-up have the potential to improve sexual outcomes after partial penectomy surgery. There is very limited literature related to post-operative penectomy surgery, especially in the African context. A high quality cancer population registry is a very important tool for all countries. However, this feature was absent in most of the reports evaluated by the scholars.

1.3 Purpose of the study

The purpose of the study was to explore the lived experiences of patients who have had penectomy surgery in a particular public hospital in KwaZulu-Natal.

1.3.1 Research question

What are lived experiences of patients who had penectomy surgery at a particular public hospital in KwaZulu-Natal?

1.3.2 Objectives

The main objective of the study is to determine the lived experiences of the patients who have undergone penectomy surgery in order to:

- Assess the impact of penectomy surgery on the sexual function and urinary function of the patient ;
- To examine self-esteem of the patients, post penectomy surgery; and
- To determine the overall psychological effects of penectomy surgery.

1.3.3 Sub-questions

- How has penectomy surgery affected patients' urinary and sexual function?
- What is the experience of domestic re-integration for penectomy surgery patients?
- What are the overall psychological effects of penectomy experienced by patients?

1.4 Significance of the study

The results of the study can possibly:

- Assist hospital management to consider a multi-disciplinary team in counselling of men pre- and post-operatively.
- Assist policy makers to evaluate approaches in men health seeking behaviours.
- Encourage men to seek medical help early and to practice proper personal hygiene.
- Help patients who have had penectomy to acknowledge life as it is and be able to move on without any psychological consequences such as loss of self-esteem.

1.5 Structure of the dissertation

This study consists of six chapters.

Chapter 1: Introduction and background to the study

In this chapter, the introduction and background to the study is presented regarding penectomy and its causes. The chapter also presents the problem statement, purpose and significance of the study.

Chapter 2: Literature review

A discussion of the recent literature and the theoretical framework is provided in this chapter.

Chapter 3: Research Methodology

This chapter outlines the research methodology used to conduct this study. Techniques and methods of the research process are discussed.

Chapter 4: Presentation of results

In this chapter, the findings of the collected data are presented in line with the objectives of the study.

Chapter 5: Discussion of results

This chapter offers a discussion of the findings, through making sense of raw data and integrating them within the findings of the reviewed literature.

Chapter 6: Conclusion, limitations, further research and recommendations

This is the last chapter of the study, which consists of a conclusion and a discussion of the study limitations and puts forward recommendations.

1.6 Chapter summary

This chapter presented the background context and aim of the study. It made known the research question, objectives and the significance of the study. The next chapter will review the relevant literature in order to gain a deeper understanding and insight of lived experiences by patients who have had penectomy surgery.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Literature review is the critical appraisal of the current collective knowledge of a particular subject and an extension of information gathering in order to gain a personal insight into the background of the topic (Winchester and Salji 2020: 308). According to Gray, Grove and Sutherland (2017: 120), “it is an interpretative, organized and written presentation of what the study’s author has read around the subject of interest.” A literature review is an evidence-based, in-depth analysis of a subject. The purpose of conducting a review of the literature is to discover the most recent and the most relevant information about a particular phenomenon (Gray, Grove and Sutherland 2017: 120). This is essential for developing a research idea; to consolidate what is already known about the subject, and to identify any knowledge gaps (Winchester and Salji 2020: 308). A literature review assists in evaluating the data and determines its relevance. It also enables the researcher to, in due course, identify other research that supports or corroborates the researcher’s findings as well as the results that differ, enabling the researcher to position the research in the field of study (Winchester and Salji 2020: 309).

This review pertains to the study of lived experiences of patients who have undergone penectomy surgery. Different terms were used in order to retrieve literature related to the study: ‘quality of life’, ‘penectomy’, ‘penile cancer’, ‘penile neoplasm’, ‘penile carcinoma’, ‘penile amputation’, ‘partial penectomy’, ‘Human papilloma virus’ (HPV), ‘effects of penectomy on urination’, and ‘effects of penectomy on sexuality’. Various sources of literature were studied using Google Scholar, DUT Library, PubMed and textbooks.

This chapter has six sections, starting with a discussion of the effects of losing body parts on quality of life for humans, followed by various causes of penectomy which include circumcision and penile health, other physical injuries, penile warts and penile cancer. The main part of this chapter discusses the life changes and lived experiences after penectomy surgery, which involve effects on micturition, sexuality, psychological, and emotional effects and also effects on quality of life.

2.2 Effects of losing body parts on quality of life for humans

The human body is designed for the anatomical and physiological functions necessary for effective living. As such, if a part/s is removed from the body there are certain effects that are a consequence (CANSA, 2018). Amputation is a major burden on individuals, families, society, and medical services (Sahu *et al.* 2016: 1). Traumatic limb amputation is a catastrophic injury and an irreversible act which is sudden and emotionally devastating for the victims. In addition, it causes inability to support self and the family and drives many patients towards various psychiatric disorders (Sahu *et al.* 2016: 1). Losing a limb can have a huge effect on a person's quality of life (Kondo et al: 2015: 2). Kondo *et al.* (2015: 2) state that patients who have had surgical removal of an eye (enucleation, evisceration or exenteration) can have depressive challenges in everyday activities, perceived problems with physical appearance and coping difficulties. Some patients experience hallucinations associated with loss of vision, and for small portion of patients, their hallucination can be debilitating.

Effects of major medical operations used as solutions to cancer have also been assessed. Przezdzieck and Sherman (2016: 1143) note that although effective at reducing mortality, breast cancer treatments (i.e., surgery, chemotherapy, radiation, hormone treatment) often result in unwanted physical side effects that may include alterations to breast appearance and scarring following whole or partial breast removal; arm and shoulder mobility restriction. Unfortunately, these treatment effects can lead to serious challenges to the integrity of a woman's body, and hence, her body image, with possible resultant distress (Przezdzieck and Sherman 2016: 1143). It is uncontroversial, therefore, to assume that anybody-altering surgeries not wilfully desired by the owner can lead to a number of physical and psychosocial effects, and negatively impact on the lived experiences of individuals.

According to Liu et al. (2019: 878), Patial, Sharma and Raima (2017: 1), Fazi et al. (2019: 1) and Musa et al. (2016: 786), traumatic amputation of the penis is a rare surgical emergency, which can be due to self-mutilation, circumcision, assault, accidents, and animal attacks. Liu *et al.* (2019: 878) state that in their study there were two cases of patients with injuries that led to penile amputation: one was injured by

sharp scissors due to family conflict, while in the second case it was a mechanical injury. For both cases, microsurgical approaches were adopted. Fazi *et al.* (2019: 1) state that penile amputation is an uncommon and highly morbid injury. Many mechanisms have been reported ranging from self-mutilation and domestic violence to traumatic circumcisions. In their study they had two unusual cases of traumatic penile amputation. An older gentleman endured extensive perineal trauma after being trapped underneath an industrial-sized lawnmower, and a young adolescent was bitten by an English bulldog and suffered amputation of the glans of his penis. There has also been a traumatic penile amputation following a trauma from a grinding machine injury (Musa *et al.* 2016: 786), while a 9-year-old boy was referred to a hospital after his sister amputated his penis with a sickle. The sister was being treated for a mental illness (Patial, Sharma and Raima 2017: 1).

2.3 Various causes of penectomy

2.3.1 Circumcision and penile health

According to Douglas *et al.* (2018: 77), male circumcision is the oldest and most prevalent surgical procedure among boys and old men. It is estimated that 33.3% of men worldwide have undergone circumcision and it is performed in different societies for reasons ranging from medical, ritual, traditional to cosmetic. In South Africa, men can opt for one of two types of circumcision: traditional male circumcision (TMC), performed in initiation schools by traditional circumcision practitioners, or medical male circumcision (MMC) performed at private or public health facilities (Palmer, Rau and Engelbrecht 2020: 1). According to Palmer, Rau and Engelbrecht (2020), attempts in South Africa to integrate MMC with traditional manhood initiation rituals still lack acceptability; 70% of Black men fear being stigmatized if they are circumcised medically and not traditionally. In the Eastern Cape, traditional male circumcision is a more common method than medical circumcision because it is part of the Xhosa culture and it is honoured as such (Douglas *et al.* 2018: 23).

In the Zulu culture, traditional circumcision was suspended 200 years ago by King Shaka for military strategic reasons. This king believed that septic wounds from circumcision left many men unable to participate in war (Naidoo et al. 2012: 3). However, circumcision was re-introduced in 2010, as a strategy to prevent HIV by the

KwaZulu-Natal Member of the Executive Committee (MEC) for health, supported by the Zulu king, King Goodwill Zwelithini, which was to be performed by medically trained practitioners and known as medical male circumcision (MMC) (Naidoo et al. 2012: 3).

The procedure herein referred to as traditional male circumcision is usually performed in non-clinical settings by traditional surgeons with no formal traditional training and/or lack of experience (WHO 2018: 23). Current ritual circumcision practices in South Africa have raised serious health concerns (Van der Merwe *et al*. 2017: 2; Moodley and Rennie 2018: 88). Complications of the procedure result in severe penile mutilation or varying degrees of penile amputation, and deprives the young man of the ability to urinate standing up, and to enjoy normal sexual intercourse (Moodley and Rennie 2018: 87). Currently, it is estimated that roughly 250 traditional circumcisions lead to penile amputation every year in South Africa (Moodley and Rennie, 2017). Ritual circumcision complicated by gangrene is the leading cause of penile loss in young men in South Africa. Traditional circumcision is deeply rooted in cultural tradition and is unlikely to be abolished as it is known as part of traditional rites of passage to manhood, but the psycho-sociological effects of penile loss in a young man are devastating.

2.3.2 Other physical injuries

Men can incur penile injuries due to other activities too. In the case of soldiers wounded in war, damage to the genital area can result in impairment of excretion, urinary incontinence, sexual dysfunction, hormonal imbalance and infertility. Those who have sustained penile injuries and penile loss also commonly suffer from feelings of emasculation, suicidality and post-traumatic stress disorder (Moodley and Rennie 2018: 86). There are a significant number of penile injuries that result from sexually transmitted infections and cancer, that complicate to the point of necessitating amputation.

2.3.3 Penile warts

Penile warts are the most common sexually transmitted disease in males and are caused by human papillomavirus 1-3 (HPV). Risk factors include lack of personal hygiene, promiscuity, smoking, chronic irritation, presence of foreskin and

immunodeficiency (congenital and acquired) (Leung *et al.* 2018: 1). The tumour comes from the confluence of multiple condyloma acuminata and is clinically manifested by warty, exophytic, ulcerated lesions, with aggressive behaviour, rapid growth, invasion and destruction of adjacent structures. Patients with severe penile defects often suffer from debilitating physical and psychosocial sequelae, including inability to have sexual intercourse or urinate while standing, feelings of emasculation, disruption of interpersonal relationships, and profound loss of quality of life (Tuffaha *et al.* 2017: 4417: 86). Furthermore, despite benign histology, conservative treatment may be without any effective response, for which a partial penectomy is performed.

2.3.4 Penile cancer

Penile cancer is one of the major causes of penectomy (Sosnowski *et al*. 2016; Yu *et al*. 2016). Penile cancer is a uniquely male-specific cancer, situated in a sexual organ and is fundamentally associated with sexual function and sexuality (Bullen *et al.* 2014). Penile cancer can develop anywhere on the penis (including the soft tissue) but most commonly develops under the foreskin, in men who have not been circumcised, or on the head of the penis (glans penis) (CANSA 2018:3). According to Hakenberg *et al.* (2018: 654), it as an aggressive squamous cell carcinoma of the skin of the glans or of the inner layer of the prepuce, characterized by invasive growth and early metastatic spread to lymph nodes. Etiological factors include poor penile hygiene, phimosis, tobacco smoking, and human papillomavirus (HPV) infection (Sansalone *et al.* 2015: 2). In 50% to 60% of squamous cell carcinomas of the penis, human papilloma virus infection, particularly Types 16 and 18, is part of the pathogenesis (Triano *et al.* 2018: 141). Ngendahayo *et al.* (2018: 225) conducted a study in Rwanda between 2015 and 2016. They concluded that phimosis and lack of sub-preputial hygiene leading to the build up of smegma resulting in chronic inflammation, and lack of circumcision, were the most prevalent risk factors for invasive penile carcinoma.

According to CANSA (2018: 3), the first sign of penile cancer is a change in the skin of the penis. Symptoms are: skin thickening, appearance of a painless nodule or a warty growth especially on the glans penis or foreskin, change in the colour of the penis, and swelling at the end of the penis (CANSA 2018: 3). Later signs may include a growth or sore on the penis especially on the head of the penis or the foreskin, but

also sometimes on the shaft of the penis. There may be discharge or bleeding and a smelly discharge under the foreskin. Most penile cancers are painless. Any abnormality of the penis, including warts, blisters, sores, ulcers, white patches, rash, bumps or lumps, need to be investigated. Sometimes the cancers appear as flat, bluish-brown growth, or as a red rash, or small crusty bumps. Penile cancer is easier to treat if it is diagnosed early (CANSA 2018: 3).

2.3.4.1 Incidence of penile cancer

According to Slaoui *et al.* (2015: 2), tumours of the penis are the rarest tumours of the genitourinary system; it represents 0.5% of malignant tumours of men. Ngendahayo *et al.* (2018: 224) state that cancer of the penis has a marked variation in geographic distribution. Literature (Bullen *et al.* 2014: 1, Hakenberg *et al.* 2018: 648, Lindner *et al.* 2019: 3) indicates that penile cancer accounts for only 0.4% to 0.6% of malignancy diagnosed in Europe and USA. The highest global age-standardized incidence is in the state of Maranhao in Brazil (6.15 per 100 000) occurring at the mean age of 60 to 70 years. Djordjevic., Palminteri and Martins (2014: 427) further state that the incidence of this malignant tumour is higher in developing countries of Africa, South America and Asia, constituting about 10% of oncologic burden in these countries, thus posing a considerable public health concern.

While penile cancer is rare in developed countries, it is a significant clinical problem in some developing countries especially in Africa (Ngendahayo *et al.* 2018: 278). According to Cardona and Garcia-Perdomo (2017: 3), the highest incident rate of penile cancer in Africa is in Uganda, with an incidence of 6.3 cases per 100 000, followed by Malawi and Zimbabwe with 3.25 and 2.41 respectively. However, lack of cancer registries and epidemiological surveillance program in developing countries makes it difficult to estimate the prevalence and incidences of penile cancer (Ngendahayo *et al*. 2018: 225).

In Rwanda between January 2015 and June 2016, 30 patients between the ages of 50 to 70 years presented with penile cancer and were enrolled for a post-penectomy surgery study, but there was a lack of a cancer register and epidemiological surveillance (Ngendahayo *et al.* 2018: 276). According to Cassell *et al.* (2020: 2),

between 2017 and 2016, 432 black patients were treated for penile cancer according to data collected from Guinea, Kenya, Senegal and Tanzania. Between January 2004 and December 2013 there was a retrospective study conducted in Tanzania at the Bagando Medical Center with 236 patients who were treated for penile cancer and their age group was between 41 to 50 years (Chalya *et al.* 2015: 1). According to the national cancer register of South Africa, there were 172 males who presented with penile cancer and had to undergo penectomy surgery in 2014 (CANSA 2018: 2). This number rose to 244 in 2018 (Bruni, et al., 2019; Globocan, 2019).

According to Slaoui *et al.* (2015), the incidence of penile cancer increases with age with an age peak during the sixth decade of life. However, the disease does occur in younger men. CANSA (2020: 4) indicates that the incidence of penile cancer is approximately eight-fold higher in HIV-infected men. Wentzel *et al.* (2018: 47) state that male partners with cervical intra epithelial neoplasm have a significantly higher incidence of penile intraepithelial neoplasm as well as human papilloma virus infection.

2.3.4.2 Effects on quality of life of the patient with penile cancer

Beilin *et al*. (2017: 224) state that penile cancer can take a devastating toll on both the quantity and quality of life for affected men and their partners. The cancer leads to physical genital disfigurement, which may alter normal male voiding pattern, impair normal penetrative intercourse, lead to psychological and emotional distress, and even to death (Morris 2015: 559). Morris (2015: 559) further states that in a society where masculinity is defined by and associated with the presence of the phallus, penile cancer affects male self-esteem and may lead to depression. According to Hakenberg *et al.* (2018: 646) early metastatic spread of penile cancer to regional lymph nodes can be life-threatening. Kieffer *et al* (2014: 3) state that penile cancer and its treatment can seriously impact sexuality and intimacy, and body image, urinary function, mental health, and health-related quality of life.

2.3.5 Sociological factors: Why do men delay seeking medical help?

While there are several causative factors for penectomy, the main challenge is delays in the diagnosis and onset of treatments, especially in ailments related to sexuality and sexual organs in men. Men are far less likely to visit their general practitioner with

bothersome symptoms because of fears of appearing neurotic or unmanly (Bullen *et al*. 2014: 22). According to Bullen *et al.* (2014: 22), evidence supports the view that factors such as embarrassment, fear, the potential impact on sexuality and a cancer sited in a sexual organ, all impact on patients' help-seeking behaviours, resulting in a delay in first presentation. Sosnowski *et al.* (2016: 205) agree that many patients delay seeking medical attention due to embarrassment, fear, and ignorance. They further state that as a uniquely male-specific cancer, situated in a sexual organ fundamentally associated with sexual function and sexuality, it is understandable that there is delay in presentation when symptoms are noticed because of the distressing symptoms such as a foul-smelling discharge, or frank ulceration.

Patient related delays in diagnosis and treatment are common and is associated with low socioeconomic status and low levels of education (Ngendahayo *et al.* 2018: 229; Hakenberg *et al*. 2018). Patients tend to report the first symptoms experienced to be itching, discharge or smelling from the preputial sac (Ngendahayo *et al.* 2018: 229).

2.4 Penectomy: primary treatment for penile cancer

Surgery is the most common treatment of penile cancer; more invasive cancers may require extensive surgery, including removing part of or the entire penis. Removing lymph nodes that are in the region of the penis is often necessary during extensive surgery (CANSA 2020: 5). According to Sosnowski *et al*. (2016: 205), primary treatment for penile cancer is surgery; the surgical treatment involves the removal of the primary tumour lesion with or without performing inguinal lymphadenopathy. The central aim of successful cancer treatment is to remove cancerous tissue with sufficient margin of healthy tissue to prevent local recurrence. According to Yu *et al*. (2016: 1), partial penectomy is a common treatment for penile cancer. Pompeo *et al*. (2015: 122) reported that another typical surgical treatment for penile cancer is total penectomy with perineal urethrostomy.

Djordjevic, Palminteri and Martins (2014: 430) states that removing part of the penis (partial penectomy) is the technique which seems to be oncologically well tolerated with a 100% recurrence free outcome. Contrary to Pompeo *et al.* (2015: 122) who stated that partial penectomy is recognized as an effective procedure for local disease

control, with low local recurrence rates. Kieffer *et al.* (2014: 3) state that although historically partial penectomy has been the primary treatment, more recently various penile-sparing procedures have been introduced and lymph nodes dissection is carried out when necessary, as determined by the sentinel lymph node biopsy.

2.5 Life changes after penectomy

2.5.1 Effects on micturition

According to Pompeo *et al.* (2015: 1and Wan *et al.* (2018: 1425), surgical treatment is inevitably mutilating. Despite its therapeutic effectiveness, total penectomy leads to mutilations that affect the ability of patients to void urine while standing upright, their corporal image, genital sensibility and self- esteem. The American Cancer Society (2016: 5) reports that men who have had a total penectomy often must sit to urinate. Djordjevic, Palminteri and Martins (2014: 428) in their study discovered that in many cases traditional penectomy leaves the patient with a short stump, unsuitable for voiding while standing up and with limited or no sexual function. Similarly, Kieffer *et al. (*2014: 3) in their study found that a large majority of men who had undergone partial penectomy indicated experiencing leakage while urinating, and that the most frequently reported reason for leakage included spraying urine flow and too short a penis. Sansalone *et al*. (2015: 2) state that if a sufficient portion of a penile shaft is preserved (partial penectomy) the urinary stream can be comfortably directed.

2.5.2 Effects on sexuality

Bullen *et al.* (2014: 22) state that apart from breast cancer which can be experienced by both women and men, the main disease sites that differ between sexes are associated with sexual organs. The American Cancer Society (2018: 6) states that removing all or part of the penis can have a huge effect on a man's ability to have sex. They further state that satisfying sex is possible for many but not all men after partial penectomy, but intercourse is not possible after total penectomy. Yu *et al.* (2016: 1) and Beilin *et al*. (2017: 224) reported that after partial penectomy patients reported erectile function. Kieffer *et al.* (2014: 3) reported that penile cancer treatment negatively affected patients well-being by 40% and decreased sexual function by 60%, and radical partial or total penectomy was associated with significant functional, sexual

and psychological deficit. Sosnowsky *et al.* (2016: 205) conducted research with patients after partial penectomy and found erectile function “most times” or “always” allowed sexual intercourse, or that the penis was “sometimes” or “a few times” hard enough for penetration, while some patients reported having “no sexual activity” or “almost never.” Yu *et al.* (2016: 3) found that when attempting sexual intercourse some patients “most times” or “always” felt satisfied, some patients “sometimes” or “a few times” felt satisfied, while some patients “never” felt satisfied or “did not attempt intercourse”. Some patients reported their sexual intercourse to be “highly” or “very highly” enjoyable.

Patients who undergo full or nearly total penile amputation often do not resume sexual intercourse, which might be caused by their feeling of shame in having a short penis size (Li *et al.* 2017: 493). Men’s self-image and sexual life may profoundly be influenced by a diagnosis of penile cancer (Sansalone *et al*. 2017: 3), also by alterations of patients’ sexual function and of their partners’ sexual satisfaction. Triano *et al.* (2018: 143) state that maintenance of an adequate sexual function is the most common concern for men undergoing treatment for penile cancer, and may promote patients return to satisfactory sexual intercourse. In a study by Sosnowski *et al*. (2016: 225) on sexual pleasure after amputation of the penis and total penectomy, patients reported that stimulation of their remaining genital tissue, including the mons pubis, healed surgical site, perineum, and scrotum, can produce an orgasm. They further studied that another form of arousal was visual stimulation. The overall relationship, for most patients, was good, because patients claimed that the relationship with their partner had not deteriorated, and one patient found that his relationship with partner had improved. According to Yu *et al.* (2016: 8) patients are affected psychologically due to sexual dysfunction, so multidisciplinary follow up with psychologists is necessary. Appropriate preoperative education and multidisciplinary follow up have the potential to improve sexual outcomes after partial penectomy (Pompeo *et al*. 2015: 122).

2.5.3 Effects on self-image with psychological and emotional effects

Yu *et al*. (2016: 8) state that removing all or part of the penis can have a devastating effect on a man’s self-image, and morbidity of anxiety and depression increase

significantly after partial penectomy. Bullen *et al*. (2014: 24) found that patients reported an altered sense of self because of changes in self-image, their age, their changed masculinity and disfigurement, and that they had to learn to cope with psychological changes such as anxiety and depression, altered physical function of urination, sexual activity and fatigue. While penile carcinoma is a rare malignant disease, it has significant physiological and psychological effects on the patients. Partner support is an important factor that helps patients to overcome their difficulties after partial penectomy (Yu *et al.* 2016: 8; American Cancer Society 2016: 8). Although reconstructive surgery is well established for patients with penectomy, an aesthetically perfect penis is not possible. According to Triano and Nante. (2018: 143) it is understandable why patients often are reluctant to undergo radical treatment due to the devastating effect it has both physically and psychologically. Support groups can have many benefits, especially being with people who have similar cancer experiences; research shows that joining a support group improves quality of life and enhances survival along with high oncological control rates (Lindner *et al.* 2019: 3).

Losing part of one's body can have a huge effect on a person's quality of life. These patients can develop depression, perceived problems with physical appearance, and coping difficulties (Kondo *et al:* 2015: 2). Removal of part of the body is a major health burden on families, society and medical services. It can be perceived as a catastrophic and an irreversible act, which is emotionally devastating for the patient. In addition, it causes inability to support self and the family and drives many patients towards various psychiatric disorders (Sahu *et al.* 2016: 1). Additionally, removal of part of the body is typically equated to loss of a spouse, loss of perception of wholeness, symbolic castration, and even death. This may result in the patient being severely affected emotionally, thus resulting in poor quality of life. This may cause distress not only due to loss of a body part but also due to the role limitation and the need for adjustment to the required changes of lifestyle.

Sahu *et al.* (2016: 1) state that although studies reported that symptoms of anxiety and depression become better over the course of time, surgical treatment providers need to liaise with psychiatrists and psychological support and deal with the psychological disturbances. In their study they found that amputation represents an irreversible surgical option which may result in physical challenged and bodily

disfigurement. The individual undergoing amputation may be at risk of developing depression disorder due to multiple factors such as feelings of loss, self-stigma and difficulty in coping up with the impairment (Sahu *et* al. 2016: 2).

Body image is an important aspect of self-evaluation that has complex psychological effects (Imeni *et al.* 2018: 2). Studies indicate that individuals who have undergone amputation due to diabetes are at risk for developing mental distress and that impact on body image in patients who have undergone an amputation to the extent that even advances in the field of prosthesis are not able to compensate for the disruption to the body image of these patients (Imeni *et al*. 2018:2). According to Manikum, Ramklass and Madiba (2019: 3) patients with lower limb amputation characteristically present with decreased mobility, which impacts negatively on the performance of their activities of daily living thus integration into society.

2.5.4 Effects on quality of life

Sosnowski *et al.* (2016: 205) and Triano and Nante. (2018: 142) reported that the amputation of the penis, especially if it is total amputation, represents a very debilitating procedure, which clearly modifies patient's Quality of life (QoL), particularly sex life. Evaluation of the QoL is often difficult to assess because there are no validated and standardized research tools specific for this procedure (Sosnowski *et al.* 2016: 207). Penis is both a cultural and an individual symbol of masculinity, potency and fertility, so it is fundamental for males' self-perception and it plausible that penile disease may affect patients' QoL (Mortensen and Jakobsen, 2013). According to Triano and Nante. (2018: 144), contrary to the initial expectations of the authors, patients who underwent penectomy were found to be well-adapted to their condition and, in general, the quality of their lives was maintained especially in patients who underwent a partial penectomy. However, as Sansalone *et al*. (2017: 9) affirmed, these patients are likely to live with the sexual and psychosexual effects of penile surgery for a long time.

In contrast, the partial penectomy and subsequent lack of capacity to perform coitus was important for the younger patients (40 years old and younger) and the perceived impact on their prospects of finding love and companionship were decisive to their

QoL. Patients with severe penile defects often suffer from debilitating physical and psychosocial sequelae, including inability to have sexual intercourse or urinate while standing up, feelings of emasculation, disruption of interpersonal relationships, and profound loss of QoL (Tuffaha *et al.* 2017: 441).

2.6 Gaps in the literature and rationale for current study

The literature has comprehensively covered the causes and practical descriptions of penectomy in various contexts. In addition, there is agreement in the literature regarding the negative effects of unintended loss of body parts. However, the literature is very thin on the effects of penectomy on the physiological, psychological and sociological lives of patients. Given the significance of the male organ in many cultural contexts, it would be informative to analyse the effects of penectomy within the cultural contexts of KwaZulu-Natal. At the moment, there is no study that explicitly discusses the lived experiences of men who have undergone penectomy. This study therefore aims to bridge that gap, with the hope of informing healthcare procedures in order to mitigate any negative effects that are discovered.

2.7 Chapter Summary

This chapter presents a literature review on the prevalence of penectomy and the burden of penile cancer in South Africa but specifically KwaZulu-Natal province, covering the incidence of penile cancer, effects on quality of life of the patient with penile cancer, and penectomy as the primary treatment for penile cancer. The following chapter looks at the methodology of the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

Research methodology is the study of research methods in order develop a coherent and logical scheme based on views, beliefs and values that guides the choices researcher makes (Gray, Grove and Sutherland 2017: 251). In this section, the researcher discusses the research design which was used to explore the lived experiences of patients who have undergone penectomy surgery. The study setting and data collection methods are also discussed.

3.2 Research design

The study is based on Edmund Husserl's (1859-1938) descriptive phenomenology, which is a qualitative descriptive phenomenology design within the constructivist paradigm (Gray, Grove and Sutherland 2017: 66). According to Gray, Grove and Sutherland (2017: 66), phenomenology is a method of inquiry that assists the researcher to discover subjective data from participants as they have lived the phenomena under investigation in their daily experience, which in this study refers to the life experience of post-penectomy surgery. Husserl's form of phenomenology is considered descriptive or eidetic and is described as the science of the essence of consciousness or inquiry into the consciousness of the researcher (Porter, 1998 cited in de Chesnay 2015: 4). This design is a deliberate attempt to enrich the world of human experience by bringing out neglected aspects of experiences with the deeper motive of reverence for the phenomena (de Chesnay 2015: 9). Husserl's descriptive phenomenology involves four steps, namely: bracketing, intuiting, analysing and describing.

Table 3.1: The four steps of Husserl's descriptive phenomenology

Bracketing	An effort to maintain objectivity, where the researcher's pre-conceived attitudes, opinions, values, and beliefs are held in abeyance reduction (de Chesnay 2015: 4).
Intuiting	The researcher grasps and remains open to the meaning of the phenomenon that those that have experienced it attribute to it, prior to analysing data (de Chesnay 2015: 4)

Analysing	Categorizing significant statements and making sense of the meaning of the phenomenon (described later in data analysis) (Giorgi *et al*. 2018: 180)
Describing	This occurs when the researcher understands and is able to define the phenomenon (Giorgi *et al.* 2018: 180)

Phenomenology's main concern is with lived experiences as described by the experiencer i.e. the participant (Giorgi *et al.* 2018: 178). The current study is a qualitative phenomenology design which seeks to explore the lived experiences of patients who have had penectomy surgery. The researcher seeks to find out the meaning of the imaginations and emotions of these participants in relation to the phenomena, and their existence in the world and their consciousness thereof (Polit and Beck 2017: 470). The aim in this study was to gather thick descriptions from a small number of participants with a narrow inductive approach (Polit and Beck 2017: 503). The qualitative methodology known as phenomenology is a suitable approach of inquiry by the researcher seeking to examine the experience of participants.

3.3 Study setting

The study was conducted on patients receiving post penectomy surgery health care at St Aidan's hospital in the eThekwini district in the province of KwaZulu-Natal. KwaZulu-Natal has an estimated population of 10.27 million and has a total of 71 public hospitals (KwaZulu-Natal annual report 2018: 34). St Aidan's is a regional hospital that has 146 beds, 4 operating theatres and an outpatient department (KwaZulu-Natal Department of Health report 2021). The hospital is a referral surgical and nephrology hospital. Surgical referrals are from the majority of the province. The hospital sees to the entire South coast Ugu District up to Matatiele including a few from neighbouring Eastern Cape (Bizana), eThekwini District and Ilembe District, it also sees to some patients form Zululand, Eshowe, Ulundi and other who have historically come to the hospital because there was once no urologist in northern Zululand. This facility performs highly specialized surgeries such as penectomy, [1] nephrectomy, [2]

[1]Penectomy is the surgical removal of a part of or the entire penis.
[2] Nephrectomy is a surgical removal of a part or the entire kidney.

cystectomy with ileal conduit, [3] radical prostatectomy[4] and trans-urethral resection of bladder tumour.[5]

3.4 Population

The population of the study were patients that attended St Aidan's hospital for penectomy surgery. The target population was all patients who were one year or more post-penectomy surgery. These participants had post penectomy surgery experience for some time and provided rich in-depth data for the study. As a result, they were in a position to reflect on their experiences and changes they had undergone since the surgery. The hospital performs on average 25 penectomy surgeries annually.

3.5 Recruitment of participants

Participant recruitment was a collaborative exercise between the hospital and the researcher. The researcher sought access to the patient register from the hospital (Appendix 1). The pre-selection was the sole responsibility of the researcher, who confidentially dealt with the personal information of all pre-selected participants. The pre-selection was guided by the inclusion/exclusion criteria provided below. After the pre-selection, the researcher then made contact with individual patients, furnished them with information on the study, and asked for their consent to participate. The final list of participants was therefore generated. Purposive sampling was used to sample participants from the pre-selected list. This sampling method was best suited for this study because it is the deliberate method of choosing potential participants who can contribute a rich description of the phenomenon (Gray, Grove and Sutherland 2017: 345). Participants were informed that participation was voluntary and they could withdraw from the study at any time with no penalty to them (see Information Letter and Consent Form, Appendices 4A and B). The researcher also anonymised the participant data through giving pseudonyms to maintain confidentiality, as well as keeping the spreadsheet in a password protected file, accessible only to the researcher and supervisors.

[3] Cystectomy with ileal conduit: this is the surgery whereby a surgeon creates a new tube from a piece of intestine that allows the kidney to drain urine to exit the body through a small opening called a stoma.
[4] Radical prostatectomy is a surgery to remove the entire prostate and some of the tissue around it, including the seminal vesicles.
[5] Trans-urethral bladder tumor is the removal of a bladder tumor through a urethra.

3.5.1 Sample size

Sample size refers to the number of participants that are selected to participate in a study. In qualitative studies sample size is guided by the principle of data saturation, which is when no new information is obtained (Polit and Beck 2017: 502). In phenomenological studies the sample size is usually small, between 10 and 15 participants (Polit and Beck 2017: 504). In this study data collection continued until saturation was achieved, to the objective acknowledgement of the researcher and the supervisors. The final sample size was XX.

Inclusion criteria

- Patients who have undergone penectomy surgery in the selected hospital.
- Patients above the age of 18 years old.
- Patients that are one year or more post-penectomy surgery as they will have had post-penectomy surgery experience for some time and would provide rich in-depth data for the study.

Exclusion criteria

- Patients under the age of 18 years.
- Patients who are less than one-year post penectomy surgery or still admitted in the hospital.
- Patients who have not undergone penectomy surgery.
- Patients who have had penectomy surgery in other facilities or provinces.

3.6 Data collection

Data collection is the process of selecting subjects and gathering data from them; it extends from before the first participant's data are obtained and ends as the last participant's data are obtained (Gray, Grove and Sutherland 2017: 500).

Data was collected through in-depth individual face-to-face interviews using an interview guide (Appendices 5a and b). Interviews. The researcher audio recorded the interviews with permission from the participants and also wrote field notes. Field notes

are used to describe observed non-verbal behaviour of participants during the interview to provide a complete account of the interview.

3.6.1 Data collection instrument

The interview guide that was developed by the researcher was used to collect data (Appendices 5a and b). The interview guide was guided by the research questions and was designed in English and translated into isiZulu by the researcher who is fluent in both languages. The translation was checked by the supervisor who is also fluent in both languages to ensure that no meaning was not lost during translation. Both languages were used to ensure that the language preferences of all participants were accommodated. The instrument had two sections: section A consisted of demographic data such as age, relationship status, level of education and employment status, and section B consisted of a grand tour question to guide the interview with four sub-questions regarding the phenomenon. Probing was used to obtain more data and clarification of responses regarding the experiences of participants.

3.6.2 Data collection process

The process of data collection extends from before the first participant's data are obtained and ends as the last participant's data has been obtained (Gray, Grove and Sutherland 2017: 55). Data collection commenced once the research committee of the university gained approval of the study and the gatekeeper permission had been obtained from the eThekwini District office (Appendix 2), the provincial research committee, and the Chief Operating Officer (CEO) of the hospital under study (Appendix 1). Information letters (Appendices3a and 3b) were handed out during the recruitment phase and those willing to participate were given consent forms (Appendices 4a and 4b) to fill and sign. COVID-19 protocols were adhered to, including washing and/or sanitizing of hands, wearing of masks and social distancing at the venue and time that was suitable to participants. The interviews that occurred at home were prepared according to the participant's preference to ensure confidentiality and COVID-19 protocols were adhered to.

The researcher played an active role during the interview process with the aim of exploring and understanding the phenomenon through explanations and description

provided by the participants. A reflective approach was used during these phenomenological interviews which involved the researcher setting aside her beliefs to avoid contamination of data, so that the phenomenon could be presented “as is” (Giorgi *et al.* 2018: 187). The researcher wrote her preconceptions in her journal making her thoughts more conscious so that they could be deliberately set aside (bracketing). Questions were asked in the language that the participant was comfortable with. The core interest was with the phenomenon as it was presented by the participants.

The researcher facilitated an open and relaxed atmosphere to put participants at ease to participate freely in the discussions, and they were given enough time to provide a complete description of their experiences (Gray, Grove and Sutherland 2017: 345). Refreshments such as water was provided for participants in case they needed a drink and time to think. Each session took between 45 minutes to an hour depending on how long each participant was willing to talk in the session. The researcher needed to interview some participants more than once; this allowed the participant to rest from the initial interview and be refreshed to continue next time. In cases where participants became emotional, the researcher is a professional nurse had adequate general counselling skills. Arrangements were made with the hospital social worker to be on standby in case she was needed. The researcher notified the social worker every time that she had an interview with a participant.

3.7 Data analysis

Coding in qualitative data analysis is the process of assigning of meaning to data (Corbin and Strauss 2015:58). Data analysis was based on Husserl’s descriptive phenomenological philosophy in order to get the pure essence of the lived experience of the participant (Ebalos *et al.* 2016: 19). The researcher followed the seven steps of Colazzi’s (1978) data analysis.

- Data was transcribed verbatim including field notes. The researcher was immersed in the data through reading transcripts several times in order to understand the fullness of the experience described by the participants.

- Transcribed notes were reviewed, arranged in columns, and coded in order to focus on reducing the volume of the data so that the researcher could more effectively examine them and to aid in verifying the meaning of the data.
- The meaning of each significant statement was spelt out.
- The formulated meanings were then organized into clusters of themes and the cluster of themes were referred back to the original protocols to validate them. Discrepancies were noted among the various clusters, avoiding the temptation of ignoring data that does not fit.
- Results were integrated into an exhaustive description of the phenomenon under study.
- The description of the phenomenon under study was formulated as an unambiguous statement of identification (as much as this is possible).
- Participants were then asked about the findings thus far as a final validating step.

3.8 Trustworthiness

Lincoln and Guba (1985) cited in Polit and Beck (2017: 559) suggested four criteria for developing trustworthiness in qualitative research, namely: credibility, dependability, confirmability and transferability.

3.8.1 Credibility

Credibility is the confidence that can be placed in the truth of the research findings (Korstjens and Moser 2018: 121). The researcher established rapport with participants prior to commencing interviews, developing a trusting relationship (willingness to exchange information), and expressed compassion and empathy during interviews. The researcher used peer debriefing as a credibility strategy by having a peer who was disinterested in the study to question, challenge and probe the researcher to expose the researchers' biases, meanings and assumptions in an effort to keep the enquirer and thus the enquiry honest.

3.8.2 Dependability

Dependability is the stability of findings over time (Korstjens and Moser 2018: 121). The researcher established an audit trail which described the study's procedures and processes and accounted for any changes that occurred within the study (Bradshaw, Atkinson and Doody 2017: 6). This audit trail is being kept confidentially under lock and key and or password protected computer with only the researcher having access to it.

3.8.3 Confirmability

Confirmability is the degree to which the findings of the research study can be confirmed by other researchers (Korstjens and Moser 2018: 121). The researcher kept notes recorded in a reflective journal and used an audit trail to capture the data collection and analysis process. The audit trail included keeping of the reflective journal notes of raw data, data reduction and analysis. Daily journals and description of demographics of participants was also maintained. Member-checking processes to verify data accuracy were utilized; the researcher verified data collected with a group with similar characteristics as the participants if participants were not available. Findings represented the data gathered and were not biased by the researcher.

3.8.4 Transferability

Transferability is the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents (Korstjens and Moser 2018: 121). The researcher provided enough information for the readers to determine the degree to which findings are applicable or transferable. The researcher provided a rich description whereby the widest possible range of information was provided allowing for judgment of transferability. Purposeful sampling and a reflexive journal provided sufficient study details so recreation could occur (Bradshaw, Atkinson and Doody 2017: 6). Excerpts directly from participants were used to support the researcher's description.

3.9 Ethical considerations

The researcher engaged various ethical considerations during the process of conceptualizing and implementing the research process (Gray, Grove and Sutherland 2017: 159). Protection of participants were achieved through application of the following ethical principles:

Permission: The research proposal was submitted to the Durban University of Technology Institutional Research Ethics Committee (IREC). Permission was sought from the eThekwini district office (Appendix 1) Chief Executive Officer (CEO) of the hospital (appendix 2), and the Provincial Research Committee prior to data collection.

Informed consent: Complete information regarding the research purpose and objectives was given to participants in meetings that were held before commencement of data collection and they were handed a letter of information (Appendices 3a and 3b) which was either in English or isiZulu to enhance understanding. After the information sessions, informed consent was obtained in which a participant wilfully agreed to participate in the study after an explanation about the content of the study had been given (Appendices 4a and 4b).

Right to anonymity and confidentiality: Research participants have the right to anonymity so all data collected was kept confidential. Information was shared in confidence so the researcher was obligated to maintain confidentiality. Researchers, as professionals, have a duty to maintain confidentiality consistent with their professions code of ethics (Gray, Grove and Sutherland 2017: 170). Confidentiality was protected by giving each participant a pseudonym. Signed consent forms and data collection tools were not stapled together as this would have made it easy for unauthorized persons to readily identify the participant and their responses. Consent forms were appropriately stored under lock and key along with any notes or hard copies. When entering the collected data into a computer, pseudonyms instead of participant's names were used for identification. Data were stored in a password locked computer with only the researcher having access. All records will be kept confidential for five years as per DUT protocol and will be deleted and shredded by the researcher at the end of five years.

Right to self-determination: The right to self-determination is based on the ethical principle of respect for a person (Gray, Grove and Sutherland 2017: 162). The interpretation of the participants as far as their experience was concerned were encouraged and protected. Participants were informed that participation was voluntary and that they could withdraw from the study at any stage of the research without any consequences. Participants were assured of autonomy and that no harm would be inflicted on them whether deliberate or not. Participants were respected by calling them with their preferred titles or names.

Justice: The right to fair treatment is based on the ethical principle of justice. This principle holds that each person should be treated fairly and should receive what is she or he is owed (Gray Grove and Sutherland 2017: 162). To ensure justice, the race, colour, creed, socio-economic status and level of education of a participant had no effect on the researcher's approach to the participant. All participants during the course of the study were treated fairly and equally.

3.10 Chapter Summary

This chapter provided a detailed account of the study's research methodology. A descriptive phenomenological study method was used to analyse the lived experiences of patients who had undergone penectomy surgery. The sample consisted of 12 purposefully selected participants who met the predetermined criteria according to the study objectives.

Data was collected through in-depth individual face-to-face interviews using an interview guide. Data analysis was based on Husserl's descriptive phenomenological philosophy in order to get the pure essence of the lived experience of the participants. The researcher followed the seven steps of Colazzi's (1978) data analysis, and fulfilled the trustworthiness and ethical considerations of the study.

CHAPTER 4: PRESENTATION OF FINDINGS

4.1 Introduction

This chapter presents the results of the study, which were obtained from 12 in-depth interviews with participants. The researcher intended to understand the phenomenon of lived experiences of patients who had penectomy surgery who were receiving health care from a public regional hospital in KwaZulu-Natal.

4.2 Demographic characteristics of participants

All participants were males aged between 37 and 59 years. Four of the participants were unemployed, five were self-employed and three were employed in a formal setting. Most participants had achieved high school education (completed Grade 12) with only three participants having a lower level of education (primary school). Two participants were legally married, seven had fiancés and three had no partners. Eight of the 12 participants had total penectomy surgery.

4.3 Presentation of findings

To ensure confidentiality of all participants during the presentation of the results, participants were given pseudonyms. The illustrative quotations taken from the interview transcripts consist of multiple participant perspectives, which are represented as spoken by participants in their own words and translated into English as they spoke in isiZulu. The codes, subcategories, categories and the theme that emerged are presented in Table 4.1.

Table 4.1: An example of the meaning units, codes, sub-categories, categories and the theme extracted from content analysis of the qualitative data

Theme: Post penectomy surgery leads to psychological effects that involves effects of urinary and sexual function			
Meanings unit	**Codes**	**Sub-categories**	**Categories**
Pain before surgery, the unbearable pain gave me no other choice but to agree to penectomy surgery. (Mason)	Pain influenced the decision about surgery.	Feeling of severe pain.	Thought processes before penectomy surgery.
Sores in a private part that were just not going away, these sores are treated so many times at the clinic but were not healing. (Nkosi)	Persistent sores influenced the decision about the surgery.	Sores in the private part.	
Doctors explained about presence of the penile cancer. (Sphiwe)	Penile cancer led to decision making in order to prevent the spread of cancer.	Prevention of the spread of cancer.	
Sores in private part that were not healing, visiting the traditional healer first before visiting the clinic. (Octane)	Trying other treatment options healing places, instead of before thinking about visiting the clinic.	Beliefs about causation of illness.	Denial of reality/ignorance/trust in traditional healing more than western medication.
Zulu medicine and a lot of enema, was used thinking that it would help faster than going to the clinic, but there was weight loss. (Ronaldo)	Finding quicker ways of healing.	Believed that enema would cleanse the system.	
A feeling of ending one's life by using a gun due to the loss of the private part at a child bearing age. (Norman)	Life affected due to loss of a private part.	Feeling of loss of life.	Psychological effects of penectomy surgery.
Limiting taking lots of fluids when going to social places as that may lead to urinating on myself. (Osborn)	Preventing urinating on self by limiting fluids.	Bodily discomfort from disfigurement.	Difficulty in urination.

Having difficulty in urination especially in public places as having to sit down like a woman when urinating or kneeling down, very difficult to come into terms with it. (Octane)	Difficulty urinating in public spaces.	Feeling of shame or embarrassment.	
Private part shorter than before the surgery leading to the urine not coming out straight or splashing. (Nkosi)	Shorter private part, and splashing of urine.	Embarrassment splashing of urine.	
Avoiding visiting crowded places as I need a toilet to be available and cannot urinate in front of other men. (Ronaldo)	Avoided crowded spaces to prevent embarrassment during urination.	Limited visits to be comfortable at their own spaces.	
Having to find private space in order to urinate especially in rural areas and also hiding from other men when it is time for urinating. (Sphiwe)	Avoid being seen by people during urination.	Difficulty in urination in public spaces.	
When going out with family or family funerals a towel or diaper is used in order to prevent leakage from the bottom hole. (Mirage)	Fear of urine leakage in public spaces.	Prevention of urine leakage.	
No one can actually love someone who had this kind of surgery as all the girlfriends left, and new ones if they stay it is not because of love. (Osborn)	Being conscious of finding new love after penectomy surgery.	Loss of self-esteem.	Loss of self-esteem.
Touching each other but the mind says stop, as the partner may think that I am a useless man or even tell other people about the situation. (Sphiwe)	Thoughts of being shamed by the partner.	Fear of feeling like a useless man.	
Looking in the mirror or when having a bath and realization that the whole manhood is	Negative effects when realizing that the penis is no more there.	Loss of self-esteem.	

not there has negative effects and sadness. (Mason)			
Could not inform family members about the kind of surgery performed especially the elders and children. (Fuse)	Secrecy related to the type of surgery.	Fear of people knowing surgery performed.	
As the partner has diabetes and hypertension and also not having sex for the last 2 years, there is no reason to worry about sex. (Fuse)	Conclusion that the partner does no need sex due to chronic illness.	Coping with inability to perform projecting it on the partner.	Sexual function post-penectomy surgery.
Sometimes it is clearly obvious that the partner wants to have the real thing. (Franklin)	A need for a real sexual intercourse (inability to perform).	Missing the real thing.	
Use of a vibrator as another way of sexual satisfaction as there is no private part at all, the vibrator is worn over in order for the partner to still feel normal. (Mirage)	A vibrator as another way of sexual satisfaction.	Use of sexual gadgets.	
A feeling of wishing that the sexual feelings should have been removed during surgery as they make life more difficult. (Jackson)	Sexual feelings.	Struggles with a clogged catheter when sexual needs arise.	
Touching, fondling or foreplay is the best way of sexual satisfaction so far. (Mason)	Sense of touch found to be the best way of enjoying sex.	Enjoyment found in fondling and coping with sexual needs.	
Trying to have sex just makes things worse because I still have a catheter, tried before and it did not work. (Nornan)	Having a catheter makes having sexual intercourse difficult as healing is incomplete.	Difficulty in having sex.	
If something is not done soon, there is fear of a partner leaving or cheating with	Fear of losing a partner as there is no sexual satisfaction.	Inability to perform.	

someone else as sexual intercourse has not been tried for the last 2 years. (Nkosi)			
Having a plastic surgery of a new penis in order to have normal sex would really make me feel better about myself. (Osborn)	A wish to have a new penis for better sex and manhood.	A new penis for proper sex.	
Nothing really changed as a very small part of my penis was removed I am able to still lead normal sexual life, the cancer was found early. (Francis)	Not much changes, small part of penis removed.	Sexual life is normal.	

4.4 Presentation of the sub-categories, categories, and the theme

The sub categories and categories will form the basis for the presentation of the results.

4.4.1 Thought processes before penectomy surgery

This category emerged from the subcategory of severe pain, sores in the penile area and the presence of penile cancer before penectomy surgery. Surgery is something major that most people are scared of and being told about penectomy could be hard and difficult to accept. Participants presented to health facilities because of illness. Some of them had suffered for quite a while but they say it was the pain, or sores on the penis that were getting worse which made them visit the health facility.

4.4.1.1 Severe pain

When participants were informed that the management of their condition entailed an operation to remove part of or the whole penis, participants expressed that they did not delay making the decision and gave permission for surgery. This was because most of them experienced severe pain in the penis, which they felt could kill them if it did not go away. The operation came as a solution for them to get rid of such severe pain.

4.4.1.2 Sores in the penile area

One other symptom that bothered participants were sores around the penile area that were not healing. These sores had led some of the participants to seek help from traditional healers and when the sores did not heal, it is only then that they sought medical help. When they were told about surgery as one option to rid them of the sores, making the decision was easy because they did not object since the main thing for them was for the sores to disappear.

4.4.1.3 Penile cancer

All participants were told that they had penile cancer. Cancer is a scary disease and known not to have a cure. Surgery was going to remove cancer, this is one the reasons

that made participants decide on having penectomy surgery as they felt that if they were to delay or not agree to the surgery, the cancer would spread to other organs of the body. They expressed this as follows:

Mason

"It was very difficult for me to get into this idea of this kind of surgery, I even asked the Doctor if this will make a difference when it comes to the pain that I was feeling prior to surgery, I had an excruciating pain. I feel much better now and my life is back."

Fuse

"The pain that I have now is nothing compared to the pain that I had before surgery, I could not sleep I was crying day and night, absolutely painful, I cannot explain it, I would stand up the whole night, my wife is my witness."

Franklin

"I could not sleep during the day and night, the pain that I had even the pain tablets did not help, nothing even the pain injections did not help, I could not walk, I was only sleeping, only waking up when I go to the toilet, I had to hold the wall to walk, and only used shorts."

Osborn

"… it was difficult for me to agree to the surgery but due to the amount of pain that I had and my private part was getting finished, I decided that I have to do this, I had to change the life that I lived."

4.4.2 Trust in traditional healing more than western medication

This category emerged from the subcategory of beliefs about the causation of illness. Some participants believed that it would be better to consult with traditional healers, as they believed that they would heal them quicker. Others ignored the sores as they started as itchy blisters first and they waited for the sores to burst as they thought that if they burst the sores would then heal. Their expression of this was as follows:

Norman

"*I first went to the traditional healers, I had so much Muthi, my house looked like I was a traditional healer myself. I went to many of them and the last time I went to one he gave me Muthi to lick with my tongue, which I did. The following day my private part broke in half like a Russian sausage locally known as "uqhumpatsha", that is when I realized that I really needed to visit a clinic, I wasted so much money."*

Sphiwe

"I used some Zulu Muthi and used a lot of enema, I had pain a lot of pain, I even lost so much weight I became very light when walking and that is when I decided to go to the clinic."

Nkosi

"I went to the traditional healers before going to the clinic, but it didn't take me long to use traditional medicine, I decided to go to the clinic because the traditional medicine did not help."

4.4.3 Psychological effects of penectomy surgery

Ten of the participants indicated needing psychological support, particularly those participants who had total penectomy surgery. Those who had partial penectomy seemed to cope better with surgery. This was indicated by how eager participants were willing to speak with the researcher, as they took her as someone who came to see them and who is willing to listen to them without any judgement.

Some participants verbalised that they thought about taking their own lives as they thought that there was nothing else to live for after they had penectomy surgery. Others felt that they would never be loved by a woman again now that they had a short penis or none. Looking at themselves in the mirror while taking a bath made them feel less of a man. They described this as follows:

Mason

"I decided to counsel myself as there was nothing else I could do, I am grateful that I don't have those excruciating pains anymore, sometimes I think back about the fact

that I do not have my private part, but then immediately I remind myself that it is gone and is not coming back."

Mirage

"I am coping because I have the support of my family even though I am not able to do some of the duties that I used to do as a man, I used to drive my trucks and now I cannot"

Ronaldo

"Psychologically I felt very bad, I thought something else would happen after surgery because this was truly the first time finding out about the surgery like this until I came to this hospital and found others who had the same surgery."

Norman

"I truly became very ill at first especially just after surgery. It took me a long time and I realized that I have no life, my life has ended, I thought of shooting myself with a gun because I realized that my happiness is gone."

Sphiwe

"*I counselled myself to take it as it comes as there was nothing else I could do, but at first after surgery I was not good because I thought they would only cut the foreskin, but they cut my private part. I was told that it will be cut but my mind told me something else, but when I came back from theatre after they removed the bandage I saw that half my penis is gone."*

Osborn

"*I feel like my penis is left inside I can feel it inside, I am trying to lead a normal life but it is not easy for a man like me who is used to having normal sex and having a lot of girlfriends. I cried more than enough, now I think I have come into terms with it."*

4.4.4 Difficulty in urination post penectomy surgery

Almost all participants had some form of urinary dysfunction post penectomy surgery. Participants who had a partial penectomy seemed to be coping better with urinary

function even though at times the urine would splash and does not come out straight. One other participant described that he knelt down in order to passed urine so as not to wet his pants as the penis is small, which leads to him urinating on himself. Four participants who had total penectomy described that they felt as if they were women, as they had to sit down in order to urinate. Most of these participants used the urethral opening, which is the only pathway for them to urinate. Experiences with urination led to loss of self-esteem. They described this as follows:

Mason

"When it comes to urination it becomes hard for me as I now sit like a girl when urinating, if I were to visit somewhere I have to make sure that there is a toilet as no one else knows about my situation except for my family, if there is no place to urinate I do not visit anyone."

Fuse

"Urinating becomes difficult, so I do not go to occasions avoiding problems like that, I only attend the ones that have toilets, it is difficult to urinate because I sit like a woman, I explain to people who understand that I had cancer, others I tell them that it is painful to urinate."

Mirage

"Regarding urination, I still have a catheter. I still have to go for the tests in order to assist me, urine comes out on the hole that I have and also on the suprapubic catheter. Other times even though I have the catheter I still feel that my bladder is still not completely empty, I then go to the toilet and sit in order to urinate and try and push the urine through the hole that they opened under there. When I go out I use the towel to diaper, I use the catheter bags and sometimes the catheters break."

Octane

"Related to urination it becomes a problem because I used to forget that I had to sit down like a woman during urination. It was very problematic also in public toilets they send me to the male toiles where you are supposed to stand when you urinate, but I

always have to beg to go to the normal sitting toilet, sometimes the people who work there can be very rude and not understanding."

Sphiwe

"*Sometimes I pass urine on myself, that makes me uncomfortable, I avoid occasions if I go I try not to drink lots of water but when I go to some special occasions I kneel to urinate, but I hide from people. Sometimes I urinate in my sleep but it happens occasionally, I am able to hold my bladder most of the time*."

Osborn

"I sit down when urinating using the hole at the bottom I sit as if I am going to do number two. Sometimes my bladder becomes full and I have the urge and I almost wet myself because of the urge, I try to only meet with people who know about my situation."

Franklin

"I used to have a problem after surgery which also included pain when urinating, urine was also not coming out straight even now it is not straight but I do not have pain."

Ronaldo

"I am able to urinate, I had a pipe before but they removed it, I am able to continue as before, I really have no problem urinating, I stand too when urinating."

Mirage

"I go in the corner and empty my urine bag but I make sure that people do not see me."

Nkosi

"I avoid to join social gatherings, it is very hard for me really very hard, I don't join other men to urinate like before, it is painful because I am unable to do that, I know that it is my problem and there is really nothing can do about it."

4.4.5 Loss of self-esteem

Participants described how they felt about the loss of their manhood and how they experienced life and interaction with other men after penectomy surgery. Participants constantly described the difficulty in integration back to society in order to lead normal lives. They had loss of self- esteem, which was more pronounced during social gatherings. They avoided large gatherings in fear of being seen that they have lost their private parts. They expressed this as follows:

Mason

"When I have a bath and realize that I do not have my private part, that affects me at times, but I still remind myself to be positive. I do not go to social gatherings like before as it is only my partner who knows about the kind of surgery that I had."

Sphiwe

"*I have my mother who knows that I had surgery but she doesn't know that I had this kind of surgery. My partner and I we touch each other but my mind tells me that I should stop, because this person will think that I am a useless man or even tell other people about my situation, so I tell myself that I must just forget about it."*

Osborn

"I had a lot of girlfriends, I chased them all away after surgery, others went away on their own, they left me. I do not think anyone would stay with me, they disappeared. I meet girls and they would act as if they understand but later I realize that they don't love or understand they just come for what they want; I don't even try to pursue girls now because I know that no one can love me when I am like this."

4.4.6 Sexual function post penectomy surgery

Penile size is a highly sensitive topic for men, which has often raised concerns associated with human masculinity and male sexual health. Despite poor sexual function outcomes, participants were satisfied with the procedure outcomes and quality of life. They were grateful that the pain and other issues that bothered them

had disappeared even though that came with challenges for their sexual lives. Some participants treated with total penectomy described some degree of sexual satisfaction despite the inability to have penetrative sexual intercourse. Those who had partial penectomy surgery demonstrated some maintenance of sexual satisfaction and minimum change from before surgery, although some participants were not satisfied with the short stump of the penis. Participants who had partial penectomy reported moderate satisfaction or greater overall satisfaction with the outcome of their surgery. Participants shared their experiences of sexual function and described them as follows:

Mason

"So I put on the vibrator at times to ensure that my girlfriend enjoys and reaches the climax. We do a lot of fore play, it really works for me, we also discussed it with my girlfriend that the fore play truly satisfies both of us well and we both reach the climax."

Fuse

"Sexually, it became very difficult for me but I had to tell myself that life goes on, we do not have sexual intercourse here at home, we spoke about it and my wife has sugar diabetes and blood pressure so she really is usually not interested in sex. The only thing we do is kiss and Covid-19 also took over so we kept regulations. I still have feelings, sometimes I wish that I did not have the feelings or that they should have removed them, but I can control myself, we haven't tried to do fore play as yet."

Mirage

"Sexually I still have the feelings, I ended up buying the vibrator, it makes us happy. We are able to use our tool and touch each other just before the climax. We are able to satisfy each other. My life has not changed because I went and bought my tool, we use it and keep it in the room and my wife is not complaining."

Norman

“Sexually I have feelings for sex but it doesn’t work, I told myself that I should forget about sex, my woman even before the surgery she was not interested in sex she is 51 years old. Sometimes I wish that they have removed the feelings for sex when they were doing the surgery.”

Francis

“*I am able to have sex properly as they have removed a very small part of my private part.”*

Sphiwe

“Sometimes I do have an erection but when I look at my penis now, it is less than 5cm long and it was 15 cm before. Even the condom will not stay, it will stay inside her vagina, we touch each other but my mind tells me that I should stop, because this person will think that I am a useless man or even tell other people about my situation, so I tell myself that I must just forget about it.”

Osborn

“Sexually I still cry even today, I would love to have a penile transplant, I truly tried to have sex before but I realized that I am exposing myself. I meet girls and they would act as if they understand but later I realize that they don’t love or understand they just come for what they want, I don’t even try to touch each other, but me as a man I want to have the real thing.”

Nkosi

“It is absolutely painful especially that I don’t even know what my partner thinks about this situation, I don’t even know what she will end up doing, maybe she may even end up having other boyfriends to make her happy because I cannot make her happy. Sexually at this present moment we do not do anything, yes we do fondle and touch each other at times.”

4.5 Chapter Summary

This this chapter has presented a sample of the lived experiences of patients who have undergone penectomy surgery. Penectomy surgery is cited as the most common and

effective procedure to treat penile cancer. It is apparent that participants require psychological support and need for sexual advice particularly after surgery. Most participants developed coping skills related to inability to perform some bodily functions but most were achieved with the support of their partners and families.

CHAPTER 5: DISCUSSION OF RESULTS

5.1 Introduction

This chapter discusses the results that were presented in the previous chapter. The discussion of results is based on the research objectives outlined in chapter one, which described lived experiences of patients post-penectomy surgery. This chapter also presents recommendations for further research. Penectomy, as a surgical treatment of cancer and related penile health conditions, is inevitably mutilating despite its therapeutic effectiveness. Total penectomy leads to mutilations that affect the ability of patients to void urine while standing upright. It also affects the patient's corporal image, genital sensibility, and self-esteem (Pompeo *et al.* 2015; Wan *et al.* 2018).

5.2 Overview of the research discussion

The study purpose was to address the following objectives:

- To determine lived experiences of patients who have undergone penectomy surgery.
- To assess the sexual function and urinary function of the patient post-penectomy surgery.
- To examine self-esteem of the patient post-penectomy surgery.
- To determine the overall psychological effects of penectomy surgery.

The discussion of the findings of this study will be based on the categories and seven sub-categories that emerged from the study namely:

- **Category 1**: **Thought processes before penectomy surgery**
  - **Sub-categories:** feeling of severe pain, sores in the penile area and presence of penile cancer
- **Category 2: Trust in traditional healing more than western medication**
  - **Sub-categories:** Beliefs about causation of illness, beliefs that enemas would cleanse the system.
- **Category 3: Psychological effects of penectomy surgery**

- **Sub-categories:** feeling of loss of life, sense of self care coping mechanism, support system, loss of self-esteem and fear of people knowing surgery performed.

- **Category 4: Difficulty in urination**
  - **Sub-categories:** Bodily discomfort from disfigurement, catheterization medical procedure, feeling of shame and embarrassment from splashing of urine.
- **Category 5: Penectomy surgery and Loss of self-esteem.**
  - **Sub-categories:** Fear of feeling like a useless man, and fear of people knowing surgery performed.
- **Category 6: Sexual function post penectomy surgery**
  - **Sub-categories:** Being able to have sexual satisfaction, use of sexual gadgets, missing the real thing, struggles with a clogged catheter when sexual needs arise, enjoyment found in fondling and coping with sexual needs, difficulty in having sex, inability to perform, coping with inability to perform and projecting it to the partner, a new penis for proper sex, and sexual life is normal.

5.2.1 Thought processes before penectomy surgery

All study participants described unbearable pain that they endured before the surgery; this pain was in the penile area and the severity of it prevented them from having proper sleep. Participants verbalized that they survived with pain tablets and at times they could not hold back their tears. This kind of pain is one of the main reasons the participants agreed without hesitation to have the surgery. Findings of the current study, Sosnowski *et al.* (2016), Triano *et al.* (2018) and CANSA (2018: 6) report that penile cancer is painless in the first stages. The first sign of penile cancer is changes in the skin of the penis, skin thickening, appearance of a painless nodule or a warty growth especially on the glans penis or foreskin swelling. Participants described pain that was due to the sores around the penile area (CANSA 2018: 3).

Participants in this study also complained about sores around the penile area, describing these as sores that did not improve with treatment. These sores first appeared as itchy pimples or warts, which eventually broke into sores. According to Leung *et al.* (2018: 1), penile warts are the most common sexually transmitted disease in males caused by human papillomavirus 1-3 (HPV). All participants in this study had

penile cancer and when doctors explained that surgery will help stop its spread, this resulted in making the decision about surgery easier.

5.2.2 Trust in traditional healing more than western medication

Some participants decided to seek traditional healing over western medication, their reasons being that the sores were going to heal quicker with traditional medicine and that they would not need to explain themselves as they would do at the clinic. These participants used the traditional medicine, but did not get better. One participant even mentioned that his home was just like a traditional healer's home with more traditional medicine than he could ever imagine, but at the end of the day his penis broke in half and that is when he decided to seek medical help. Others mentioned becoming weaker and more sick with the traditional medicine. Hakenberg *et al*. (2018: 648) state that patient related delays in diagnosis and treatment are not rare and are associated with low socioeconomic status and low levels of education. Delay in seeking medical advice and late presentation was noted.

5.2.3 Psychological effects of penectomy surgery

The human body is designed for anatomical and physiological functions necessary for human effective living. As such, if a part or parts are removed from that body there are certain effects that are witnessed (CANSA, 2017). Participants described being affected psychologically by penectomy surgery, describing this as a feeling of shock as they never knew that there was this kind of surgery before they were told about it. According to Sahu *et al*. (2016: 1) amputation is a major burden on individuals, families, society and medical services. Lidner *et al*. (2019: 3) added that radical, partial or total penectomy is associated with significant functional, sexual and psychological deficits, despite high oncological control rates. Beilin *et al*. (2017: 224) state that penile cancer can take a devastating toll on both the quantity and quality of life for affected men and their partners. The cancer leads to physical genital disfigurement, which may alter normal male voiding patterns, impair normal penetrative intercourse, and lead to psychological and emotional distress, and even death (Morris 2015: 559). Participants took this surgery as the end of their life, but they also felt that they had no choice as the cancer would spread. These patients can develop depression, perceived problems

with physical appearance, and experience coping difficulties (Kondo *et al:* 2015: 2). It can be perceived as a catastrophic and an irreversible act, which is emotionally devastating for the patient.

Imeni *et al*. (2018: 2) reported that body image is an important aspect of self-evaluation that has complex psychological effects. This is one of the important factors related to satisfaction with quality of life in patients who have undergone amputation of the penis. Penectomy surgery leads to physical genital disfigurement, which may alter normal male voiding patterns, impair normal penetrative intercourse, and lead to psychological and emotional distress, and even death (Morris 2015: 559). Additionally, removal of part of the body is typically equated to loss of spouse, loss of perception of wholeness, symbolic castration, and even death. This may result in the patient being severely affected emotionally, thus resulting in poor quality of life (Sahu *et al.* 2016: 1). Participants after the surgery felt that they should try and move on with their lives as there was nothing else they could do, as their lives will never be the same again. They counselled themselves as time went by.

According to Kondo *et al*. (2015: 2) losing a part of the body can have a huge effect on a person's quality of life. Participants took this surgery as the end of their life, but they also felt that they had no choice as the cancer would spread. The American Cancer Society (2018: 4) states that a certain amount of feeling depressed, anxious or worried is normal when cancer is part of your life; some people are affected more than others, but everyone can benefit from help and support from other people, whether friends or family. Most of the participants had support from their families and their partners, and verbalised that their partners are still treating them the same as before surgery. Symptoms of anxiety and depression become better over a course of time; however, surgical treatment providers need to liaise with psychiatrists and psychological support to deal with the psychological disturbances (Sahu *et al*.2016: 1).

Some participants disclosed to their families and friends that they had cancer, but they did not disclose what kind of cancer and what type of surgery was performed on them, the disclosure of the type of surgery being only with their partners. Tuffaha *et al.* (2017:

86) state that patients with severe penile defects often suffer from debilitating physical and psychosocial sequelae, including inability to have sexual intercourse or urinate while standing up, feelings of emasculation, disruption of interpersonal relationships, and profound loss of quality of life. This may cause distress not only due to loss of a body part but also due to the role limitation and the need for adjustment to the changes of lifestyle options. Imeni *et al*. (2018: 2) reported that body image is an important aspect of self-evaluation that has the complex psychological effects on its entire meaning.

5.2.4 Difficulty in urination

The thought of sitting like a woman when urinating was described by the participants as one of the most devastating feelings they have ever had, and went as far as saying that they feel as if their masculinity has been taken away from them. In public toilets the participants had to go through much questioning by the staff who are caretakers of the public toilets as they would often show them the male toilets where one has to stand, while they actually needed the sitting toilet. They described this as very embarrassing as sometimes they would have to lie and say they need to pass stools in order to be given access to the toilets, and this kind of embarrassment also occurred in rural areas whereby these man had to explain themselves to other men, they said they always responded as just needing to go to the toilet. These kinds of arguments and embarrassments led to some of the participants deciding to rather avoid social gatherings. Three of our participants still had suprapubic catheters inserted in their bladders; all three had total penectomy, one of them was able to maintain sexual satisfaction even though he had a catheter, while two participants had urinary catheterization for sense of comfort so as to be able to void urine while standing up. They described this as maintenance of their masculinity. The two participants explained that having to have their catheters prevented them from engaging in sexual intercourse as the catheters would block during ejaculation. The American Cancer Society (2016: 5), Djordjevic, Palminteri and Martins (2014: 428) and Tuffaha *et al.* (2017: 86) agree that men who had a total penectomy often must sit to urinate and that in many cases traditional penectomy would leave the patient with a short stump, unsuitable for voiding while standing up. Partial penectomy left the participants enough penis to allow relatively normal urination. Those who had partial penectomy

complained of leakage and of urine not coming out straight. This finding is similar to those of Pompeo *et al.* (2015: 122) and Kieffer *et al. (*2014: 3), that a large majority of men who had undergone partial penectomy indicated experiencing leakage while urinating, and that the most frequently reported reason for leakage included spraying urine flow and too short a penis. Sansalone *et al*. (2015: 2) had a different finding, that when a sufficient portion of a penile shaft has been preserved in partial penectomy it is possible to direct urinary stream comfortably. Partial penectomy leaves enough of the penis to allow relatively normal urination. Disruption of urinary function seemed to be a major aspect that affected the participants lived experiences and loss of self-esteem, as reported by Pompeo *et al.* (2015: 1) and Wan *et al.* (2018: 1425).

5.2.5 Loss of self-esteem

Participants felt that pursuing partnership with women would only further frustrate them as they thought that no woman would ever honestly love them as they will never be able to satisfy them sexually with a real penis. Participants who had total penectomy felt ashamed to look at themselves in the mirror and realise that they no longer have a penis. Some participants who had a partial penectomy felt that their penis was too short, and felt that if they were to have relationships, their partners would shame them by telling them that they are not real men and that they would talk about them in the community. The younger participants felt worried that as much as their partners are with them they may just leave them for other men, the shame and the lack of confidence was visible in their faces. According to Reihling (2020: 3), ‘traditional masculinity’ is commonly defined through risk taking, uncontrollable sex drive, compulsory heterosexuality, physical and emotional toughness. Other participants verbalized that they used to have different girlfriends but now they feel destroyed as they can no longer live the lives they used to enjoy. Onoya *et al.* (2015: 103) state that in South African communities, multiple sexual partners are associated with a higher social status within the community and define manhood, and may be a source of power thereby contributing to men’s self-worth. Morris (2015: 559) further states that in a society where masculinity is defined by and associated with the presence of a penis, penectomy affects male self-esteem and may lead to depression.

5.2.6 Sexual function post penectomy surgery

A penis is a vital part of the reproductive system. In this study the age group of the participants was between the ages of 37 years to 59 years with a mean age of 40 years. All of the participants were still of fertile age. The study by Ngendahayo *et. al.* (2018: 1) had an age range penile cancer who had undergone penectomy surgery, was 33 years to 83 years with a mean age of 60. These participants felt that they still needed real sexual satisfaction and they also described noticing that their partners also needed the real thing, the real penis for sexual satisfaction. Penile cancer is a uniquely male-specific cancer, situated in a sexual organ and is fundamentally associated with sexual function and sexuality (Bullen et al., 2014), furthermore Shefer, Kruger and Schepers (2015: 103) state that in South Africa Zulu men have to prove their masculinity and become a man by using sex and becoming a father as a way of avoiding the shame of questioning of one's masculinity.

Some participants who had a total penectomy in this study could not provide penetrative sexual intercourse, but could maintain satisfaction by fondling with their partners and also have sexual satisfaction by use of sexual gadgets. (Stroie, Houlihan, and Kohler (2021: 2551) state that in their study patients who were treated with total penectomy did report some degree of sexual satisfaction despite the inability to have penetrative intercourse, suggesting modalities other than intercourse may confer some degree of sexual satisfaction. Not only are the genitals often central to one’s sexual experiences, gender identity, sexual orientation, and bodily self-image, but they are also commonly regarded as extremely ‘private’—not to be touched or even seen without one’s explicit consent, which is typically granted only in intimate situations (Steinfeld 2018: 2). In this situation sexual partners of the participants could not feel the participants’ genitals through touch as they were removed through total penectomy, which would lead at times for participants to not even try to have sexual intercourse, they would rather say their female partners have chronic conditions so they do not need sex, or they would say “we had lot of sex since we were together, we had enough.” Some participants in this study who had partial penectomy felt that their penis is too short to engage in sexual intercourse.

Participants in this study felt that it would have been better if their feelings for sex had been removed along with their penis as that would have made their lives easier, or that they would rather have plastic surgery for a new penis. Two participants in this study described having normal sex and sexual satisfaction after surgery as only a small part of their penis was removed. According to Yu *et al*. (2016: 2) most patients who had partial penectomy who attempted sexual intercourse reported that most times or always they felt satisfied, and described their sexual intercourse highly or very highly enjoyable.

5.2.7 Summary of the chapter

The chapter discussed the results obtained from analysis of data to answer the question: What are lived experiences of patients who had penectomy surgery at a public hospital in KwaZulu-Natal? The study found that younger males who are at child bearing age are also prone to having penile cancer which leads to the removal of their penis. The discussion on the findings of this study leads to the summary of findings, including limitations, further research and recommendations in the next chapter.

CHAPTER 6: SUMMARY OF FINDINGS, LIMITATIONS, FURTHER RESEARCH AND RECOMMENDATION

6.1 Introduction

In the previous chapter, the study findings were discussed in relation to the objectives of the study. This is the last chapter of the study, which consists of the summary of findings, discussion of the study limitations, and recommendations arising from the findings.

6.2 Summary of findings

The findings of this study indicated that the burden of penile cancer in KwaZulu-Natal is not inconsiderable and prompts significant clinical concern and management. Although not generalizable to the whole population of KwaZulu-Natal, there is a need for more efforts in the prevention against penile cancer. Penectomy for penile cancer provides adequate control of the disease, however, proper counselling is important. Preservation of penile length yields to more optimal erectile recovery. In conclusion, findings suggest that the sexual function after penectomy was significantly reduced. Penectomy surgery carries the burden of sexual dysfunction and reduced functional and urinary function, which leads to patients losing their self-esteem. Patients with partial penectomy reported more sexual and urinary problems.

6.3 Limitations of the study

The sample of the study only included participants who were receiving treatment in a public hospital. Broader data could have been obtained if patients who were receiving treatment in private facilities were included. Patients in the public sector are generally those who do not have medical insurance and may have different demographics and to patients found in the private sector.

The study used a qualitative approach, which normally uses a small sample size. Conducting a quantitative study could allow for a bigger sample making results more

generalizable. The study was conducted in one province, namely, KwaZulu-Natal and results may not be generalised to other provinces.

6.4 Suggestion for further studies

Further studies are needed which include patients who have undergone penectomy surgery at private facilities rather than one public facility and more studies on penectomy surgery in other provinces.

A quantitative study with a larger sample size might contribute more to the body of knowledge regarding penectomy surgery.

6.5 Recommendations

The following recommendations are made based on the qualitative findings of the study regarding lived experienced of patients post penectomy surgery. Education of boys and men regarding topics discussed below by male nurses, male celebrities and other prominent male figures in the communities such as chiefs, indunas and traditional healers to help men with their sexual health. Education provided by people who have had penectomy surgery can have a lasting impact on the education of boys and men.

Education on penectomy surgery will be beneficial to give boys and men knowledge but also something to be afraid of and therefor keep off bad habits. Furthermore, most participants stated that they had never heard of such surgery before, which makes it even more important for this information to be disseminated. The researcher in her capacity as a professional nurse will, in collaboration with the hospital management and other stakeholders such as the district and provincial offices of health, commission the production of pamphlets and support groups to aid in this regard.

6.5.1 Importance of medical male circumcision (MMC)

Education regarding medical male circumcision, which helps in the prevention of sexually transmitted infections including HIV, should be given to young boys by school

nurses and Life Orientation teachers while they are still in primary school. This is very important since they will still be young and not yet sexually active.

Young boys should be encouraged to seek medical help early. Since nursing is predominantly a female profession, they need to be made aware that nurses in medical facilities are not their enemies, they are there to care for them and are willing to listen to their challenges.

Older males who are not circumcised should also be encouraged to do so and not be made to feel ashamed of themselves. The men also need to be made aware that their normal behaviour of not wanting to go to medical facilities is detrimental to their health; it is not a sign of weakness but rather an indication that one cares for themselves.

6.5.2 Men to maintain proper personal hygiene practices

Education of men to take care of their personal hygiene particularly after sexual intercourse in order to prevent the accumulation of smegma, which leads to swelling of the foreskin especially for those males who are not circumcised.

Men need to be educated to avoid having multiple sexual partners as this also leads to the easy spread of sexually transmitted infections, and that they should use protection such as condoms during sexual encounters.

6.5.3 Hospital management to consider a multi-disciplinary team, partners and family members in counselling of men pre- and post-operatively

Hospital management should ensure the availability of psychologist or professional counsellors and involve them in pre- and post-operative counselling. They should be involved in the management of these patients to give psychological support, along with partners and other family members if the patient is willing to do so. Partners and family members will serve as a support structure for the patient with long-term effects of penectomy surgery. Ongoing psychological support at least up to a year is required for patients and their families and should not end when patients leave the hospital after surgery.

Sex therapists should also be involved in assisting patients and their partners through sexual challenges experienced after surgery as part of or the entire penis will be removed during surgery.

Involvement of social workers who will be able to assist patients with hospice placement and disability grants as some patients continue to suffer from cancer even after surgery.

6.5.4 The need for support groups for those patients who have had the surgery

Support groups for patients who have undergone penectomy surgery so that they do not feel alone; this will help their self-esteem to know that somebody else had the same surgery and they can share information on how they deal with their different issues.

Partners could also have their own support groups where they give each other advice on how to deal with certain challenges.

6.5.5 Updated cancer register

The penile cancer register should be updated as it was last updated in 2014 according to the available literature.

6.6 Conclusion

It has been indicated through the results of this study that penectomy surgery is due to penile cancer and affects males that are still of child bearing age. The study also found that males delay seeking medical help as they believe that traditional medicine will assist them quicker. African males still believe in having multiple sexual partners as that gives them recognition in society.

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APPENDICES

Appendix 1a: Request for permission from the hospital CEO

17 February 2021

Virginia Vuyokazi
Ndlovu 99 Montclair
Road Montclair
4004

Request for Permission to Conduct Research

The Chief Executive Officer
(CEO) St Aidans Hospital

My name is Virginia Vuyokazi Ndlovu, a Masters in nursing student at the Durban University of Technology. The title of my study is: Lived experience of post-penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal, a phenomenological study. The study aims at understanding the lived experiences of post-penectomy male patients, who have had the surgery done a year or more ago. The population of the study will be all patients that attend St Aidan's hospital for penectomy surgery and post-penectomy care,

I hereby seek your consent for Permission to conduct Research in your hospital. I have provided you with a copy of my proposal, which includes copies of the data collection tools and consent forms to be used in the research process, as well as a copy of the approval letter, which I received from the Institutional Research Ethics Committee (IREC).

If you require any further information, please do not hesitate to contact me [0843501411. kwezinjabs@gmail.com]. Thank you for your time and consideration in this matter.

Yours sincerely,

Virginia Vuyokazi Ndlovu
Durban University of
Technology

Appendix 1b: Permission from the hospital CEO

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE NURSING

Private Bag 1 Overport , Durban 4067
Physical Address 33 ML Sultan Rd , Durban 4001
Email shamla.pillay@kznhealth.gov.za
Shamlapillay0@gmail.com
Tel: 031 3142232 **Fax:** 031 3093222

Mrs SD Pillay

17 January 2022

Mrs Virginia Vuyokazi Ndlovu
99 Montclair Road
Montclair
4004

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am pleased to inform you that approval has been granted for you to conduct your research at St Aidan's Hospital in respect to the title : *Lived experiences of post penectomy surgery patients receiving health care from a Public Hospital in KwaZulu-Natal: A phenomenological study.*

Wishing you all the best and request a copy of the final thesis once completed.

Yours Sincerely

17/01/2022

Mrs SD Pillay
Deputy Manager Nursing

DEPARTMENT OF HEALTH
ST AIDANS HOSPITAL
2022 -01- 17
PRIVATE BAG 01
OVERPORT, 4067

GROWING KWAZULU-NATAL TOGETHER

Appendix 2a: REQUEST FOR PERMISSION FROM THE DISTRICT OFFICE

17 February 2021

Virginia Vuyokazi
Ndlovu 99 Montclair
Road Montclair
4004]

Request for Permission to Conduct Research

The eThekwini District Manager

My name is Virginia Vuyokazi Ndlovu, a Masters in nursing student at the Durban University of Technology. The title of my study is: Lived experience of post-penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal, a phenomenological study in one of KwaZulu-Natal Public Hospital The study aims at understanding the lived experiences of post-penectomy male patients, who have had the surgery done a year or more ago. The population of the study will be all patients that attend St Aidan's hospital for penectomy surgery and post-penectomy care.

I hereby seek your consent for Permission to conduct Research in St Aidan's Regional Hospital.

I have provided you with a copy of my proposal, which includes copies of the data collection tools and consent forms to be used in the research process, as well as a copy of the approval letter, which I received from the Institutional Research Ethics Committee (IREC).

If you require any further information, please do not hesitate to contact me [0843501411. kwezinjabs@gmail.com]. Thank you for your time and consideration in this matter.

-

Yours sincerely,

Virginia Vuyokazi Ndlovu
Durban University of
Technology

Appendix 2b: SUPPORT LETTER FROM THE DISTRICT OFFICE

KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE: Monitoring and Evaluation

Physical address: 83 King Cetshwayo Highway; Highway House; Mayville 4091
Postal Address: private Bag X 54318, Durban 4000 eThekwini District Office
Tel: 031 240 5308 Fax: 031 240 5555 Email: Ntombenhle.Ngcobo@kznhealth.gov.za
www.kznhealth.gov.za

Enquiries: Mrs. N.P Ngcobo
Date: 06/01/2022

Mrs Virginia Vuyokazi Ndlovu
Durban University of Technology
Health Sciences

RE: SUPPORT FOR RESEARCH STUDY IN "Lived experiences of post penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study."

I have pleasure in informing you that the District is granting you support to conduct the research study entitled "**Lived experiences of post penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study**" at St Aidan's Hospital in eThekwini Health District.

Please note the following:

1. Please ensure you adhere to all the policies, procedures, protocols and guidelines of the department of health with regards to this research.
2. This research will only commence once this office has received confirmation from the provincial health research committee in the KZN department of health.
3. Please ensure this office is informed before you commence your research.
4. The District office/facility will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the district office/facility.

Thanking you.
Sincerely,

Mrs. N.P. Ngcobo
(P, Monitoring and Evaluation Manager)
EThekwini Health District

GROWING KWAZULU-NATAL TOGETHER

Appendix 3a: LETTER OF INFORMATION FOR PARTICIPANTS

LETTER OF INFORMATION

Title of the Research study: Lived experiences of post penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study.

Principal Investigator/s/researcher: (Virginia V. Ndlovu)

Co-Investigator/s/supervisor/s/researcher: (Dr D. Sokhela - D. Nursing and N. Sibanda- MSc Development Evaluation Management)

Thank you for agreeing to take part in this research.

Brief Introduction and Purpose of the study:

The study is based on seeking to find out what is your experience of life in general after you have had penectomy surgery (partial or total removal of the penis). In the hospital where the study will be conducted there are 20 to 45 patients who have this surgery and there is no knowledge or information about the lives of these patients after they leave the hospital.

Purpose of the study

The purpose of the study will be to explore the lived experiences post penectomy surgery for patients receiving health care in a Public Hospital in KwaZulu-Natal: A phenomenological study. The information that will be obtained from interviews might help improve the care that you receive pre and post-surgery so that you are given coping skills after surgery.

Outline of the Procedures:

The researcher will interview 10 of you who will agree to participate in the study. Interviews will be conducted in a venue agreed upon between you and myself such as your home or a quiet room in the hospital. The researcher will audio record the interviews and will also write field notes with your consent. Water will be provided in case you need a drink and time to think. Each session will take between 45 minutes to an hour depending on how long you are willing to talk in the session. I may need to interview you more than once; this will allow you time to rest from the initial interview and will be refreshed to continue next time. I will ask only those that one year after surgery and coming into the hospital for review and if you above the age of 18years.

Risks or Discomforts to the Participant:

You may have discomfort during the interview due to the sensitive nature of the questions.

Benefits:

You could benefit from this study in that if you could receive continuous counselling from a multi-disciplinary team, which will be offered by the hospital management and this might help you cope with life after surgery. Knowledge generated from the research will extend to your families and communities, and help with understanding of health and precautionary measures that can be taken in order to prevent penile cancer. Knowledge may motivate other men to seek medical help as soon as they experience symptoms of illness. Health care workers may be more vigilant and have better attitudes when treating Sexually Transmitted Infections thus making it easier for men to come forward with their problems.

Reason/s why the Participant May Be Withdrawn from the Study:

You have the right to withdraw from the study whenever you wish and may not answer any question that you are not comfortable with. This will not compromise you or your care in anyway.

Remuneration:

You will not receive any payment for participating in the study.

Costs of the Study:

There will be no cost to you as the interview will be conducted on the day that you come to the hospital for your appointment date. If it needs to be somewhere else, I will travel and come to you. So you will not bear any cost for being involved in the study.

Confidentiality:

Your actual name will not be used in the interview guide; I will give you a different name. The consent form, which will have your name will be placed in a separate sealed envelope which will be locked in a cupboard for five years and thereafter shredded by me. Transcribed data will be kept in a password locked computer and will be deleted by me after five years.

Persons to Contact in the Event of Any Problems or Queries: For any queries you may contact (Dr DG. Sokhela Supervisor at 0722644670) or contact myself (Mrs VV. Ndlovu at 0843501411), or the Institutional Research Ethics Administrator on 031 3732375. Complaints can be reported to the Director: Research and Postgraduate Support Dr L Linganiso

On 0313732577orresearchdirector@dut.ac.za.

Appendix 3b: INCWADI ENIKA ULWAZI MAYELANA NOCWANINGO

-

INCWADI ENIKA ULWAZI

Isihloko socwaningo: Isimo sempilo emuva kokuhlinzwa isitho sangasese kulabo abebehambela isibhedlela esikhulu eThekwini Kwa Zulu-Natal: ucwaningo olunzulu.

Siyabonga ngokuthi uvume ukuba yingxenye yocwaningo.

Umphenyi oyinhloko / umphenyi: (Virginia V. Ndlovu)

Umcwaningi olandelayo/ obhekelele ucwaningo: (Dr D. Sokhela and N. Sibanda)

Isingeniso esifushane kanye nenhloso yocwaningo: Lolucwaningo lubhekelela ukuthi injani impilo yakho emva kokuhlinzwa esithweni sakho sangasese. Isibhedlela osihambayo siihlinza abantu abangu 20 kuyya ku 45 ngonyaka kanti akukho esikwaziyo ngokuthi impilo iba njani emva kokuba usuhlinziwe wakhululuwa esibhedlela.

Inhloso yocwaningo

Inhloso yocwaningo ukuthi sithole kabanzi ngokuthi injani impilo yakho emva kokuhlinzwa esithweni sakho sangasese kulesibhedlela somphakathi esikhoa la KwaZulu-Nnatal.

Uhlelo okuzohanjiswa ngalo:

Ucwaningo luzokwenziwa kinina enihlinzwe kulesisibhedlela iSt Aidan's esifundazweni saKwaZulu-Natal.

Ukuxoxisana nokubuzwa kwemibuzo kuzokwenziwa endaweni esizovumelana ngayo nawe okungaba isekhaya lakho noma isesibhedlela. Ngizoqopha konke esizoxoxisana ngakho kusiqophamazwi ngemvume yakho kodwa ngibhale futhi nokunye engikubonayo ongakuphimisanga. Amanzi azoba khona uma udinga ukuphuza nesikhathi sokucabanga bgaphambi kokuba uqhubeke nokuphendula. Ingxoxo yethu ingathatha imizuzu ewu 45 kuya ehoreni kuye ngokuthi usazimisele yini ngokukhuluma. Kungenzeka ngidinge ukuxoxisana nawe ngokwesibili futhi. Lokhu kuzokunika isikhathi sokuphumula ubuye ucabange futhi ngokunye ofisa ukukusho uma sesiqhubeka ngokulandelayo. Ngizodinga ukucela ukuxoxisana nalabo asebeqede unyaka bahlinzwa futhi abaneminyaka engaphezulu kuka 18.

Izingozi noma ukuphazamiseka kumuntu ohlanganyele:

Kungenzeka ufikelwe umunyu ngesikhathi sixoxa ngoba uhlobo locwaningo lubucayi. Mina ngiwumhlengikazi okwaziyo ukunika usizo lomqondo. Kodwa uma ngibona ukuthi udinga okungaphezulu kwalokho mina engkwazi ukukwenza, ukhona usnhlalakahle wasesibhedle a uyokubona ngokushesha akunike usizo.

Izinzuzo: Akukho nzuzo ozoyithola ngikuba ingxenye yalolu cwaningo. Uma kungenzeka uthole usizo lokwelulekwa ngokomqondo izinhlaka ezahlukene zabaluleki ongalulethelwa abaphathi besibhedlela okungakusiza ukuthi ubhekane kangcono nesimo sempilo ngenxa yokuhlinzwa kwakho. Izincomo ezivela kulolu cwaningo zingasetshenziselwa ukuthuthukiswa kolwazi emndenini nasemphakathni ukuze lwande ulwazi ngomdlavuza wesitho sangasese. Lolulwazi lungasiza namanye amadoda ukuthi afune usizo ngokushesha uma ezaw izimpawu zokungaphili. Nabahlengikazi kungenza ukuthi baqaphele babaphathe kahle nabesislisa abanezimpawu zezifo zocansi ukwenza kube lula kubona ukuthi bafune usizo emtholampilo.

Izizathu zokuthi umhlanganyeli angayeka ekubeni ingxenye yocwanigo: Ungakwazi ukuhoxa kulolucwaningo nganoma yisiphi isikhathi uma ufisa ukwenza kanjalo. Ngeke kube khona inhlawulo yokuhoxakwakho. Uma futhi kukhona umbuzo ongazizwa kahle ngokuwuphendula, ungawuyeka.

Izindleko Zocwaningo: Akukho zindleko ezizoba khona kuwena ngokuba ingxenye

yalolucwaningo. Ngizokubona ngosuku lwakho vele luka dokotela. Uma ufuna sibonane kwenye indawo imina engizoza kuwena.

Imfihlo: Amagama awazubhalwa ezincwadini noma kuma fomu aqondene nocwaningo. Uzonikwa elinye igama okungelona elakho langempela. Konke okuzobe kusetshenziswa ngesikhathi socwaningo kuzogcinwa endaweni ekhiywayo kuze kuphele iminyaka emihlanu bese kuyashabalaliswa ngokudatshulwa nokucishwa kuma computer.

Ukulimala okuhlobene nocwaningo: Kungenzeka ufikelwe umunyu ngesikhathi sixoxa ngoba uhlobo locwaningo lubucayi. Mina ngiwumhlengikazi okwaziyo ukunika usizo lomqondo. Kodwa uma ngibona ukuthi udinga okungaphezulu kwalokho mina engkwazi ukukwenza, ukhona usnhlalakahle wasesibhedle a uyokubona ngokushesha akunike usizo.

Abantu abazoxhumana nabo uma kunezinkinga noma imibuzo:

Sicela uxhumane nomsizi womcwaningi Dr D. Sokhela inombolo yocingo 0722644670 noma nomcwaningi: Mrs Vuyo Ndlovu, inombolo yocingo 0843501411 noma umqondisi we-Institutional Research Ethics ku- on 031 3732375. Izikhalo zingadluliselwa kuMqondisi: Research and Postgraduate Support Dr L Linganiso on0313732577orresearchdirector@dut.ac.za.

Appendix 4a: CONSENT FORM

CONSENT

Statement of Agreement to Participate in the Research Study:

 I hereby confirm that I have been informed by the researcher (V.V. Ndlovu), About the nature, conduct, benefits and risks of this study-Research Ethics Clearance

Number: _____,

 I have also received, read and understood the above written information (Participant Letter of

Information) regarding the study.

 I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.

 In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.

 I may, at any stage, without prejudice, withdraw my consent and participation in the study.

 I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

 I understand that significant new findings developed during the course of this research which may

Relate to my participation will be made available to me.

_____	_____	_____	_____
Full Name of Participant	**Date**	**Time**	**Signature / Right Thumbprint**

I V.V. Ndlovu herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Full Name of Researcher	**Date**	**Signature**
Full Name of Witness (If applicable)	**Date**	**Signature**
Full Name of Legal Guardian (If applicable)	**Date**	**Signature**

Appendix 4b: INCWADI YESIVUMELWANO SOKUBA INGXENYE YOCWANINGO.

ISIVUMELWANO

<u>Ukunika imvume yokuba ingxenye yocwaningo</u>

Isitatimende sesivumelwano sokubamba iqhaza eSifundweni Sokucwaninga:

• Ngiyaqinisekisa ukuthi ngitsheliwe umcwaningi, uJennifer Moodley mayelana nemvelo, ukuziphatha, izinzuzo, kanye nezingozi zocwaningo.

• Nginikeziwe, ngafunda futhi ngayiqonda kahle yonke imininingwane ebhaliwe ngenhla (incwadi yokubamba iqhaza yolwazi) mayelana nokucwaninga.

• Ngiyazi ukuthi umphumela wocwaningo, kufaka phakathi imininingwane yomuntu mayelana nobudala, ubulili, usuku lokuzalwa luzobikwa ngendlela eyimfihlo uma sekubhalwa umbiko wocwanigo.

• Ngokubheka izidingo zocwaningo, ngiyavuma ukuthi lonke ulwazi oluqoqwe ngesikhathi kwenziwa lolucwaningo ingacutshungulwa ohlelweni lwekhompyutha ngumcwaningi.

• Ngingakwazi, nganoma yisiphi isigaba, ngaphandle kokubandlulula, ngihoxise imvume yami nokuhlanganyela kulolu cwaningo.

• Nginikiwe ithuba elanele lokubuza imibuzo futhi (ngokuzithandela kwami) ngizinikezele ukuthi ngilungele ukuhlanganyela kulolu cwaningo.

• Ngiyaqonda ukuthi imiphumela emisha ezotholakala ngalolucwaningo etholakale

ngoba mina ngibe ingxenye yalolucwaningo kungenziwa ukuthi ngiyithole uma ngiyidinga.

_____

Igama eliphelele Usuku Isichicelelo isikhathi

Mina, Vuyo Ndlovu ngiyaqinisekisa ukuthi lo mhlanganyeli ongenhla uye waziswa ngokugcwele ngemvelo, ukuziphatha kanye nezingozi zocwaningo oluchazwe ngenhla.

_____ _____ _____ _____

Igama eliphelele lomcwaningi Usuku isichicilelo Isikhathi

_____ _____ _____ _____

Igama eliphelele likafakazi Usuku Isishicilelo Isikhathi

Appendix 5a: INTERVIEW GUIDE (ENGLISH)

Section A: Demographic data

Age in years: ☐

Marital status:

Married	
Divorced	
Never married	
Have a fiancé	
Widowed	

Level of education:

Never went to school	
Primary	
High School	
Tertiary/Degree	

Employment status:

Student	
Employed	
Unemployed	
Retired	

Is your penectomy surgery

Total	

Partial	

Section B: Interview Questions

Tell me about your life experiences after you have had penectomy surgery.

Sub-questions

- How has penectomy surgery affected you psychologically?
- How has penectomy surgery affected your family life?
- How has penectomy surgery affected your urinary function?
- How has penectomy surgery affected your sexual function?

Probing will be used to obtain further information, which could be based on the participant's response.

Appendix 5b: UHLA WEMIBUZO

Section A: Demographic data

Iminyaka: ☐

Isimo somshado:

Ngishadile	
Ngihlukanisile	
Angikaze ngishade	
Ngine ngoduso	
Ngashonelwa	

Izinga lemfundo:

Angikaze ngiye Eskoleni	
Amabanga aphansi	
Amabanga aphezulu	
Imfundo ephakekme/iziqu	

Isimo sokuqashwa:

Ngiwumfundi	
Ngiyasebenza	
Angisebenzi	
Ngathatha umhlalaphansi	

Isitho sakho sangasese sakhishwa

Sonke	
Ngokungaphelele	

Section B: Imibuzo

Uyithola injani impilo yakho selokhu wahlinzwa isitho sakho sangasese?

Sub-questions

- Ukuhlinzwa isitho sangasese kukuphathe kanjani ngokomqondo?
- Ukuhlinzwa isitho sangasese kukuphathe kanjani empilweni nomndeni wakho?
- Ukuhlinzwa isitho sangasese kukuphathe kanjani mayelana nokuchitha amanzi?
- Ukuhlinzwa isitho sangasese kukuphathe kanjani mayelana nokuya ocansini?

Imibuzo yoku gomba izosetshenziswa ukuze kutholakale ulwazi olujulile noma ukuhlaziya izimpendulo.

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Health Research & Knowledge Management

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3169/ 3123 Fax: 033 394 3782
Email:
www.kznhealth.gov.za

NHRD Ref: KZ_202201_026

Dear Mrs VV Ndlovu
(DUT)

Approval of research

1. The research proposal titled '**Lived experiences of post penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study**' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at St Aidans Hospital.

2. You are requested to take note of the following:
   a. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   b. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to* ***HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200*** *and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 23/02/2022

Fighting Disease, Fighting Poverty, Giving Hope

Yours Sincerely

Dr K Padayachy

Appendix 7: PROVISIONAL ETHICS APPROVAL

Institutional Research Ethics Committee Research and Postgraduate Support Directorate 2nd Floor, Berwyn Court
Gate 1, Steve Biko
Campus Durban
University of Technology

P O Box 1334, Durban, South

Africa, 4001 Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

30 November 2021

Mrs V V
Ndlovu 99
Montclair
Road
Montclair
4004

Dear Mrs Ndlovu

Lived experiences of post penectomy patients receiving healthcare from a Public Hospital in KwaZulu- Natal. A phenomenological study.

I am pleased to inform you that **PROVISIONAL APPROVAL** has been granted to your proposal subject to:

- Obtaining and submitting the necessary gatekeeper permission/s to Institutional Research Ethics Committee (IREC).

PLEASE NOTE THAT THIS IS NOT A FINAL APPROVAL LETTER. KINDLY SUBMIT THE ABOVE MENTIONED DOCUMENTS WITHIN THREE MONTHS TO THE IREC OFFICE. DATA COLLECTION CAN ONLY COMMENCE WHEN IREC ISSUES FULL APPROVAL

The Proposal has been allocated the following Ethical Clearance number **IREC 180/21**. Please use this number in all communication with this office.

Approval has been granted for a period of **ONE YEAR**, before the expiry of which you are required to apply for safety monitoring and annual recertification. Please use the Safety Monitoring and Annual Recertification Report form which can be found in the Standard Operating Procedures [SOP's] of the IREC. This form must be submitted to the IREC at least 3 months before the ethics approval for the study expires.

Yours Sincerely

Dr K Padayachy
Deputy Chairperson: IREC

Appendix 8: FINAL ETHICS APPROVAL

Institutional Research Ethics Committee Research and Postgraduate Support Directorate 2nd Floor, Berwyn Court
Gate 1, Steve Biko Campus
Durban University of Technology

P O Box 1334, Durban, South Africa,

4001 Tel: 031 373 2375
Email: lavishad@dut.ac.za
http://www.dut.ac.za/research/institutional_research_ethics

www.dut.ac.za

1 March 2022

Mrs V V Ndlovu
99 Montclair
Road Montclair

Dear Mrs Ndlovu

Lived experiences of post penectomy patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study
Ethical Clearance number **IREC 180/21**

The Institutional Research Ethics Committee acknowledges receipt of your gatekeeper permission letters.

Please note that FULL APPROVAL is granted to your research proposal. You may proceed with data collection.

Any adverse events [serious or minor] which occur in connection with this study and/or which may alter its ethical consideration must be reported to the IREC according to the IREC Standard Operating Procedures (SOP's).

Please note that any deviations from the approved proposal require the approval of the IREC as outlined in the IREC SOP's.

Yours Sincerely

Prof J K Adam
Chairperson:
IREC

Appendix 9: EDITING CERTIFICATE

DR RICHARD STEELE
BA HDE MTech(Hom)
HOMEOPATH
Registration No. A07309 HM
Practice No. 0807524
Freelance academic editor
Associate member: Professional Editors' Guild, South Africa

154 Magenta Place
Morgan Bay
5292
Eastern Cape

082-928-6208
rsteele@vodamail.co.za

EDITING CERTIFICATE

Re: **Virginia Vuyokazi Ndlovu**
Durban University of Technology master's dissertation: **Lived experiences post-penectomy surgery for patients receiving healthcare from a Public Hospital in KwaZulu-Natal: A phenomenological study**

I confirm that I have edited this dissertation and the references for clarity and language. I returned the document to the author with track changes so correct implementation of the changes and clarifications requested in the text and references is the responsibility of the author. I am a freelance editor specialising in proofreading and editing academic documents. My original tertiary degree which I obtained at the University of Cape Town was a B.A. with English as a major and I went on to complete an H.D.E. (P.G.) Sec. with English as my teaching subject. I obtained a distinction for my M.Tech. dissertation in the Department of Homoeopathy at Technikon Natal in 1999 (now the Durban University of Technology). I was a part-time lecturer in the Department of Homoeopathy at the Durban University of Technology for 13 years and supervised many master's degree dissertations during that period.

Dr Richard Steele
14 August 2022
per email