# Lived Reproductive Life Experiences of men below 55 years with Prostate Cancer: A Phenomenological Study of men receiving treatment at Uganda Cancer Institute.

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## Dedication

This research is dedicated to my dear mother: Nakigudde Margret Bulega, who encourages me to be the best I can be and supports me in all my life endeavors. To my two lovely daughters: Nambooze Rahma and Nassimbwa Rhaniah for you are the reason I strive hard each day to be a better person. Also, to my late father: Bulega Steven Bunkeddeko, thank you for instilling in me the greatest values, the love of education and belief in myself to pursue my dreams. Lastly but not least to the Margret family, to each of you, this would not have been possible without your unconditional love and confidence in me. I look upon each of you with great admiration, for you are my role models and your inspiring qualities have contributed to the person I am today.

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**List of abbreviations**

| | |
|---|---|
| ACS | American Cancer Society |
| ADT | Androgen Deprivation Therapy |
| BMJ | British Medical Journal |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature. |
| CRUK | Cancer Research UK. |
| EKR | Elizabeth Kubler Ross |
| HINARI | Health Inter- network Access to Research Initiative |
| NHS | National Health Service |
| NICE | National Institute of Clinical Excellence |
| TNM | Tumor Node Metastases |
| UCI | Uganda Cancer Institute |
| USA | United States of America. |
| WHO | World Health Organization |

## Operational definitions

The following terms were used in the research study therefore the definitions are presented below to help the reader understand their meaning as applied to the study context.

### Chemotherapy

This is a form of treatment where drugs are given intravenously or orally to kill or stop the growth of cancer cells.

### Lived experience

This describes first- hand accounts and impressions of living as a member of a minority or oppressed group. In this study first-hand accounts and impressions of men below 55 years living with prostate cancer are described.

### Prostate cancer

Prostate cancer is a tumor of the prostate gland.

### Prostate gland

It is a gland found below the bladder in men and it is responsible for producing part of semen in males.

### Prostatectomy

Refers to removal of the prostate gland

### Radiotherapy

It refers to the killing of cancer cells and surrounding tissues with radiations.

### Reproductive life.

In this study reproductive life refers to the ability to have sex, have control over urine and socialize with people.

# ABSTRACT

**Introduction**: Worldwide cancer is still one of the major killers. In Uganda prostate cancer is ranked as the most rapidly increasing cancer especially in the young men with an incidence rate of 5.2% annually and an incidence: mortality ratio of 71%. This poses significant physical and psychosocial challenges on men's reproductive health. Furthermore, this cancer does not only affect the man but possess challenges to the family and the health system. The perception that prostate cancer is rare among Ugandan men is incorrect due to underreporting and the absence of cancer registries. Many men and families with prostate cancer continue to face a lot challenges at the backdrop of clear documentation of the ordeal. Despite the extensive research in this area, there are still gaps such as the lived reproductive life experiences of men below 55 years with prostate cancer in Uganda. Therefore, the researcher thought it necessary to conduct a research in this area hence the study.

**Objective**: This study aimed at exploring the lived reproductive life experiences of men below 55 years with prostate cancer so as to understand the challenges they face in meeting life and their reproductive health needs.

**Methodology**: Qualitative phenomenological approach was used. Face to face in –depth interviews were used to collect data from eight care givers and twelve purposively selected men below the age of 55 years receiving care and treatment of prostate cancer from Uganda cancer institute for a period of time ranging from 1 to 8years.

Thematic-content analysis of data was done using Tesch's eight steps then themes and sub-themes were generated.

**Findings**: From the study, men below 55 years living with prostate cancer in Uganda expressed fear of the disease and had challenges of disclosure. There were varied experiences ranging from social withdrawal, pain and communication challenges with their significant others. Such experiences added to the physical illnesses associated with sexual and urinary dysfunction modifying the quality of life as well as straining their marital life. The modified life situation coupled with the cost on medicines make the disease economically unsustainable. They also expressed lack of support groups which in addition to the non-disclosure influenced by gender and cultural beliefs further denied them support from peers.

**Conclusion**: It is therefore concluded that prostate cancer in men below 55 years is associated with physical, social, financial and emotional challenges yet it is not given the attention it deserves. Men with the disease often suffer in silence and if left unattended to prostate cancer will continue causing pain and suffering to the entire family and health system at large.

**Recommendations**: From the study, voluntary screening, awareness creation through health education and increased availability of resources to address men's health issues so as to aid early diagnosis are highly recommended. As a means of improving the quality of life of men with prostate cancer, support groups to address the non-disclosure should be established. Further research is recommended in areas of: Experiences of health workers in managing prostate cancer patients: Relationship between prostate cancer and disclosure/non-disclosure: Also expanding the study to involve prostate cancer patients receiving care in private hospitals so as to generate several views.

# CHAPTER ONE:

# INTRODUCTION

## 1.0 Introduction to the study

Cancer has been a problem of developed countries, but today cancer is common in low and middle-income countries including Uganda. Prostate cancer is the second leading cause of cancer related deaths in men (American Cancer Society, 2015). It is the most common cancer among men in Africa. In Uganda, it is ranked as the most rapidly growing cancer at a rate of 5.2% annually with a high incidence: mortality ratio of 71% (Wabinga, et al., 2014).

These men experience medical, physical and psychosocial issues which impact on their immediate family because a man is a part of a family system. Despite that, health workers put much emphasis on the physical issues ignoring the psychosocial issues, yet they are associated with poor adherence, emotional stress and reduced quality of life (Watts et al, 2014). In addition, few studies have explored the range of psychosocial experiences associated with prostate cancer among Africans, yet like any other cancer, prostate cancer brings uncertainty to the patients and their families. It is therefore important that health care providers understand the disease as well as the psychosocial implications to have a holistic approach.

Therefore, this study explored the lived experiences of men below 55 years with prostate cancer in Uganda so that its psychosocial impact on their reproductive health can be understood. It is also believed that once understood, challenges associated with disease and disability can be addressed in a much more extensive way than it has been. This can have profound implications beyond reproductive health to other aspects of development such as agriculture due to increased years of productivity.

## 1.1 Background of the study

Worldwide there is a growing burden of cancer especially in developing countries with reproductive cancers especially breast, cervical and prostate being the top causes of deaths (Salomo,2015). Prostate cancer is the second most common cause of cancer related death in men (American Cancer Society, 2015). In Africa, it is the most common cancer in men accounting for more than 60% of the cases and over 70% of the world's cancer deaths with a higher burden in sub-Saharan Africa representing 20.3% of all cases (Parkin et al, 2012; WHO, 2014). This burden is highest in Zimbabwe and Uganda with incidence rates of 38.1 and 37.1 per 100, 000 respectively. This is lower than the incidence rates in African-Americans which is at 172.8 per 100,000 (Chu et al, 2011). The lower incidence rates in Africa are attributed to underreporting of prostate cancer cases due to lack of cancer registries.

In Uganda, Prostate cancer is ranked as the most rapidly growing cancer at a rate of 5.2% annually with a high incidence: mortality ratio of 71% (Wabinga, et al., 2014). According to Okuku (2013), 70% of the cases present with advanced disease. In addition, the age-standardized incidence of prostate cancer in Uganda is 39.6 per 100,000 and is the highest recorded in Africa (Parkin, et al., 2010). This was attributed to Ugandans' low health literacy levels, poor health seeking habits and low socio-economic status.

Prostate cancer is a tumor that affects the prostate gland. The Prostate gland is an exocrine gland of about 20-25g found in males below the urinary bladder and surrounding the urethra. It is responsible for producing fluid for semen, a white substance that carries sperms. So any condition that affects the prostate gland affects the sexual function of a male (Urological Care Foundation, 2016).

Diagnosis of prostate cancer is done using biopsy and later followed by TNM (Tumor, Node, Metastases) staging and treatment as shown in table 4 and 5 in the appendix. The diagnosis of a chronic illness throws people out of the ordinary life, order becomes disorder and what was controllable becomes uncontrollable (Crinson, 2007). They experience a lot of changes which affect their emotional, physical, social, marital and financial life as explained below:

### Emotional aspect

Once the diagnosis of prostate cancer has been confirmed, the victim goes through the emotional stages described by Kubler- Ross (1969) in the appendix as shock, disbelief, anger, guilt and readjustment. Dealing with these emotions requires disclosure which enables the family to cooperate so as to transform into positive behavior.

### Psychological aspect

At psychological level the cancer diagnosis is perceived to be synonymous with death, pain and suffering (WHO, 2008). It causes confusion and despair to the patient and the family.

### Physical aspect

Numerous physical conditions arise as a result of prostate cancer and its treatment such as urine incontinence and muscle weakness which lead to decreased performance status and physical functioning.

### Sexual aspect

Normal erectile function is disturbed in prostate cancer patients. They normally have disturbances in libido, fertility and ejaculation. These are challenging aspects for men to communicate and this not only prevents them from screening and seeking medication but also affects the quality of life of both the patient and partner.

### Marital life

The changes in sexual and physical functioning cause severe assault to the family. There is a reversal of family roles where the female partner becomes the dominant family figure and business manager.

### Social aspect

Cancer patients experience abandonment, lack of support and feelings of loneliness (WHO, 2008). Therefore, an external support system of friends, families, church members and colleagues is important for the patient during this time.

### Financial aspect

Prostate cancer patients need special dietary requirements which are usually expensive, transport due to restricted mobility and access to public means; they may also suffer restriction or loss of paid employment and also their partner may give up a job to become a full-time care taker.

From the above, men living with prostate cancer go through a complex journey because the diagnosis affects their health as a whole and not just the physical aspect which is given much emphasis today in Uganda’s health care system. In addition, man is part of a family system and community at large meaning living with prostate cancer is not personal but also a shared experience which involves interactions with others. This therefore may involve re-negotiating relationships both at work and at home.

In the recent work about cancer, a lot of information as well as resources have been developed but tend to focus on the health system and treatment support. Limited research work has been carried out with individuals and families affected with the disease especially in countries like Uganda with a high prevalence and incidence rate.

Therefore, the researcher found it befitting to generate information on lived reproductive life experiences of men below 55 years with prostate cancer which when used can contribute to addressing the reproductive health needs of people suffering from prostate cancer.

## 1.2 Problem statement

In Uganda, Prostate cancer is ranked as the most rapidly growing cancer at a rate of 5.2% annually with a high incidence: mortality ratio of 71% (Wabinga, et al., 2014). This cancer affects men physically, socially and psychologically (Macmillan Cancer Support, 2017). In the recent work, less emphasis is placed on the psychosocial aspects yet they are associated with poor adherence, emotional distress and reduced quality of life.

In addition, there is scarcity of literature on individuals and families affected with the disease especially in Uganda yet there are theories which can be used to explore these experiences and the meanings attached to them.

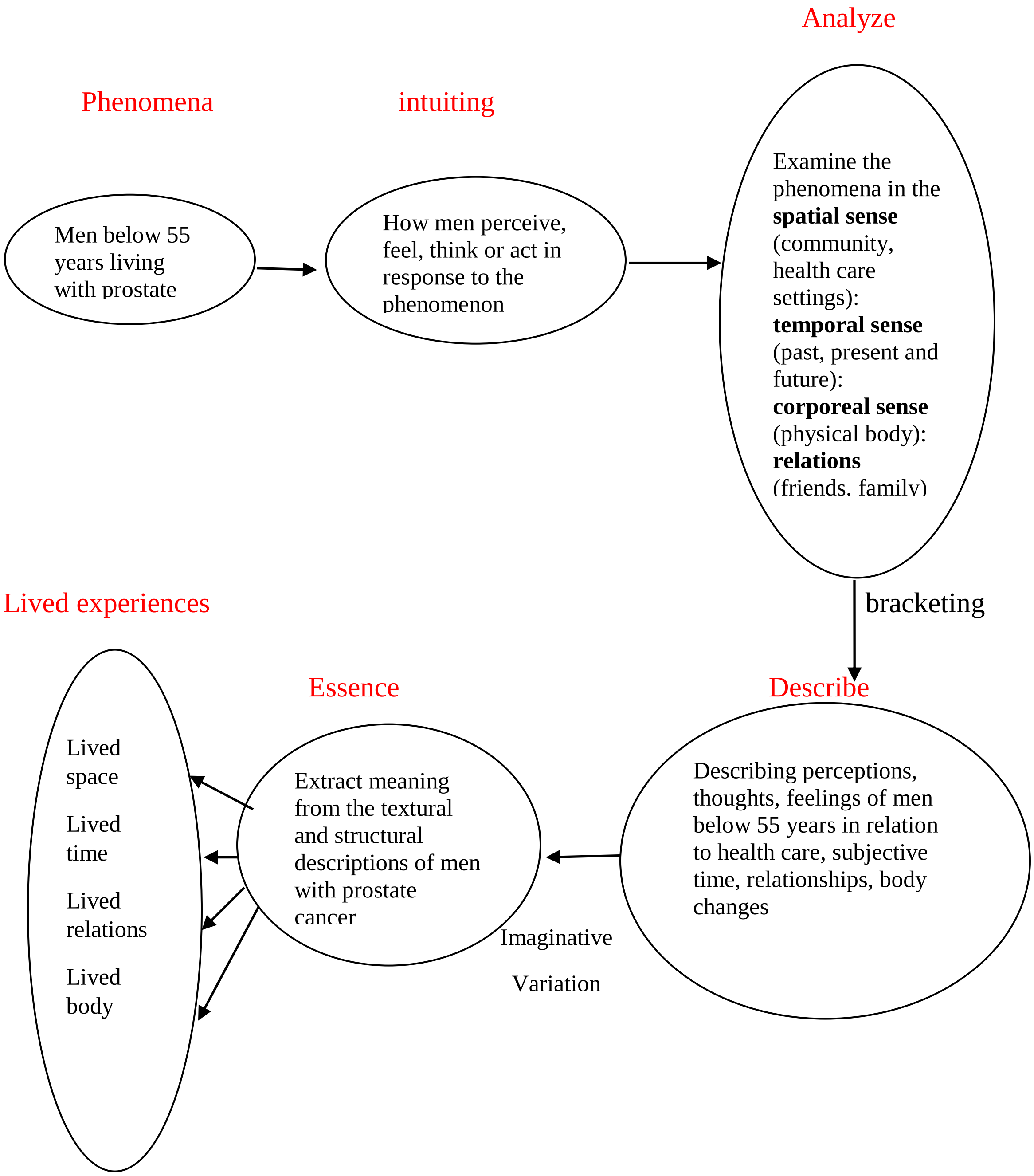
For that reason, the researcher used a phenomenological approach to explore the lived reproductive life experiences of men below 55 years with prostate cancer in Uganda and generated information which if used will contribute to addressing the reproductive health needs of men living with this reproductive health cancer.

## 1.3 Phenomenological theory

Phenomenology is an effort at improving our understanding of ourselves and our world by means of careful description of the aspects of human life as they are lived (Husserl, 1900). It was considered as an ideal inductive approach for this study because it is exploratory in nature and seeks reality in individuals' narratives of their lived experiences of the phenomena (Cilesiz, 2009). It includes different theories: transcendental, existential and hermeneutic (interpretive). While transcendental is mainly connected with bracketing, existential is concerned with individuals being conscious of their existence in the world. On the other hand hermeneutic emphasizes interpretation rather than just description (Cilesiz, 2010). All the three were used in this study as recommended by Van Manen (2014) to ensure flexibility.

Phenomenological research aims to reach the essence of the individual's lived experience of a phenomenon while ascertaining and defining the phenomenon. For the above reason it was used in this research and brought out meanings people attach to these experiences.

Figure 1: concepts of experiences in phenomenology Spiegelberg (1965)



Narrative of the conceptual framework

## Phenomena

Phenomenology begins with a phenomenon-what an individual experiences. In this study the phenomena was men below 55 years with prostate cancer

## Intuiting

This encompassed how men recalled the phenomenon, how men held it in their awareness, how they lived or got involved in it, how one dwelled in it.

## Analyzing

Many aspects were investigated in the inward (thoughts, images, and feelings) and outward form (actions): looked for parts in the spatial sense, sequences in the temporal sense, interaction with environment, clarity of the phenomena, qualities of the phenomenon.

## Description

A description of information that was gathered during intuition and analysis was made. At this point bracketing was required to guard against including things in the descriptions that do not belong there.

## Essence

Meaning was extracted from the men's descriptions which formed their lived experiences with prostate cancer. While extracting the essence imaginative variation was ensured to avoid losing the phenomenon.

## 1.4 Research question

What are the lived reproductive life experiences of men below 55 years with prostate cancer in Uganda?

## 1.5 Objectives of the study

### 1.5.1 General Objective

The main objective of this study was to explore the lived reproductive life experiences of men below 55 years with prostate cancer enrolled at Uganda cancer institute –Mulago

### 1.5.2 Specific objectives

1) To describe the lived experiences of men with prostate cancer as they navigate through their interaction with the health care professionals in Uganda.

2) To explore the experiences of men with prostate cancer with the different treatment modalities of prostate cancer.

3) To explore how prostate cancer affects the social relationships (families, relatives) of men suffering from cancer of the prostate.

## 1.6 Scope of the study

The scope of this study was to explore the lived reproductive life experiences of men below 55 years with prostate cancer enrolled at Uganda cancer institute. It was limited to those men below 55 years who had received a diagnosis of prostate cancer at least 1 year ago and on any of the treatment modalities: radiotherapy, chemotherapy, hormonal therapy, prostatectomy, brachytherapy, cryotherapy or those who had completed any of the treatment modalities.

## 1.7 Significance of the study.

Despite increasing incidence of prostate cancer in Uganda, the experiences victims of prostate cancer go through as a result of the disease are unknown. Conducting a study that explores the lived reproductive life experiences of men with prostate cancer has provided information that:

i. Is instrumental in designing effective interventions that will be responsive to patients' needs hence reducing the disproportionate burden they face.

ii. The district directors of health and program implementers in the community can use to design more appropriate strategies that will culminate into minimizing these undesirable experiences.

iii. Health care providers can use to gain a better understanding on how to serve these patients.

iv. Prostate cancer patients will base on to seek early treatment for the condition hence averting progression of disease, undesirable experiences and morbidity from other diseases.

## 1.8 Justification of the study

Due to the growing prostate cancer burden, myths that prostate cancer is relatively rare among younger Ugandan men and its psychosocial implications on reproductive health of male patients, the researcher found it relevant to conduct a study on the experiences of men below 55 years with prostate cancer which provided a better understanding of living with disease, challenges faced and the support they need to cope with the condition.

# CHAPTER TWO:

# THE LITERATURE REVIEW

## 2.0 Introduction

Prostate cancer has continued to rise in developing countries with limited knowledge on how to meet the needs of men with prostate cancer. Therefore, exploring the lived experiences of men below 55 years with prostate cancer in Uganda yielded information on how cancer and its treatment impact on men's lives. This information will be used by health care providers, district directors of health, and program implementers in communities to improve care.

Selected aspects that are central to documentation of experiences have been reviewed.

## 2.1 Men's lived experiences as they interface with health care professionals

### 2.1.1Communication

Effective communication between patients and health care providers can help men have positive memories about their cancer journey, which is an important factor during recovery. The relationship established with health care providers through continuous communication, provision of information about prostate cancer and guidance through decision making is pivotal through the cancer journey ( Ervik, et al., 2010; Walsh and Hegarty, 2010; Jones, et al., 2011; Thomas, 2013).

Unfortunately, men in Ireland expressed dissatisfaction about the information received from healthcare providers and preferred general practitioners to urologists because they gave them better explanation of what was happening to them (Walsh and Hegarty, 2010). It was worth noting that under such circumstances emphasis was more placed on the bio-physiological symptoms and outcomes of treatment other than psychosocial issues yet these issues lead to humiliation, desperation and despair. Psychosocial support is an important consideration for health workers if they are to appropriately support and care for men with prostate cancer.

Urologists are urged not to communicate to patients using scary words such as ‘aggressive’ or ‘invasive’ cancer because they worsen the fear of clients about cancer. Unfortunately, consultants were reported to be communicating in an insensitive manner hence the need to examine relationships and communications between patients and health care providers since patients and their physicians were usually men (Ervik, et al., 2010; Thomas, 2013). Also, health care providers should always individualize information and improve on their communication skills and this might necessitate training health care professionals to enable them to communicate effectively (O’Brien, et al.,2011).

In addition, health care professionals did not communicate clearly the potential negative effects of different treatment forms (Salomo, 2015; Ervik, et al., 2010; Galbraith, et al., 2012) and this could be attributed to low health literacy levels, lack of empathy and continuity of care. Under such instances of poor provider-client relationship, men could not address sexual changes with professionals because they did not have prior knowledge of what might happen. When they realized these changes, they reacted with compulsive behaviors and opted for private problem solving which was a reflection of being in denial (O’Brien, et al., 2011; Galbraith, et al., 2012).

Letts, et al (2010) explored the impact of prostate cancer on men’s sexual well-being found that the onus was on the men not the health care providers to bring up such aspects and also seek information that explained most of the challenges they faced during the illness. This may not have happened because of the social constructs of men for which they considered it shameful and embarrassing, so they preferred to deal with their symptoms. This on several occasions resulted into depression and isolation thereby affecting the social relationships.

In an attempt to share their challenges, they instead opted for cancer specialist nurses because they were more supportive and willing to discuss non-medical issues which helped men go through their cancer journey with a positive attitude (King, et al., 2015). This shows that men are not willing to discuss their sexual issues and prostate cancer diagnosis with fellow men because it is a form of disclosure which might lead to loss of control.

Furthermore, cultural differences are one of the reasons why communication challenges exist between the men and healthcare providers. Nanton and Dale, (2011) conducted a study on 16 African-Caribbean men living with prostate cancer in the UK where he employed interviewers who were of the same background as the participants and the study yielded rich results because within different cultures emphasis on masculine roles and sexuality may vary. Although it is not clear whether these interviewers' being part of the culture could have impacted on the results, it is an important finding to note especially in a country like Uganda with a lot of cultural diversity and implies that employing translators in cases of language barriers is important to meet the needs of these men effectively.

### 2.1.2 Knowledge about prostate cancer

Both the provider and the client require health literacy skills so as to make informed decisions. Without health literacy, communication across the continuum of care will remain a critical factor.

Australian men in Hagen (2007) cited in King, et al (2015) described it as '*fumbling in the dark'* in an attempt to obtain information from health care providers. This is evidenced by Nakandi, et al (2013) who found that in Uganda 85.7% of men had never been counseled by any physician to undergo screening for prostate cancer which could explain why most men in Uganda present with advanced prostate cancer (60%) accounting for the low survival rate of 46.9%. This shows that there is a knowledge gap about prostate cancer in Uganda.

In an attempt to increase on the awareness, relevant information sources such as media, internet and friends are used (Ervik, et al., 2010; Carter, et al., 2011). However, health care providers are expected to have a role to play because as much as these different sources raise awareness at a time when a man is faced with different treatment options and side effects, they do not educate or inform them adequately (Walsh, 2010; Oliffe, et al., 2011; Kazer, et al., 2011a).

This may be attributed to poor health literacy which presents both oral and written communication challenges that limit their understanding of symptoms of cancer and cancer screening, adversely affecting their stage at diagnosis (Pagan, et al., 2012). This is because they obtain less information from cancer control messages, conversations and brochures. This was evidenced by a national adult literacy survey (NALS,1993) in USA where 2,500 patients were tested in their native language (English/Spanish) and found that 42% could not understand directions of taking medicine on an empty stomach, 26% could not understand the significance of an appointment slip and 60% could not understand a standard informed consent document.

Therefore, there is need to identify successful methods for educating and communicating with patients who have limited health literacy.

### 2.2 Men’s experiences with different treatment cancer modalities

Prostate cancer treatments vary from surgery, radiotherapy, hormonal therapy to watchful waiting. All the above are used with a goal of cure, prolonged survival or palliation depending on the tumor stage (Resnick, et al., 2013). Current evidence provides information on the impact of the different treatment modalities on the health of men. These were experienced by both men and partners as adverse effects of the diagnosis and treatment for prostate cancer. They ranged from fear to depression, in addition to the physical changes such as incontinence and loss of libido. (O'shaughnessy, Laws, & Esterman, 2013).

Issues concerned with living with treatment outcomes were a dominant theme across all of the studies and reflected the challenges that men faced in their daily lives, and the subsequent effect on their sense of self-worth. The most common side effects reported are urinary incontinence and sexual changes which affected the social lives of men.

### 2.2.1 Urinary incontinence

Urinary incontinence is associated with leakage and odor, and the need to have trips within areas of public conveniences (O’Shaughnessy, 2009; Nanton and Dale, 2011; King, et al., 2015). This arises mainly from surgery. The embarrassing nature of incontinence impedes men’s ability to work and maintain the role of household breadwinner because it causes them to refrain from social activities or even giving up work (O’Shaughnessy & Laws, 2009).

Although in unpartnered men issues of incontinence are barriers to contemplating new relationships, participants in Kicki (2011) believed that incontinence was not so much of a challenge if a man was in loving and a caring relationship. Moreover, published literature (Meyer et al (2003) cited in Chung and Gillman (2014) shows that 70% of men believe that male erectile dysfunction has greater adverse impact than urinary incontinence on their quality of life. This is similar to findings from a longitudinal population-based study where the sample was from six different regions of United States with varying ethnic groups. Incontinence was reported by 8.4%

of men and impotence by 59.9% and these men were embarrassed to talk about their sexual difficulties and were always in isolation. This calls for continuous discussion of psycho-sexual matters throughout the men's cancer journey by healthcare providers so as to provide more opportunities for men and their partners to discuss issues as they become more salient.

### 2.2.2 Sexual dysfunction

As noted earlier, this is one of the most dominant themes that arose from the literature review. Sex is perceived by men as a means to pleasure and achieving intimacy with their partner (Letts, et al., 2010). Therefore, the negative impact of prostate cancer treatment on men's sex lives affects relationships. The major sexual difficulties included: full or partial loss of erection, reduced force of ejaculation, decreased orgasm, loss of libido and reduced emotional changes. The extent to which these are experienced varies and is dependent on factors such as age, nature of their sexual function prior to the cancer journey and treatment (Carter, et al., 2011).

The above sexual difficulties lead men into opting for inferior forms of treatment in an attempt to preserve their potency (Salomo, 2015). This is because men accentuate the importance of sexual encounter to satisfy their role expectation and view it as a contest in which they feel obliged to dominate. Therefore, inability to meet these expectations contributes to negative feedback that ranges from frowns to disappointments especially if the inability is due to a disease condition.

For other men, the loss of sexual function and libido enabled them cope better with impotence. This was evidenced by Letts, et al (2010) where men were less frustrated about their inability to perform because they were void of any sexual desire. Unfortunately, an intact libido with loss of sexual function was bothersome for some men because they could not fulfill their sexual desires and were afraid of initiating sexual intimacy with their partners. This strained communication and in so doing they could not discuss sexual matters. On the other hand, it was less challenging for others because they felt that at least something about their sexuality had remained the same and this made them cope better (Walsh & Hegarty, 2010).

Erectile dysfunction is embedded within the social contexts of men's lives. Men's psychological adjustment to sexual difficulties is conveyed as a sense of loneliness and isolation. This was shown by Lett's, et al (2010) where participants were glad to talk to someone about their experiences for the first time which calls for multidimensional assessments to capture men's emotional and physical state of health.

Due to the fact that sexual performance is an integral expression of manhood, men felt pressured to maintain the social expression of being able to sexually perform so they opted for the use of erectile aids and medication. However not all men were willing to use them because it was a reminder of what they had lost. For example, in a study on the Latino and African-American men, it was found out that the Latinos were not willing to bother themselves with the use of the aids yet the African-Americans were willing to do anything to preserve their sexual function. This difference could be attributed to the difference in cultures where African-Americans consider masculinity in terms of sexual function and Latinos in terms of family provision but also to the high ratio of single men in African- Americans concerned about maintaining an active sex life (Maliski, et al., 2009).

Despite the fact that the African-Americans were more willing to use the aids, they were frustrated because there was pain, lack of spontaneity, and it was at a cost (Letts, et al., 2010; Walsh & Hegarty, 2010). This made them loose the sense of hope they had in technology. Thus, in an African culture which encourages marriage there is need to find out if men would trade off their survival for sexual function or will be willing to use the aids to preserve sexual function. Unfortunately, sexuality is not only about function, it is an integral part of man's sense of sexual self therefore sexual difficulties are associated with a sense of stigma, hesitation and apprehension of disclosure due to fear of shame and embarrassment (Jones, et al., 2011; Kazer, et al., 2011; Nanton & Dale, 2011).

This shows that erectile dysfunction is embedded more in the social contexts of men therefore researches focusing on determining disease and illness out comes may not adequately reflect the wider range of emotional problems associated with sexuality hence the need for a qualitative study to have a deeper understanding of these changes.

### 2.2.3 Body image changes

Changes in body image is another outcome, reported more by men undergoing hormonal therapy (ADT), the most dominant form of treatment in prostate cancer. The most frequently mentioned changes are breast enlargement, weight gain, loss of muscle, hair loss and reduction in penis size, most of which are feminizing thereby resulting in feelings of embarrassment (Ervik, et al., 2010; Carter, et al., 2011; Grunfield, et al., 2012).

This was evidenced in a UK study where men did not want to disclose these problems to those around and suffered in silence (Grunfield, et al., 2012). They felt they were not men anymore and wished for a life they had prior to prostate cancer. This shows how body image is closely linked to masculinity and calls for psychological support from health workers especially for men undergoing hormonal therapy. Unfortunately, it was found to be lacking and their psychosexual issues remained unaddressed (O'Brien, et al., 2011). However, as much as some of these men were frustrated, others reframed their scars in a positive light and were glad that they were still alive.

The information from these experiences is important especially for the pre-treatment stage. In spite of that, Ream, et al (2008)'s survey which was one of the largest surveys had poor representation of Africans and mixed ethnic groups which would have represented the unmet supportive care needs of Africans.

Though there are no studies on Africans especially Ugandan men with prostate cancer, the experiences of African-Americans raise curiosity of whether these experiences cut across a developing country with limited resources and a high patient- doctor ratio which limits the time of interaction between the patient and healthcare provider.

### 2.2.4 Reframing

Men used several strategies in order to adapt to the long-term changes of prostate cancer and its treatment. Several men decided to assume a normal life, by going back to work and running their families the usual way (Walsh and Hegarty, 2010). To some men it was a tradeoff for staying alive. Since prostate cancer occurs at an older age, it was looked at as a natural aging process by some men and they were lucky that it had not occurred at a tender age (Kicki, 2011). They believed it had served its purpose because they had had children (Maliski, et al., 2008). Others chose to adopt healthier life styles such as avoiding red meat and fatty foods, then exercising more often to increase their physical strength and sense of worth.

Men tried to hide their physical hindrances to appear strong and capable. This is evidenced by Grunfied, et al (2013), in exploring the meaning of work among those diagnosed with prostate cancer, where most participants returned to work by 12 months after treatment and had no change in duties. However, there was an expressed anxiety of dealing with incontinence while maintaining their normal work routines. This shows that after treatment men feel challenged by their social and work-related roles hence the need to explore experiences of men with different cultures, variety of labor laws, and cultural norms emphasizing the breadwinner role of men.

Several men considered being optimistic rather than looking at the negative outcomes. They focused on the good things that had happened to them, they became more loving and caring. Despite the fact that they looked at it in terms of losing the game of life, they considered themselves to be at an advantage in comparison to those who had lost their lives to cancer. They refrained from extramarital affairs and started looking at their wives as administrative assistants. Others joined groups were they shared and this deepened their male friendship (Kicki, 2011). This is a reflection of acceptance in the stages of grief and calls for continuous social support throughout their cancer journey.

Some men chose to use technical aids and / or pills to regain their sexual function in an attempt to renegotiate their masculinity (Kicki, 2011). All this was due to the external and internal pressures to sexually perform according to the normative ways all because they were not accepting what had happened to them which is a reflection of bargaining.

Despite all those positive changes, other men continued to look at prostate cancer as a cancer that has only impacted negatively on their lives compromising their activities of daily living.

The articles did not discuss the differences in the narratives of different ethnicities. They mainly focused on narratives of white heterosexual men hence the need to explore the experiences of the Africans.

### 2.2.5 Uncertainty

Prostate cancer and it's treatment is full of uncertainties especially for men under active surveillance, those with advanced disease and recurrence (Ervik, et al., 2010; O'Brien, et al., 2010; Walsh and Hegarty, 2010; Carter, et al., 2011; Nanton and Dale, 2011; Galbraith, et al, 2012; O'Shaughnessy, et al, 2013; Rivers, et al, 2013; Thomas, 2013). Uncertainty is in terms of what side effects to expect and for how long; for example those receiving hormonal therapy, PSA testing for those under active surveillance and also those with advanced and recurrent disease faced uncertainty during their pathway of care where they were unable to predict what was next and who to approach in case of certain aspects of care (Nanton and Dale, 2011). Men in kicki (2011) analysis of sexuality in the aftermath of breast and prostate cancer were paralyzed for a while not knowing how long they were to live and this uncertainty led to a feeling of loneliness.

Although there are negative aspects of living with uncertainty, other aspects can be adaptive. Kazer, et al (2011b) found that experiencing uncertainty led some men to adopt healthier lifestyles, in an attempt to stay healthier for longer. As this study excluded men under the age of 65, it is difficult to know whether men of a younger age would have also adopted similar habits. However, the study demonstrates that some men are able to reframe their lives, by adopting a more positive attitude which enables them to function healthily and normal in future. This calls for need to learn how to integrate uncertainty into men's lives.

Therefore, health care providers have a role to play in ensuring that men receive enough information about their disease conditions so as to be certain about changes in their lives.

## 2.3 Prostate cancer and psychosocial support/ social networks

Men receive support from health care providers, family, friends and God. (Salomo, 2015; King, et al., 2015; Galbraith, et al., 2012). Men seek more informal support for instance from their peers rather than formal support from health care professionals. This was evidenced by King, et al (2015) in a systematic review to understand men's experiences and unmet needs about prostate cancer and supportive care. The unmet need was attributed to lack of empathy among health care providers, low health literacy levels and also because others were ashamed to explain what they were going through hence the need for health workers to be more supportive.

In another study conducted by Chambers, et al (2012) among Australians, peer support was evident at all the three stages of the disease that is diagnosis, treatment decision and treatment follow up. Galbraith, et al (2012) while looking at experiences of survivors of cancer, observed that peer support provides a sense of meaning in men's experience of the disease. Despite that, some men are interested in information about the disease rather than support and were noted in Carter, et al (2012) to stop going to support groups once they were not receiving any new information. This requires health care providers to have support groups with health educators that give continuous updated information about new treatment trends and medications.

In an attempt to find support, men also turn to God, attend church services more often and participate in church activities (Rivers, et al., 2012; Nanton, 2011.) Jone, et al (2011) reported that men in rural areas were more reliant on faith than those in urban areas. The reason was not well laid out but this prompts one to find out whether this would be the same in a country like Uganda where there is inequitable distribution of resources between urban and rural areas such as chemotherapeutic drugs, skilled trained personnel and access to health facilities.

In addition to spiritual support, families, friends and partners are an important source of support (O’Shaughnessy et al., 2013; Rivers et al., 2012; Evirk et al., 2010). Men prefer reliance on partners than friends because they never want to be perceived as weak from the expression of their emotions and experiences (Gannon, et al., 2010). Others do not want to witness the deterioration and progression to death of their friends (Ervik, et al., 2010) and some men were willing to accept alteration in sex life if their partners would also accept them because they are crucial in helping them understand the importance of preserving life over potency (Letts, et al 2010). Unfortunately, some men reported abandonment by their partners during this trying moment which partly resulted from cultural differences and the different communication styles where some men were not expressive. This created emotional distance and decreased intimacy. Since Uganda has cultural diversity there is need to find out whether this influences the support they receive from their partners despite the fact that our culture encourages caring for the sick.

Furthermore, partners become more of care givers than lovers and the relationship becomes dominated by stress from sexual issues (Hawkins, et al., 2009). This leads to increased conflicts and decreased communication between the couples. In view of the above, sexual dysfunction from prostate cancer has negative impact on the relationships which leads to couples going through turmoil of emotions and challenges therefore acknowledgement of the changes in sexual relationships of couples with cancer is important in promoting relationship satisfaction. Also promotion of communication and education about intimacy issues are essential for enhancing the quality of life of these couples.

In addition to the above, men did not want to disclose to so many relatives who they believed had their own stresses (Walsh, 2010). Other men wanted to prove that they still had a fighting spirit and disclosing to them would show that they were weak. This suggests that conforming to masculine ideals, even when facing a terminal illness is an important part of men's identity and helps them cope with social pressures. Others were afraid of face to face encounters with other men so they opted for online support (Carter, et al., 2011). This is because they wanted to refrain from expressing their feelings and discussing issues that represent areas of weakness and subordination. Therefore, in Uganda where men are socially superior and strong there is need to find out how having prostate cancer impacts on their lives and the support they offer to their families.

Men express dissatisfaction in the care and support they receive from the health professionals, yet they are regarded as an important source of formal support especially for the widowers and un-partnered men (Jonnsson, et al., 2010; Walsh, 2010; Nanton, et al., 2011). For instance, they had concerns of not receiving clear explanations of what was happening to them such as PSA (prostate surface antigen) test and prostate biopsy, why the tests were being carried out and what the results implicated (Walsh, 2010). They were also unable to freely open up to them because each time they went to see a health practitioner they would find someone different. This prevented them from creating rapport and were therefore unable to discuss what they felt (O'Brien, et al., 2011).

Health care professionals were reported not to be empathetic (Galbraith, et al., 2012; Ervik, et al., 2010). On the other hand, general practitioners were more empathetic than urologists (Thomas, 2013). In addition to the general practitioner it was found out by Nettina (2014) that having a specialist cancer nurse for support allayed their anxiety, helped them in treatment decision making and coping with treatment side effects. However, it was reported by Salomo

(2015) that this support was also inconsistent, and men felt devalued. This calls for consistency in service delivery and holistic approach while attending to these men.

Finally, note was made that all the studies that were used in the literature review were qualitative in nature. Ten studies mentioned phenomenology as an approach, one ethnography and one mentioned grounded theory. Most studies had no approach, and this was considered by the researcher as vague for one to use qualitative method without an approach. From the studies with a phenomenological approach only one study used in-depth interviews as a method of data collection. Others mentioned focus group discussions and interviews without specifying the type of interviews yet for a researcher to make essence out of the narratives of the lived experiences of a phenomenon; in-depth interviews are recommended (Creswell, 2007). Furthermore, six phenomenological studies had no clear sampling strategy, two mentioned purposeful, one snowball and one mentioned use of multiple strategies. Those that used purposive and snowball had selection criterion well explained and justification as to why which yielded thick rich findings. Therefore, the researcher opted to select men below 55 years with prostate cancer using purposive sampling so as to use co-researchers with significant and meaningful experiences with the phenomenon which is also recommended by Creswell (2007) and remains the most commonly used method in qualitative studies.

## Conclusion

The purpose of this literature review was to identify studies that explained the experiences of men below 55 years living with prostate cancer in Uganda. The experiences discussed in the literature focus on all men with prostate cancer in different countries or regions of the world. This review brought out the experiences of men with prostate cancer, the side effects of the treatment forms and how they impact on the activities of daily living and it has been clear that it is not easy to live with the cancer because it affects not only the men but also their families.

African men experiences more so Ugandan men were not represented at all, most studies were reflecting experiences of African-Americans as a group of men with the highest incidence of prostate cancer and its believed that it's high because of the African descent. However, all studies were conducted outside Africa and may not translate to the healthcare systems generally, and also community care differs between countries hence the reason for this study.

There is need to find out whether the relationship between healthcare providers and Ugandan men with prostate cancer is similar to that of the African-Americans since Uganda is a developing country faced with a lot of challenges of high population growth rate, inadequate staffing, low budget to health sector among others.

African-American men are willing to do all it takes to regain their sexual function which was partly attributed to the fact that they are single and more likely to take on new relationships. Literature does not mention an African man's stand in this context, yet African culture encourages marriage thus a need to find out whether an African man would trade off sexual function for survival.

Finally there so many themes that emerged from this literature search of exploring the lived experiences of men with prostate cancer, however there is a noticeable gap that no literature has been established about the experiences of Ugandan men below 55 years yet according to Uganda cancer institute (2012), 60-80% of Ugandan men present with advanced prostate cancer and it's the leading cancer among males with a poor outcome of 46.9% being alive after 5 years compared to the 98% in USA.

# CHAPTER THREE:

# METHODOLOGY

## 3.0 Introduction

In chapter two, the main themes arising from the literature review in relation to lived experiences of men with prostate cancer were discussed. It stated a need for future research in relation to experiences of Africans diagnosed with prostate cancer in order to improve their care. This is because of the growing prostate cancer burden among men in Uganda which affects them physically, socially and psychologically. In addition, there is paucity in knowledge on how to meet their needs. Therefore, this study aimed at exploring the lived reproductive life experiences of men below 55years with prostate cancer in Uganda facilitating a breakthrough into the silence surrounding their experiences.

In this chapter, a brief overview of the paradigm that underpins this study and the justification is stated. I adopted an interpretive phenomenological approach to answer the research question of what are the lived reproductive life experiences of men are below 55 years with prostate cancer in Uganda. Later I described the area of study, study population, methodology of choosing the participants, sample size, instruments for data collection and justification as to why. Finally, the data analysis, ethical considerations and limitations were mentioned.

## The research paradigm

Research paradigm is defined as a world view, a general perspective, a way of breaking down the complexity of the real world (Patton, 1990). It was defined by Guba (1990) as an "interpretive framework, which is guided by a set of beliefs and feelings about the world and how it should be understood and studied." Therefore, it is important to make explicit these assumptions and differences throughout the research process.

This study is based on the principles of social constructivism, which are similar to those of phenomenology. They both seek to understand and explain the social world from the perspective of the actors directly involved in the social process. Unlike positivists and post positivists who are objectivists, they collect data to either support or refute a theory, the phenomenological constructivists hold assumptions that individuals seek understanding of the world in which they live or work (Lincoln, et al., 2000). They develop subjective meanings of their experiences which can be influenced by their prior knowledge, culture and personal beliefs. The researchers often address the processes of interaction among individuals and recognize that their own background shapes their interpretation (Creswell, 2009).

Thus, in this study through phenomenological constructivism the researcher sought to understand the lived reproductive life experiences of men below 55 years with prostate cancer in Uganda.

## 3.1 Research methods

Due to the nature of this study that intended to explore the lived reproductive life experiences of men below 55 years with prostate cancer, a qualitative research approach utilizing in-depth qualitative interviews was considered appropriate.  This is because it allows the participant to narrate their experiences with little interference from the interviewer and gain deeper understanding of the phenomenon under study. The approach was chosen firstly due to the paucity of knowledge surrounding the experiences of men with prostate cancer in Uganda. Secondly, qualitative research approach enables the researcher to discover, understand and describe meanings people assign to their lived experiences (Denzin, et al., 2011). In addition, phenomenology also seeks a description, analysis and understanding of lived experiences (Edmonds and Kennedy, 2013).

Furthermore, studies utilizing qualitative research approaches have a distinct advantage of helping healthcare professionals and researchers to better understand the context in which illness and treatment are experienced. It helps a researcher understand how patients experience disease and treatment (Creswell, 2009).

Thus, with all the above reasons a qualitative approach was much more befitting than quantitative approach.

### Justification for an interpretive phenomenological approach

Phenomenology is considered the ideal approach from as far back as Moustakas (1994) for studies of an exploratory nature. In these studies, a small number of subjects are studied through extensive and prolonged engagement to extract patterns and relationships of meaning. The main advantage in using this approach to explore how illness is experienced is the conveying of meaning that individuals attach to their experiences as they are lived rather than how they are conceptualized (Holloway and Wheeler, 2010). Hence, by employing in-depth interviews this approach brings out essential features of this phenomenon.

## 3.2 Area of study

Data collection took place at Uganda Cancer Institute –Mulago, which is the country's national cancer centre. It is located close to the national referral hospital upper Mulago Hill Road Kampala and functions as an independent unit.

All cancer patients are received daily and they go through triage then to the general outpatients where they are either admitted to the wards or scheduled for review by a specialist depending on the type of cancer.

Private and general prostate cancer patients are seen on Friday and Wednesday respectively on an outpatient basis by a physician who runs the clinic. Patients requiring admission are accorded all the care they need and are admitted either on the general or private ward. Study subjects were recruited from general outpatients, Wednesday and Friday clinic and from the wards. A working research relationship was established between the staffs and study subjects. This was advocated for by Silverman (2011) that it makes the interviewee feel comfortable and competent. Face-to-face interviews were conducted at Uganda Cancer Institute, in a room that was provided by the in-charge. This allowed for a naturalistic setting so that the phenomenon of interest is not manipulated. This is in agreement with Leary (2012), who says that the researcher must structure an interview setting which promotes patients' comfort. Only the participant, interviewer and in a few instances the carer were present to encourage comfort and openness of the participant.

## 3.3 Study population

Study population is defined by Brink (2010) as the whole group of persons or objects that meets the criteria which the researcher is interested in studying and from whom the sample is selected. The researcher recruited men below 55 years with prostate cancer at Uganda Cancer Institute between 17th/July/2017 and 14th /august/2017. The reason why the researcher chose this age group is because of the growing cancer burden among young people and the greater reproductive health implications this poses on them.

## 3.4 Sampling procedures

### 3.4.1 Sources of Data.

Data was collected between 17th/July/2017 and 14th /august/2017 at Uganda Cancer Institute from;

Men with prostate cancer below the age of 55 years and care givers/spouses of men with prostate cancer.

### 3.4.2 Sampling and sample size

Due to the large data yielded by the phenomenological approach the researcher kept the number of participants small and reasonably homogenous to ensure analysis is reasonably penetrative. Whenever possible, patients and family members/close friends were matched in pairs. Brink, et al (2013) advocates that a size can be considered adequate if new participants fail to generate any new findings and at that point the data is considered to be rich and thick. Creswell (1998) advocates for 5-25 participants and Morse (1994) says they should be at least six.

Therefore, for this study, I interviewed 12 men with prostate cancer and 8 care givers. Since twenty was in a range advocated for by Thomson (2004) and Creswell (1998) it was considered adequate. Some participants were interviewed more than once, in case of clarity they would be called using a mobile phone and the interviews occurred in a mutually convenient place and proceeded at the participant’s pace. Interviews were stopped and reconvened when participants felt able to continue.

### 3.4.3 Sampling technique and Recruitment

This research used purposive sampling because within phenomenological inquiry purposive sampling is normally used in order to obtain participants who have direct experience of the phenomenon being studied (LoBiondo-Wood and Haber, 2010). A number of issues were considered prior to the recruitment stage to ensure that the phenomenon of lived experiences of men below 55 years with prostate cancer in Uganda could be reflected as accurately as possible using an interpretive approach.

Below was the inclusion and exclusion criteria

**Inclusion criteria for men below 55years with prostate cancer**

Men who have received a diagnosis of prostate cancer and are enrolled in care at Uganda cancer institute, currently undergoing or have completed treatment such as prostatectomy, chemotherapy, radiotherapy and hormonal therapy with ability to understand and speak English/Luganda.

**Exclusion criteria for men below 55 years with prostate cancer**

Criteria included men below 18 years, survivors of prostate cancer, men who are critically ill and unable to talk and those who do not speak/understand English/Luganda.

**Inclusion criteria for family/close friends**

For recruitment into the study: willingness to participate, knowledge of English/Luganda or both as well as being 18 years and above were considered.

After ethical approval of the research, the researcher met with staffs at general and private OPD, who offered advice on how to best recruit men into the study. Using the above criteria and the help of staffs at the Uganda Cancer Institute who would call the researcher in case they came across any participant who met the criteria, eligible participants were selected purposively, and the researcher met them in person in a room provided by the in-charge.

The participants were explained to the study and its relevance, whoever expressed interest was given an information sheet and consent form.  English and Luganda versions of study instruments and informed consents were available for participants to choose their preferred language. The translation to Luganda was done by an independent linguist from Makerere institute of languages then back to English by another independent Luganda speaker on UCI REC. During the time of giving out the information sheet and consent form, the researcher had another opportunity to create rapport with the participants as stated by Silverman (2011) that building rapport in the early stages of an interview can pay enormous dividends. It helped allay anxiety and provided opportunity for the researcher to answer any questions participants had about the study.

### 3.5 Data collection methods and instruments

Data collection involves selecting subjects and gathering information from these subjects (Grove, et al., 2013). There two main methods of data collection in qualitative research; interviewing and observation. In this study data was collected from men below 55 years with prostate cancer and from the care givers by;

#### 3.5.1 Interviewing

This is the most common form of data collection method in qualitative research. Interviews in qualitative research are either semi-structured or in-depth. Since a phenomenological interview focuses on the deeper meanings participants attach to their experiences, at least two in-depth interviews for each man with prostate cancer and care givers were conducted for this study (Seidman, 2013). Being a full-time employee data was collected during my annual leave from 17th /July/2017 to 14th /august/ 2017 between 8am and 3pm. This is because after 3pm the clinics were always no longer running.

The participants who were men below 55 years diagnosed with prostate cancer at least 1 year ago and their carers from the general and private outpatients’ prostate cancer clinic where interviewed personally by the researcher. This process continued until the researcher had interviewed twelve men with prostate cancer and eight care givers. Twenty participants were interviewed because there were no more new participants and the themes had become repetitive. At this point, the sample was considered adequate as recommended by Brink,et al (2013).

Prior to the interview, the participant was welcomed into the room, offered a seat and assured of confidentiality about the information shared. After explaining the study's relevance, verbal consent was sought and also consent to tape record the interview. Participants were informed of their right to withdrawal from the interview if they wished so.

Verbatim transcription was done as soon as possible to maintain rich descriptions.

### 3.5.2 Data collection instruments

- An interview guide with five open ended questions

An interview guide was used during data collection to ensure consistency of the interview questions and not to miss out any questions for which data was relevant. The interview process started by one broad open-ended question for men below 55 years with prostate cancer which was, ‘‘Tell me about what it was like for you on that day you were told you had prostate cancer.’’ During this, the researcher was expected to have good listening and personal interaction skills therefore both verbal and non-verbal communication skills were used. Other questions which are as below were brought in to ensure no important information is left out.

- How was your encounter with the healthcare professionals?
- How has prostate cancer affected your life?
- How have your relatives and friends been affected?

- How has your outlook on life been affected?

For the care giver

Information was also sought from the care givers to ensure an in-depth understanding of the phenomenon of men below 55 years living with prostate cancer and also to aid triangulation of data. The questions below were used as a guide.

- Tell me how (name) life has changed from the time he was diagnosed with prostate cancer
- How has (name) illness affected your family?

This was just a guide which helped the interviewer to remember the questions to cover but questions kept changing during the interview depending on what the participants were sharing with the researcher (Creswell, 2014).

Probes were also used as shown in Table VI in the appendix in order to stimulate the respondent to produce more information and clarity on the responses (Bernard, 2013). At the end of the interview, both the researcher and the participant listened to the audiotape to ensure audibility and completeness as recommended by Botma, et al (2010).

- A tape recorder was also used for tape recording to ensure that all participants expressions are captured as it was pointed out by Holloway and Wheeler (2010) that tape recording is the best way to record the exact words of the respondent.

- Note book and pen for taking field notes. All the observed expressions that could not be captured by the tape recorder were written down to account for the things the researcher feels, thinks and experiences during the course of the interview. Observations were translated into records. Field notes were also taken during recording so that in case the recording equipment fails, the notes can back up.

### 3.6 Establishing rigor

Trustworthiness is the degree of confidence that qualitative researchers have in their data and it was assessed using a framework with four key areas; credibility (confidence in the truth of the results), transferability (showing that the results can apply to other contexts), dependability (consistency of the findings), conformability (how findings have been arrived at) (Polit and Beck, 2012).

#### 3.6.1 Credibility

It refers to steps in qualitative research to ensure validity, accuracy or soundness of data (LoBiondo-Wood and Haber, 2010). Credibility is enhanced when a researcher spends more periods of time with the participants in order to understand them better and gain insight into their lives (DuPlooy-Cilliers, et al., 2014).

In order to achieve this, the researcher spent a lot of time interacting with the patients at the Uganda Cancer Institute by attending health education sessions at the waiting area and observed briefly what happens in the treatment room. This gave the researcher an opportunity to become familiar with the environment, what happens during the different treatment sessions and how healthcare workers interact with these patients. This strategy of prolonged engagement in the field helped the researcher to know more about the research participants (Silverman, 2011).

Next, the researcher did member-checking which is the most critical technique of establishing credibility (Creswell, 2013). The researcher presented the main themes of the findings through a follow up interview with the participants to find out whether their views were well presented, and this was carried out on their next visits to avoid change of opinions (Creswell, 2013). However, this is not a practice that is widely advocated for in phenomenology (McConnell-Henry, 2011).

Peer debriefing provides an external check of the research process. This was carried out by the researcher having physical meetings with the supervisor as the peer debriefer who reviewed and asked questions about methods and interpretations of the study (Creswell, 2013).

### 3.6.2 Transferability

This refers to the ability of the study to be applied in a broader context than the one in which it is being studied (Polit and Beck, 2012). In qualitative research, large samples are not recommended. Thus, emphasis is put on the quality of information generated rather than the size. Creswell (2014) states that, a rich thick description allows a reader to make decisions regarding transferability because of the detailed information provided. Thus, in this study thick rich descriptions of different contexts are provided, and they give a feeling of shared experiences allowing for inductive generalizations from the sample to the target population.

### 3.6.3 Dependability

Dependability refers to the stability (reliability) of data over time (Weiten, 2014). This was ensured by providing a decision trail at each stage of the research process. Evidence as to why certain methods have been adopted and not others was provided, and self-reflection was ensured throughout the research process which will eliminate bias (Creswell, 2013). This is exemplified in the reflection statement in the appendix XI.

### 3.6.4 Conformability

It refers to objectivity. It guarantees that the findings, conclusions and recommendations are supported by data and that there is internal agreement between the researcher’s interpretation and actual evidence (Brink, 2010). Here a researcher clearly explains how conclusions and interpretations have been reached at from the study so that others who look at the data must derive a similar conclusion as the researcher (Du Plooy-Cilliers, et al, 2014). In this study the researcher provided longer quotes so that other researchers can see how the interpretations were reached. Bracketing and reflection throughout the whole process was also done so as to eliminate personal biases and motivations (Polit and Beck, 2012). This is shown in the bracketing statement in appendix VI.

## 3.7 Data analysis plan.

Data analysis is an ongoing process involving continual reflection about the data and making an interpretation of the larger meaning of the data (Creswell, 2013). In qualitative research data analysis goes hand-in-hand with data collection. There is development of an essence description from analysis of significant statements (Creswell, 2014).

In this study, thematic content analysis was used. This is an inductive approach of analyzing qualitative data (May and Holmes, 2012). It involves analyzing transcripts, identifying themes within those data and gathering together examples of those themes from the text. During this stage, the researcher identified and described patterns and themes from participants’ perspectives. The data was organized categorically and chronologically, reviewed repeatedly and continually hand coded using color code schemes as per Creswell (2013). Participants taped interviews and diaries were transcribed verbatim. Open coding was carried out where the researcher read each transcript and made notes in the margins of words, theories or short phrases that summed up what was being said in the text.

This followed Tesch's (1992) eight steps of the coding process which were applied to the study as follows;

- All the necessary background information was obtained by carefully listening to the audio taped information and compared it with the field notes. This was done to make sense out of the interview by breaking it into main parts of the conversation.
- Relevant data parts from the interview were searched and written down in relation to the research question
- After noting down these data parts, they were compared and grouped into topics, putting similar topics together and unique ones aside.
- Codes were then attached to different topics and similar topics were given the same code
- Data was checked for coherence then sub-themes and themes were generated that were describing the topics. These were the major findings of the study.
- They were then written down clearly to avoid duplication by giving similar topics the same code.
- After the initial coding some data was re-coded to ensure topics are well grouped.

## 3.8 Ethical issues

May and Holmes (2012) state that research ethics are central to all research involving human participants. Prior to seeking approval from the faculty of health sciences Nkozi and UCI research ethical committee (see appendix XV), issues of safety, confidentiality, informed consent, handling and storage of data then safety issues of the researcher were addressed.

### 3.8.1 Informed consent

All participants were provided with an information sheet about the study and how the data will be handled upon completion of the study prior to the interview (see appendix IV, V). They were given time to decide voluntarily if they wanted to participate. If one agreed he was given a consent form to sign. Permission to tape record the participants was sought before starting the interview.

### 3.8.2 Confidentiality

All interviews were recorded, and the audio recorder was kept in a closed place with restricted access. Participants were informed that audio recordings are to be kept until the dissertation is approved by the university and that all identifiers are not to appear on any of the reports.

### 3.8.3 Participant safety

The information sheet contained the contacts of the researcher and lead supervisor so that incase of any queries or questions the participant can call any of them. Since it was a distressing topic, it was made clear at the start of the interview that it will proceed at the participant’s pace and that one was free to withdrawal from the interview at any point if they so wished to. In case he remembered something distressing the interview was paused or terminated and only resumed if they were ready to start.

### 3.8.4 Researcher safety

Since the interviews were conducted at the Uganda Cancer Institute, the Head of the Institute, research ethics committee and the in-charge on duty were informed prior to conducting any interview. A phone call was made to the lead supervisor before starting and at the end of the interview to inform him/her that it is going on well. Before leaving the cancer institute the in-charge would be informed.

### 3.8.5 Data handling and storage

Data was stored in hardcopies, audiotapes and locked away in a secure cabin accessible to only the researcher and supervisor, then also on a personal laptop secured with a password, to prevent invasion of privacy. All identifiers were replaced by pseudonyms (Holmes, 2012). Audiotapes are to be kept until the dissertation has been approved by the university. The transcribed data was backed up by an external hard drive then kept secure under lock and key and is to be stored for at least 3 years.

## 3.9 Limitations of the study

The most obvious limitation of the study was the small sample size of participants from Uganda Cancer Institute which may not represent all the views of men below 55 years with prostate cancer in Uganda. In overcoming this, the researcher focused on a detailed description of the patients views rather than the number to yield quality results.

The other challenge was in the process of recruiting men diagnosed below 55 years, since prostate cancer is common among men above 50 years. It was time consuming for the researcher to get the participants. In overcoming this, the researcher worked with the nurses who are always in constant care of these patients to identify those eligible for the study.

In addition, due to the sensitive nature of the topic and cultural barriers it was not easy for the men to discuss their experiences with a young woman (researcher) therefore the researcher spent a lot of time with the participants so as to build trust.

Another limitation was the absence of the perspectives of the health professionals who care for these men. If care is to be improved there is need to understand the barriers that interfere with communication between the two parties.

# CHAPTER FOUR

# RESULTS

## 4.0 Presentation of results

## 4.1 Introduction

This subsection presents the findings of the study. It starts with the background characteristics of the participants. This is followed by a table summarizing the themes and sub themes that arose from the study.

## 4.2 Characteristics of the study sample

Twelve men were recruited from Uganda cancer institute. The participant characteristics are summarized in the table below.

Table 1: Participant's background characteristics

| Identifiers | Age at diagnosis | Treatment | Duration with the cancer | Marital status | Tribe | Education level | Employment status |
|---|---|---|---|---|---|---|---|
| LG [P1] paired with wife during the interview | 52 | Radical prostatectomy<br>Hormonal therapy | 5 years | married | Ankole | Secondary level | Employed |
| KG[P2] paired with wife during the interview | 48 | Hormonal therapy | 1 year | married | Muganda | Secondary level | Employed |
| KJ[P3] paired with son during the interview | 53 | Hormonal therapy<br>Radical prostatectomy | 5 years | separated | Ankole | Secondary level | Employed |
| KE[P4] paired with son during the interview | 52 | Hormonal therapy | 8 years | married | Ankole | Secondary level | retired |
| LJ[P5] paired with first wife during the interview | 54 | Hormonal therapy | 4 years | married | Muganda | Primary level | Non-employed |
| SK[P6] not paired during the interview | 50 | Hormonal therapy | 1 year | married | Musoga | Primary level | Non-employed |
| MJ (P7) paired with wife during the interview | 49 | Hormonal therapy | 5 years | married | Muganda | Primary level | Non-employed |
| MJ(P8) paired with wife during the interview | 55 | Hormonal therapy | 4 years | married | Muganda | Primary level | Non-employed |
| SE(P9) Not paired during the interview | 48 | Hormonal and radiotherapy | 3 years | married | Muganda | Tertiary level | Employed |
| RE(P10) Not paired during the interview | 50 | Hormonal therapy | 6 years | separated | Muganda | Primary level | Non-employed |
| BA(P11) Paired with wife during the interview | 46 | Hormonal therapy | 8 years | married | Muganda | Secondary level | Employed |
| PQ(P12) Not paired during the interview | 55 | Hormonal therapy | 5 years | widowed | Ankole | Primary level. | Non-employed |

## 4.3 Introducing the participants

Below is a short synopsis of the twelve men with prostate cancer and the eight care takers who took part in the study.

### 4.3.1 LG

LG, a 57-year-old man living in western Uganda was diagnosed with prostate cancer in 2012 from Mbarara regional referral hospital where he presented with acute urine retention. He was informed of the diagnosis one month later which shocked him because he had never had of such a condition in his family. He was informed of the possibility of removal of the prostate. Upon the wife hearing about the surgical procedure she informed the daughter who was staying in Kampala. The daughter decided to bring the father to Kampala for a second opinion and management. He had surgery carried out from Mulago then later he was referred to Uganda Cancer Institute (UCI) for follow up. At the UCI, he was started on hormonal therapy an injection given every month. This resulted into reduced libido which depressed him leading to missing appointments especially in the initial stages of treatment because he needed to dodge the injections just to maintain his sexual desires. Later, after several discussions with the wife about the sexual changes, he learnt to accept them and would not miss his appointments for treatment. LG did not report seeking for other sources of support or information about the cancer and in his five years of the cancer journey he was neither informed nor did he attend any support groups. Due to cultural and gender beliefs he never talked about this disease to other men due to fear of being perceived as less masculine in society. At the time of the interview, LG was still working and living with his wife who he had come with to hospital. When asked about when he was to stop receiving treatment, he reported that he was neither aware of the duration of treatment nor the stage of the disease. He was positive that he was to live long with the disease and promised to inform his son who was 18 years about the disease when he finishes university.

**LG's wife**. She reported that she had to take on a new job so as to support her husband in providing for the family because they had three children who were still in school. She said that they were also receiving financial support from their daughter to whom they were grateful.

### 4.3.2 KG

KG, from central Uganda was 48 years when he was diagnosed with prostate cancer. After being managed for recurrent urinary tract infections from peripheral clinics in Kiboga, he made a decision to go to St.Francis Hospital Nsambya. After several blood tests, a biopsy was taken off which confirmed that he had prostate cancer. Upon hearing the diagnosis, he cried because of fear of death since he knew that cancer has no cure. Despite the doctor's attempt to explain to him the next steps, he could not take in the information at that time. After about a month, he decided to return to hospital following advice from the wife. They decided to go to Mulago hospital instead of Nsambya due to the fear of financial costs in a private hospital. In Mulago Hospital several other blood tests were carried out before starting hormonal therapy a month later. They were neither given information about other treatment options nor the duration of hormonal therapy. At the time of the interview, KG who had come with his wife described himself as 'half man' because he had experienced reduced libido and was afraid that his wife would leave him for another man. KG admitted that he was burdened with the condition and chose to discuss it with his mother for emotional support. Despite the mother and wife's support, KG still has limited hope for survival.

**KG'S wife**. The wife reported that she takes a day off duty to accompany her husband to hospital during the reviews because of the long waiting hours at the hospital. She also reported that she takes on extra working hours as a teacher to increase her income since her husband no longer works as hard as he used to before the diagnosis. She expressed fear of the future because she had not yet paved a way of how she will ensure that their four children remain in school.

### 4.3.3 KJ

KJ, from western Uganda was 53 at the time of diagnosis. This was after undergoing tests from an orthopedic clinic in Mbarara to ascertain why he had had long standing back ache with associated paralysis of the lower limbs. A biopsy of the prostate was done which confirmed prostate cancer. Upon hearing the diagnosis, he was scared for his life, so he informed his eldest son who took him to Mulago Hospital after medical advice from the orthopedic doctor. In Mulago Hospital, they were scheduled for surgery which was done two months later due to the long queue of patients waiting for the same treatment. He was started on hormonal therapy. After surgery he developed urine incontinence for which he had a urine catheter inserted worsening his sexual dysfunction. This made him feel uncomfortable and the stench from urine made him withdraw from social gatherings. He chose to disclose to two of his workmates who gave him social support but did not disclose to parents because he did not want to worry them as he was their source of financial support. At the time of the interview, he was with son and daughter who he said had supported him throughout his cancer journey. He had separated with the wife 3 years after diagnosis due to adultery which he attributed to his sexual dysfunction. KG reported that for the time he had been on treatment the bone pain had reduced and was now able to walk with minimal difficulty which gave him a positive outlook that he will live long if continues treatment as per the doctor's instructions.

**KG's son**. All the three (father, son and daughter) admitted to not having heard of prostate cancer before and despite the son being 40 years he had not received screening for cancer of the prostate. The son attributed this gap in information to health workers. He also confessed that he had not searched about the disease his father was suffering from.

### 4.3.4 KE

KE, from western Uganda was 52 when he was diagnosed with prostate cancer. This was preceded by tests to ascertain why he had developed acute urine retention. He had a catheter inserted. Due to the fear of the procedure for biopsy, he had it done three months later after developing paralysis of the lower limbs. Upon diagnosis he was anxious to know whether he was to be cured but he was dismayed when he was told that it was not possible. He blamed himself for having delayed returning to hospital for the biopsy. KE was advised to have surgery from a medical Centre in Mbarara which he declined because it was devastating for him since it had no cure and was associated with impotence, so he preferred to retain his potency. Due to the progressive weakening he retired 2 years after diagnosis and this is when he chose to inform his son about his disease status. The son decided to bring him to UCI. He was started on hormonal therapy and reported improvement. He cared less about sexual function because at that time it had also reduced. At the time of the interview, he was still married and depended on his wife and sons for support.

### 4.3.5 LJ

LJ, 58-year-old male from the central region, was only 54 years when he was diagnosed with prostate cancer. This happened a few months after his marrying a second wife. He had been managed for recurrent UTI from peripheral clinics which he assumed was due to his having more than one partner. He was advised to have removal of the prostate gland but opted for hormonal therapy and radiotherapy. This was due to the fear that surrounded him about impotence and his new relationship. He chose to disclose only to his first wife for fear of losing the second wife. The experience was challenging but it brought him even closer to his first wife. He however did not receive radiotherapy from the cancer institute because of the long queue and later the machine broke down.

### 4.3.6 SK

SK a 52-year-old man from eastern Uganda was diagnosed with prostate cancer in 2015. This followed a series of investigations due to abdominal pain which revealed an enlarged prostate that was later biopsied and confirmed cancer of the prostate from Mulago. This took him by surprise because he had not had any symptoms suggestive of cancer. He was started on hormonal therapy, he says he was not told of other treatment options. SK has been challenged in this one year with effects of reduced libido and financial constraints because they have to do tests on every visit of which some of them are to be paid for and since he was only a peasant farmer he found it hard to cope with the demands. The wife currently manages the home and at the time of the interview, he had come alone because the wife was preoccupied with other responsibilities. He says he is now more of a burden at home.

### 4.3.7 MJ

MJ 54-year-old man from central Uganda, was diagnosed with prostate cancer at the age of 49years from Mulago Hospital. He described his cancer journey as one full of frustration and disruption due to the long delays in between the appointments and financial constraints. MJ spoke to his wife who always accompanied him for appointments and one other friend within his local area in an attempt to find social support. At the time of the interview, he was with wife who he acknowledged for being supportive.

**MJ’s wife**. She expressed her frustration with the long waiting hours and the few health workers who do not explain to them the condition of the patient but just write medicines. She therefore felt that they were not offered the support they required and urged the government to increase on service providers.

#### 4.3.8 MJ

MJ 59-year-old man from central Uganda who had been diagnosed with prostate cancer 4 years prior to our interview following blood tests and a scan to ascertain why he was straining while passing urine. Reportedly the blood tests suggested that he could be having prostate cancer which was later confirmed by biopsy. Upon diagnosis he recalled that his father had died of a similar condition where he was unable to pass urine and had catheter inserted. This brought fear of death. He was subsequently scheduled for surgery in Mulago Hospital but due to the delays in the appointments resulting from a high patient number he ended up only on hormonal therapy. He was told that he would also benefit from radiotherapy. Prior to the diagnosis, MJ used to make bricks, but due to disease progression and side effects of the treatment which made his muscles weak, he could no longer afford to do strenuous activities. This made MJ feel *role-less*.

He had been in a supportive relationship with his wife for over 20 years and they had five children of which one was still in school.

**MJ's wife**. She reported that she took on the responsibility of taking care of the last child's school fees for which she admitted that it has not been easy because she only runs a small retail business as a source of income. she acknowledged that MJ occasionally feels lonely because of her work commitments. She also said that he has made attempts to talk to some men in his local area to go and test for the cancer.

### 4.3.9 SE

SE, 51 years old from central Uganda was diagnosed with prostate cancer in 2014, determined that he did not want to be left with impotency and incontinence as a result of surgery, he chose to go to India for radiotherapy and considers his story a *success story*. Upon return from India, he was started on hormonal therapy which he has been continuing with up-to-date. Although hormonal therapy affects his libido, he is at least glad that he can satisfy his sexual desires as a man. He encourages all men to test early because they can get better outcomes if diagnosed early. He is supported by his wife whom he has been with in a relationship for 10 years. He still works and is able to support his family.

### 4.3.10 RE

RE, 56 from central Uganda diagnosed with prostate cancer 6 years ago after an episode of bloody urine. This came as a shock since he had not had of anyone with such a disease in his family. He was started on hormonal therapy but was sad about the impact it had on his sexual life because he had not been briefed earlier. Although RE was in a relationship at the time of diagnosis, he did not receive the support he needed while undergoing treatment. The relationship deteriorated and later ended. He is now being supported by the sister.

### 4.3.11BA

BA is a 54-year-old man from central Uganda who was diagnosed 8 years ago at the age of 46 years. This was preceded by tests to ascertain why he was having recurrent UTIs. He was shocked when he learnt that he had cancer of prostate from the biopsy results he received from Nsambya Hospital. He then made a decision to go to Mulago hospital due to financial constraints.

While in Mulago Hospital, he was started on hormonal therapy and but was not informed of other treatment options and possible outcomes. Initially he experienced reduced sexual desires that troubled him so much that he opted to use herbal medicine to improve the situation and occasionally missed his appointments. Over time he has learnt to live with the condition and is grateful to the wife for having understood his condition. He says his condition brought the couple together.

**BA’s wife.** The wife says his husband spends most of his time at home and it has helped him bond with the family.

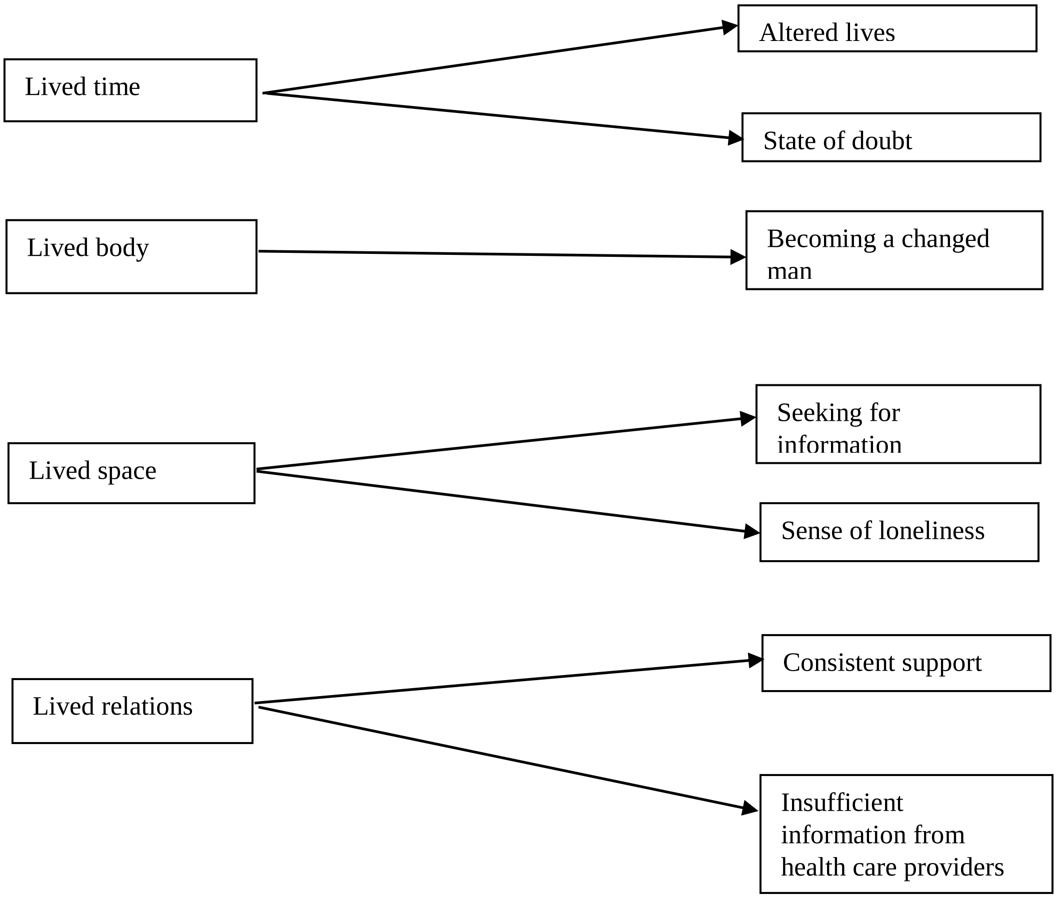
### 4.3.12 PQ

PQ, 60-year-old man from western Uganda who was diagnosed at the age of 55 years with prostate cancer from what was initially an enlarged prostate. He had been doing follow up blood tests from a urology clinic in Mbarara which showed features suggestive of prostate cancer. This was later confirmed by biopsy. He was always filled with un certainty each time he was coming for the test. He was started on hormonal therapy but since it was a private clinic he had financial constraints he requested to be referred to Mulago where he has continued receiving treatment up to date. He reported that at his age he is no longer bothered about sexual desire, what matters is that he is able to survive. PQ had been in loving relationship for 20 years and lost his wife 2 years after being diagnosed with the cancer. He is currently receiving care from his two sons although he occasionally feels lonely. He further says that he is positive about life that he will live long.

## 4.4 LIVED EXPERIENCES

The table illustrates the lived experiences that emerged from data collection and analysis. Data from each participant was processed and organized separately, later it was grouped together to form the experiences.

Table 2 lived experiences



To develop central and meaningful structures of the experience, the researcher used the four existensials: lived time, body, space, relations. The explanations with examples are presented.

### 4.4.1Lived time (temporality)

This is subjective time as opposed to objective time or clock time (van Manen, 1990). Lived time is time that appears to speed up when we are enjoying ourselves or slow down when we are experiencing a disinteresting situation.

### Altered lives

Following diagnosis, planned time was disrupted in terms of the things/achievements they looked forward to in the future.

> *[.....] I do not know how our children are going to stay in school because he is now sick therefore I have work harder (KG's wife).*

### State of doubt

Following treatment, time was perceived as being more unpredictable as men had to find their own way of living in the moment.

> *[.....] Each time I was going for the follow up blood tests I was scared of what the doctor would say, what will happen to me. After the diagnosis, I did not care about sexual desires what mattered was that that I am alive, and I have hope that I will live long. (PQ)*

PQ's example shows that as time passed by he came to terms with his condition and time took on more regularity than it had for many months and he became accustomed to living in the moment. Therefore, plans and life change according to the will of the ill body and what seemed to be important in the past loses its meaning when life is at stake.

### 4.4.2 Lived body (corporeality)

In this existensial, the researcher describes how participants perceived their bodies through their cancer journey and the limitations or demands that the cancer brought through one theme.

### Becoming a changed man.

Men described their bodily experiences from the symptoms they had prior to diagnosis to the changes they encountered while on treatment. Prostate cancer came as stumbling block in men's path. Participants presented with ''*bloody urine*, *urine retention, straining while urinating, back* *pain''* These symptoms disrupted the normal flow of life. Upon diagnosis participants were *'shocked'' ''surprised''* others were filled with *''fear''* with limited time for adjustment. The example of KJ illustrates how prostate cancer affected men's bodily experience of the world.

> *[....] I went to see a doctor because I had back pain which he attributed to my work and gave me medicine, however later I developed paralysis of the lower limbs and also the pain worsened that I could no longer help myself and that is when I realized that my health was at stake (KJ).*

For other men the illness became evident through the troublesome treatment side effects of *'' reduced libido, urine incontinence, muscle weakness.* BA's example explains how he struggled with the unnoticeable changes in his life.

> *[.....] When I started treatment, I realized my sex function was going down, so I used some herbal medicine, but it did not work, so I decided to stop going for treatment because I thought I would be better (BA).*

The examples illustrate a direct impact of the cancer on the physical body. It shows that we are bodily in our world although we may not be conscious of it. We only realize when we encounter pain or disability because health does not actually present itself to us.

### 4.4.3 Lived space (spatiality)

This is the existential theme that refers us to the world or landscape in which human beings move and find themselves at home. The space in which we find ourselves affects the way we feel, and we become the space we are in (van Manen, 1990). In this study, prostate cancer had a profound impact on men's lives and created much grief in response to the loss encountered. Prostate cancer caused interruptions and required adjustments to the unexpected changes in personal, professional and social life. Two themes arose:

### Seeking for information

Visiting doctors for follow up blood tests are part of the spectrum of living with prostate cancer which requires a supporting health care system and if not, well oriented life becomes overwhelming as MJ reports:

> *[….] Whenever we go to the hospital we always wait for long before we see the doctor and they are usually few and, in a hurry, so we don't get time to ask questions or even explain how we are feeling. We leave when we tired and frustrated. The government should help us (MJ).*

This shows that besides men with prostate cancer living with the impact of being chronically ill, they also have barriers to overcome in accessing health services.

### Sense of loneliness

The other difficult aspect of the disease that was portrayed was those times when men felt isolated and lonely as a result of living with this chronic illness. This was illustrated in SK and MJ's story

> *[…..] When I was diagnosed with the cancer I became weak and could not support my family, so my wife does most the work. Due to her work commitments I come for hospital appointments alone, I feel I am a burden (SK)*
>
> *[….] Due to her work commitments I sometimes stay home alone, and I find myself worrying a lot (MJ)*

### 4.4.4 Lived relations

Being relational means living in relation to others, in recognition of interconnectedness with others. Therefore, everything we do in relation to others and our world matters because our experience of the world includes and is dependent upon experience of the social world (Van Manen, 1997). As human beings we are part of the social network that is impossible to ignore therefore external actions have an effect on our lives especially our health. In this study, lived relations were expressed in two themes: consistent support and insufficient information from health workers.

### Consistent support

Majority of the men were grateful for the support they received from family. BA felt that, "*spending time with family is time well spent because they offer the greatest support*" during challenging experiences. Being supported by family made decision making easier. LG stated, "*My wife was very supportive. she helped me accept my sexual changes and I stopped missing my appointments*.'' Men felt that family should support the treatment decision and the couple should talk about the options together. All of the married men indicated that the most significant emotional and physical support was received from their spouse. This provided a sense of belonging. Two men reported that their relationships deteriorated after the diagnosis and this frustrated them the more.

### Insufficient information from health care workers

Sufficient information and communication with one's healthcare provider has a significant impact on the men's comfort level during their experience. However, in this study all men reported not to have received enough information from health care providers about their illness (duration, treatment options, and expected outcomes). This strained the doctor-patient relationship. More than one participant commented on how the physicians' shortage impacted on the waiting hours and delayed management and in so doing they lost trust in the healthcare system.

# CHAPTER FIVE

# DISCUSSION OF FINDINGS

## 5.1 Introduction

This chapter discusses the findings of the study in relation to the aims and objectives that were outlined at the outset. The findings will be discussed and simultaneously integrated with more recent or relevant literature in this section. Furthermore, limitations of the current study and recommendations for future research are presented.

## 5.2 Interaction with health care providers.

The findings suggest that upon hearing the cancer diagnosis, the men in this study experienced a defining moment. Participants described it as a shock that hits men and leaves them with uncertainty about the future. Others had already taken a step from an old life into a new life of challenging events. Some men heard what was being said by those around them, but could not take it in. This indicates that men needed more time to understand their illness and also to absorb the shock of the diagnosis before health workers could take them through the treatment options hence the need for follow-up appointment.

The findings further provided evidence that the diagnosis of a chronic illness like cancer involves a progression through the five stages of grief by Kubler-Ross (1969). The first stage being *denial;* it involves an unconscious refusal to accept the facts and in this study it is the confirmation of prostate cancer. It is usually associated with shock and lasts a few days though some people may be locked in it. The second stage is *anger* followed by *bargaining* where participants where asking *'why me'*. The fourth stage is *depression;* it involves sadness, fear and uncertainty. The last stage is acceptance which lasts several months.

All participants experienced fear/shock after the diagnosis but those who had ample time with the doctors accepted their diagnosis earlier than those who did not receive support. This brings out the fact that man is not an island and the concept of significant others (relationality) is important because in this study it helped participants to cope better with the condition. Thus, social and psychological health aspects are important.

From the study, no man had ever received voluntary screening. This is further evidenced by Nakandi, et al (2013) who found out that in Uganda, 85.7% of men had never been counseled by any physician to undergo screening for prostate cancer. In an attempt to increase on the awareness, relevant information sources such as media, internet and friends should be used. However, health workers have a role to play because as much as these different sources raise awareness at a time when a man is faced with different treatment options and side effects, they do not educate or inform them adequately (Walsh, 2010; Oliffe, et al., 2011; Kazer, et al., 2011a).

Following the diagnosis, men developed a heightened need for information about the illness for which health workers had an important role to play, however they felt that the healthcare system did not provide them with consistent information which caused desperation and loss of trust in the health care system. This is supported by Krumwiede, et al (2016) and King, et al (2015), where men expressed inconsistent care from the nurses and lack of understanding of the support received from health care workers in dealing with treatment side effects such as urinary incontinence and erectile dysfunction. Neukrug, et al (2013) attributed this to limited training of counselors in men’s issues such as erectile dysfunction, prostate cancer, and enlargement of the prostate. This calls for a heightened need to train health workers in men’s health issues so as to be able to provide accurate, complete and consistent information to enable patients determine appropriate treatment and prognosis of the illness (Potter, 2012; Mogotlane et al, 2015).

In the process of seeking care, participants encountered challenges such as the limited access to treatment because some drugs and blood tests were at a cost. They also encountered long waiting hours due to overwhelming numbers of patients in relation to the available doctors to attend to them. Therefore, the lived space that they found themselves in because of the illness created much grief. This calls for a need to recruit more health workers to provide a multidisciplinary approach to enable men cope with the illness (American Society of Clinical Oncology, 2015).

### 5.3 Experience with the treatment of prostate cancer: understanding the treatment given and impacts of treatment modalities on reproductive health.

All the twelve participants interviewed were on treatment and had received hormonal therapy. Only two participants had received surgery. This could be due to the fact that 60% of the men in Uganda present with advanced prostate cancer (Okuku, 2013) and hormonal therapy is the main stay of management in such cases. The late presentation is attributed to the low levels of awareness about the cancer.

At a point when men had accepted their status, new waves appeared, e.g. treatment side effects, problems with sexuality, a new awareness of the physical body, a feeling of being left alone and distress in the marital relationship. Men often spoke about their bodies before in comparison to what they are now especially since treatment had impacted on important domains of their lives. This reflected the subjective time. All the participants reported sexual dysfunction and a few reported urine incontinences. These were the main concerns confirmed to have had a serious impact on their lifestyles. The less visible bodily changes especially sexual dysfunction was brought into focus when men tried to fulfil their sexual desires and realized that they were unable to maintain an erection, this meant that they had to reveal themselves which exposed them to rejection, loss of intimate relationships and social withdraw. From this, men realized that one of the most important aspects of their lives that used to define them is now left in the past. In an attempt to preserve sexual function some men defaulted on treatment. Men who had urine incontinence always avoided public places due to the odor and leakage. Other least frequently mentioned changes were loss of muscle, body weakness and breast enlargement.

These findings are in agreement with literature which showed that incontinence and impotence are the most feared complications of prostate cancer and men were noted opting for inferior forms of treatment to preserve potency (Krumwiede, 2012: Salomo, 2016). Research has further showed that men are left with little control of urine which results in social isolation and embarrassment as consequences (Howlet, et al., 2010). The constant use of diapers and catheter is a constant reminder of the cancer which causes discomfort. These impacts express the life world as it was experienced in terms of lived body and space. Therefore, health care should not only be placed in biological context but also in the social context as well to enable cope with the disease.

Despite all the men in the study having been diagnosed at least one year ago, only a few reported having had ample time to discuss the treatment with the health care providers. This affected their commitment to treatment because they did not know what to expect from the treatment and when to stop so some men would hold treatment so as to improve their sexual function. This was supported by Barraclough (1994) who found out that when patients are not prepared they are unable to tolerate unwanted effects. Furthermore, men were dissatisfied with the treatment information they received on subsequent visits because it could not address their challenges thereby affecting disclosure, decision making and adherence. This is similar to findings from Salomo, (2015); Ervik, et al (2010); Galbraith, et al (2012) where health care professionals were reported not to communicate clearly the potential side effects of different treatment forms. This calls for a need for health workers to always provide sufficient information about the illness so as to facilitate informed decision making and adherence (Mogotlane, et al., 2015).

### 5.4 Support systems

Support means helping somebody who is facing a difficult time. ‘‘Support is perceived comfort, caring, esteem or help a person receives from other people’’ (Salomo, 2016). It is relevant especially when dealing with a chronic illness because it is a shared experience and patients desire to have social support. Support can come from a person’s friends, lover, family, health care provider and community. People who always receive it feel loved and valued.

From this study, out of the twelve men interviewed nine were still married and living with their long-time partners. They revealed that their partners were the greatest source of support. Participants who disclosed to their children received support from them while those who did not disclose to them never got their support. For this reason, men’s partners are looked at as anchors because they offer a sense of stability during difficult times (Fergus, 2011; Hagen, et al., 2011; Nanton and Dale, et al., 2011; Ervik, et al., 2010).

Men were noted disclosing to a few family members thereby limiting their support system. This placed a huge burden on the family’s shoulders. One of the main reasons for non-disclosure is maintenance of their masculinity thereby not appearing weak in front of anyone. This concurs with society’s expectation that men must be independent which leads to social isolation and not asking for help hence the non-disclosure (Walsh, 2010). This brings out the fact that environmental factors in our space where we live contribute to the support men seek and receive. Therefore, in preparation of dealing with men within the minority groups they have to be put into consideration.

It was further noted that due to sexual dysfunction and role reversal, the integrity of the family system suffered severe assault which led to some men separating from their partners. This is similar to what Ross and Deverell (2010) stated that previously strained marriages may collapse under the stresses of financial changes, medical costs, impaired communication and changes in family roles. These lived family relations portray the importance of social support on the quality of life of men.

From the study, it is evident that participants expected support from health workers but were frustrated because it was insufficient. They did not mention receiving care from health workers like counsellors and psychologists who are key in their journey, so this means many of their challenges like impotence, incontinence and other social issues were not addressed. This is supported by Krumwiede, et al (2016) and King, et al (2015), where men expressed inconsistent care from the nurses and lack of understanding of the support received from health care workers in dealing with treatment side effects such as urinary incontinence and erectile dysfunction.

Therefore, for health workers to respond adequately to the biological, psychological and social aspects of this cancer, there is need for a holistic approach putting into context the importance of all the four-life world existensials.

### 5.5 challenges experienced by participants

Through the life world existensials, the study brought forth the challenges faced by men below 55 years in the different aspects of health.

The main issues that were found challenging to men living with prostate cancer were broken down under lived body, lived relations and lived space in order to better understand the impact. The issues confirmed that their life before the diagnosis was different from their present life.

#### Lived time

Men in the study suffered emotional pain after the diagnosis which affected their emotional well-being. They were in shock, took steps into a new life of challenging events thereby expressing fear and uncertainty about the future. This was similar to findings from Galbraith et al (2011) that the diagnosis of prostate cancer has an emotional impact on the health of these men.

Despite all the pain, the participants never wanted their partners to know. This confirms that culturally speaking men do not want to be perceived as weak they want to maintain their masculinity. Therefore, in addressing health issues intercultural competence is required to better understand the concept of living with prostate cancer because culture is part of the space we live in.

#### Lived body

Participants experienced pain in the lower back and some of them found it had to even walk especially before starting treatment. They also reported urine retention and incontinence, to some of them that was the reason for seeking treatment.

The physical impact of prostate cancer results mainly from treatment rather than the disease itself. They experience pain, discomfort and lower urinary tract symptoms (Howlet, et al., 2010). Less visible bodily changes were also brought into focus like chronic pain which usually arises from bone especially lower back due to metastases (Nettina, 2014). It is prevalent and affects about 75% of patients with advanced cancer (Holland, et al., 2010). It also arises from nerve damage, which makes it difficult to control and this leads to distress, insomnia and difficulty walking. During the interviews some men expressed difficulty walking due to pain in the lower back, which made them depressed because they were unable to walk freely like they used to. This made some to view it as a punishment and others as a progression to death. This is in agreement with Holland, et al (2010) who reported that patients with pain are more depressed and anxious than those without pain.

Men also experienced incontinence and this was supported by Salomo (2016). Men overcame this problem by use of pampers and when they developed pain around the catheter they would visit the health worker, and have it changed, although they always wanted it to be removed due to fear of leaking urine and pain. This in agreement with Holland, et al (2010) that men develop a feeling of humiliation due to leakage of urine and constant use of diapers.

This further shows that prostate cancer and its treatment has significant impact on the physical aspect of health hence the need for a holistic approach.

Sexual life is of great importance to married men and thus sexual dysfunction (loss of libido, erection, dry orgasms) emerged several times during the discussions. From the study, all participants were worried about sexual life. They felt incomplete whenever they were unable to fulfil their husband duties, and this affected their adherence to hormonal therapy. Some men felt shy and when asked about their sexual life, they were seen smiling before giving any response.

During the discussion, the researcher observed from the facial expressions of these men that the change in sexual life impacted greatly on the lives of these men. The changes that occur in the sexual lives of these men either due to cancer or the treatment itself is supported by literature and that it may be irreversible (Krumwiede, 2012). The fear of these changes in sexual function affects men’s decision making in terms of treatment and screening.

Other studies show that men who have undergone prostatectomy experienced loss of function, reduced libido and urinary incontinence. Those who underwent hormonal therapy developed reduced libido which was an advantage for some men. However, for others it caused humiliation and shame because they had lost an integral part of themselves. This explains the reluctance of some men to undergo certain procedures (Galbraith et al., 2011).

This study also revealed that some participants had not discussed their sexual issues with their partners and some had opted to use herbal medicine in order to maintain their masculinity. This was so because of their age where sexual performance is key to their lives. This is similar to findings from Alemazoffar, et al (2011) where men reported use of sexual enhancing regimens to boost their sexual performance.

Sex issues are difficult to communicate because they are associated with embarrassment. The strained communication decreases physical intimacy making couples vulnerable to distress (Salomo, 2016).

From the study, prostate cancer ended the sexual life of some of these participants. It made them realize that an important part of their identity which used to define them had been left to their past thereby defining their lived body and space. Furthermore, the wives and participants were not given this information prior to treatment. Since prostate cancer is a reproductive health cancer, it did not only affect the participants but also their relationships with their wives (lived relations) hence the need to always involve partners in decision making.

### Lived space

Participants' encountered financial challenges as majority were non- employed and did not have medical aid schemes/ insurance. In addition, some services like investigations and treatment were not available and had to be outsourced at a cost. Therefore, participants were strained in terms of travel costs, diet, some medical tests and treatment. Furthermore, they had to meet expenses at home like school fees, family medical costs, and food among others. For those that were working challenges were not as grave as for those that were non-employed. For those non-employed it was uncovered that their wives were either peasant farmers, housewives or small/medium entrepreneurs which put a double strain on the family. For the working partners they had to take on the responsibilities that were initially for their husbands and children were also noted to come in and support financially.

It is therefore evident that living with prostate cancer poses a lot of financial burden to the family. This is supported by Tanner et al (2011) where he found out that partners of men living with prostate cancer had challenges to deal with hence the role reversal. This reveals that the impact of prostate cancer extends beyond the corporeal experience of the disease.

Men experienced challenges with the health care system such as the long waiting hours, few health workers, insufficient information which made them frustrated thereby losing trust in the health care system.

**Lived relations**

As mentioned earlier, the diagnosis of prostate cancer affects the significant others, it affects the integrity of the family system. There is role reversal where the husband is no longer the dominant family figure, instead the wife takes on the responsibility (Ross and Deverall, 2010). As much as this brought some couples together, others agreed that they had challenges in their marriages ranging from financial, sexual to communication issues which strained them. This is supported by Ross and Deverall (2010) that previously strained marriages may collapse due to financial, sexual and communication challenges. This calls for a need to sufficiently prepare couples for the dysfunction that may occur in their sex lives to ensure that their expectations are realistically managed.

## 5.6 Conclusions

It was concluded that prostate cancer not only affects the physical health but also the social life and relationships of the men living with prostate cancer. It affects sexual life, communication and causes a financial burden. It causes relationships to break down especially for those that were already strained.

Gender and cultural values were also noted to be external factors affecting decision making and disclosure of men living with prostate cancer. Men tend to keep certain health matters to themselves because they associate them with less masculinity.

Treatment options at Uganda cancer institute are limited especially for those presenting with advanced prostate cancer and are associated with mainly sexual dysfunction and urinary incontinence which affects the social life of these men.

Support systems for men living with prostate cancer are limited due to non –disclosure. They receive support from mainly wives, children, a few relatives and close friends.

It is therefore concluded that prostate cancer in men below 55 years is associated with several health issues, yet it is given less attention, men are suffering in silence and if left unattended to it will continue causing pain and suffering to the entire family system.

Below are the recommendations.

## 5.7 Recommendations

The researcher recommends the following basing on the above conclusions.

### 5.7.1 Increase availability of Resources

The government should improve on the allocation of resources into men’s health in all facilities, both public and private such as medicines, doctors, counsellors, cancer nurses.

The health team should improve on advocacy to increase on collaboration with NGOs which will increase on the availability of resources for management of prostate cancer thereby improving the quality of life of these men.

### 5.7.2 Prostate cancer health education

Basing on the increasing burden of prostate cancer, prevention other than treatment is key, therefore health education in terms of awareness campaigns should be conducted so that even the illiterate can know about this cancer thereby addressing the inadequate knowledge. It will also help reduce on the non-disclosure rate plus the influence of the cultural and gender issues that hinder health seeking in men.

### 5.7.3 Voluntary prostate cancer screening

There is need to encourage voluntary screening to reduce on the incidence of advanced prostate cancer through setting up mobile clinics both in rural and urban areas. This will encourage regular check –ups for men above 40 years hence early detection and treatment.

### 5.7.4 Setting up prostate cancer support groups

Since prostate cancer affects the entire family system, it is necessary to have both individual counselling and support group sessions to address the needs of these men. It also helps the family better understand the condition and develop coping strategies.

In a nut shell oncology is not only about knowledge of the disease and treatment, it includes the significant others who affected by the disease, therefore a multidisciplinary team approach including a reproductive health specialist is necessary to be able to address the psychosocial aspects of this disease.

## 5.8 Suggestions for further research

Further research is needed in the following areas

- Experiences of health workers in managing men with prostate cancer
- Relationship between prostate cancer and disclosure/non-disclosure

It would be necessary to expand the study to involve prostate cancer patients receiving health care in private hospitals so as to generate several views and recommendations to address the challenges.

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# APPENDICES

## Appendix I : Stages of grief

Table 3 showing EKR staging and interpretation

| EKR STAGE | INTERPRETATION |
|---|---|
| Denial | Denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. It's a defence mechanism and perfectly natural. Some people can become locked in this stage when dealing with a traumatic change that can be ignored. |
| Anger | Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Knowing this helps keep detached and non-judgemental when experiencing the anger of someone who is very upset. |
| Bargaining | Traditionally the bargaining stage for people facing death can involve attempting to bargain with whatever God the person believes in. People facing less serious trauma can bargain or seek to negotiate a compromise. For example "Can we still be friends?.." when facing a break-up. Bargaining rarely provides a sustainable solution, especially if it's a matter of life or death. |
| Depression | Also referred to as preparatory grieving. In a way it's the dress rehearsal or the practice run for the 'aftermath' although this stage means different things depending on whom it involves. It's a sort of acceptance with emotional attachment. It's natural to feel sadness and regret, fear, uncertainty, etc. It shows that the person has at least begun to accept the reality. |
| Acceptance | Again, this stage definitely varies according to the person's situation, although broadly it is an indication that there is some emotional detachment and objectivity. People dying can enter this stage a long time before the people they leave behind, who must necessarily pass through their own individual stages of dealing with the grief. |

## Appendix II : prostate cancer staging

Table 4: showing TNM staging for prostate cancer

| **Staging** | **Description** |
|---|---|
| TX | Main cancer (primary) cannot be assessed |
| T0 | No sign of cancer |
| T1 | Means cancer is too small to be seen on scan, or felt during examination of the prostate. It is divided into T1a, T1b, T1c. |
| T1a | Found on surgery unexpectedly and cancer is <5% of removed tissue. |
| T1b | Cancer is more than 5% of removed tissue. |
| T1c | Cancer found beyond the biopsy for example in raised PSA levels |
| T2 | Means cancer is completely inside the prostate gland. It is divided into; T2a,T2b,T2c. |
| T2a | Means cancer is only in only half of one side of the gland |
| T2b | Means cancer is in more than half of one side of the gland. |
| T2c | Means cancer is in both sides but still inside the prostate gland |
| T3 | Means cancer has broken through the capsule of the prostate gland. It is divided into T3a, T3b. |
| T3a | Cancer has broken through the capsule of the prostate gland |
| T3b | Means cancer has spread into the tubes that carry semen (seminal vesicles). |
| T4 | Cancer has spread into other body organs such as bladder, pelvic wall. |
| NX | Means lymph nodes cannot be assessed |
| N0 | Means nearby lymph nodes do not contain cancer |

| | |
|---|---|
| | cells. |
| N1 | Means their cancer cells in nodes near the prostate. |
| M0 | Means the cancer has not spread to other organs |
| M1 | Means cancer has spread to other parts of the body outside the pelvis. It is divided into M1a, M1b and M1c. |
| M1a | Means there are cancer cells in lymph nodes outside the pelvis. |
| M1b | Means there cancer cells in the bone |
| M1c | Means there are cancer cells in other places |

(Adopted from Cancer Research UK, 2017)

## Appendix III : treatment of prostate cancer and side effects

Table 5 showing prostate cancer treatment options and side effects

| Treatment | Brief description | Possible side effects |
|---|---|---|
| Radical prostatectomy | Removal of the prostate gland | Erectile dysfunction, urinary incontinence, infertility |
| Hormonal therapy | Injections or Tablets are given to reduce the level of testosterone. Also orchiectomy where the testes are removed can be carried out. | Bone thinning, mood changes, loss of libido, breast swellings, hot flushes, muscle loss |
| brachytherapy | Radioactive seeds are inserted into the tumor. It can be used hand in hand with external beam radiotherapy | Diarrhea, urinary incontinence |
| chemotherapy | Drugs are given intravenously to kill the cancer cells or shrink the tumor | Hair loss, peripheral neuropathy, mood changes, fluid retention, nausea and vomiting. |
| cryotherapy | Cancer cells are killed using freezing method. | Erectile dysfunction, urinary incontinence |

Adopted from prostate cancer UK, 2016

## Appendix IV: Participant information sheet for men below 55 years

### Title of the proposed study

Lived Reproductive Life Experiences of Men Below 55years With Prostate Cancer at Uganda Cancer Institute.

**Researcher:** Nabisubi Prossy a master's student at Uganda martyr's university Nkozi

**Academic supervisor;** Vivienne Liang, lecturer Uganda Martyr's University Nkozi

**1.0 Introduction:** This study is being conducted in partial fulfillment of the requirements of master's Degree in Public Health-population and reproductive health at Uganda Martyrs University Nkozi. You are therefore being requested to take part in this study. This consent form gives you information about the research.

**2.0 Purpose of the study:** The purpose of this study is to describe the lived reproductive life experiences of men below 55 years with prostate cancer in Uganda. This research seeks to find out how this cancer has affected men in Uganda and whether there are any issues in particular that they have found challenging.

**3.0 What will be done when you accept to participate in this study:** In case you have agreed to take part in this study, about two separate face-to face interviews will be conducted at a mutually convenient place and will proceed at your pace. With your consent I will start by obtaining some identifying information such as age, duration of cancer and treatment received then the interview will carry on as I audio-record to avoid missing out vital information. You are here by being requested to permit me to audio-record this discussion. This interview can continue until you have no more information to give.

**4.0 Benefits:** There are no direct benefits for you from this study. The information gathered from this research will be used by health care workers and the Government of Uganda to generate strategies for improving health care for men with prostate cancer.

**5.0 Risks/Discomforts:** There will be no probability of physical harm because the study does not involve invasive procedures. However emotional/psychological harm may occur when you remember distressing issues. Also, total confidentiality cannot be guaranteed but measures will be taken to minimize the risk.

**6.0 Confidentiality:** All interviews will be recorded, and the audio-recorder will be kept in a closed place with restricted access. Audio recordings will be deleted at the end of the study and your identifiers will not appear on any reports.

**7.0 Voluntariness:** you are free to participate or not to and even if you refuse to participate you will continue receiving care. You are also free to withdrawal from the interview at any point if you wish to. If during the interview you remember something distressing, the interview will be stopped and can only be resumed when you are ready to start.

If you have questions/ queries about this study, please contact:

Dr. Nabisubi prossy on: +256777542184, +256703170382
Principle investigator
Dr. kyaddondo David on: +256 772410806
Chairperson UCIREC.

**Statement of consent**

I confirm that I have read the participants information sheet. I have had enough time to ask questions and also to think about whether to be interviewed or not. I agree that taking part in this interview is voluntary and that I can withdrawal at any time of the interview without giving a reason. I accept to be audio- recorded and that I can pause the audio-recording at any time of the interview~~.~~ I also understand that the information will be kept confidential and none of my identifiers will appear on any form of transcription.

I accept to be interviewed as part of the above study and also that I can be re- interviewed but am under no obligation to accept any further interviews and I do not have to give a reason as to why I have refused.

| | | |
|---|---|---|
| ______________________ | ______________________ | ____ |
| Name of the participant | participants signature | Date |
| ______________________ | ______________________ | ____ |
| Name of witness | witness’s signature | Date |
| ______________________ | ______________________ | ____ |
| Name of person obtaining consent | signature of person obtaining consent | Date |

## Appendix V: Participant information sheet for care givers.

**Title of proposed study:**

Lived Reproductive Life Experiences of Men below 55 years with Prostate Cancer at Uganda Cancer Institute.

**Researcher:** Nabisubi Prossy a master's student at Uganda martyr's university Nkozi.

**Academic supervisor;** Vivienne Laing, lecturer Uganda Martyrs University Nkozi

1.0 **Introduction:** This study is being conducted in partial fulfillment of the requirements of master's Degree in Public Health-Population and Reproductive Health at Uganda Martyrs University Nkozi. You are therefore being requested to take part in this study. This consent form gives you information about the research.

2.0 **Purpose of the study:** The purpose of this study is to describe the lived Reproductive life experiences of men below 55 years with prostate cancer in Uganda. This research seeks to find out how this cancer has affected men in Uganda and whether there are any issues in particular that they have found challenging.

**3.0 What will be done when you accept to participate in the study**: In case you have agreed to take part in this study, about two separate face-to face interviews will be conducted at a mutually convenient place. With your consent I will start by obtaining some identifying information such as age, relationship with patient and duration of care then the interview will carry on as I audio record to avoid missing out vital information. You are hereby being requested to permit me to audio-record this discussion. The interviews can continue until you have no more information to give.

**4.0 Benefits:** There are no direct benefits for you from this study. The information gathered from this research will be used by health care workers and the Government of Uganda to generate strategies for improving health care for men with advanced prostate cancer.

**5.0 Risks/Discomforts:** There will be no probability of physical harm because the study does not involve invasive procedures. However emotional/psychological harm may occur when you remember distressing issues. Also, total confidentiality cannot be guaranteed but measures will be taken to minimize the risk.

**6.0 Confidentiality:** All interviews will be recorded, and the audio recorder will be kept in a closed place with restricted access. Audio recordings will be deleted at the end of the study and your identifiers will not appear on any reports.

**7'0 Voluntariness:** you are free to participate or not to and even if you refuse to participate you will continue receiving care. You are also free to withdrawal from the interview at any point if you wish to. If during the interview you remember something distressing, the interview will be stopped and can only be resumed when you are ready to start.

If you have questions/ queries about this study, please contact:

Dr. Nabisubi prossy on: +256777542184, +256703170382
Principle investigator
Dr. kyaddondo David on: +256 772410806
Chairperson UCIREC.

**Statement of consent**

I confirm that I have read the participants information sheet. I have had enough time to ask questions and also to think about whether to be interviewed or not. I agree that taking part in this interview is voluntary and that I can withdrawal at any time of the interview without giving a reason. I accept to be audio- recorded and that I can pause the audio-recording at any time of the interview~~.~~ I also understand that the information will be kept confidential and none of my identifiers will appear on any form of transcription.

I voluntarily accept to participate in this study.

| | | |
|---|---|---|
| ______________________ | ______________________ | ____ |
| Name of the participant | participants signature | Date |
| ______________________ | ______________________ | ____ |
| Name of witness | witness's signature | Date |
| ______________________ | ______________________ | ____ |
| Name of person obtaining consent | signature of person obtaining consent | Date |

## Appendix VI : Bracketing statement

In this statement I declare what I knew about this area of study both from an academic and personal experience. This statement is not meant to make me forget what I know about this area of study but to use it as a reference so that I present the participants experiences not mine.

### Academic experience

My knowledge about men diagnosed and living with prostate cancer from the literature was limited about the topic. From the reviewed papers I got the impression that prostate cancer is more in Africans because most papers showed that men of African descent in other countries had the highest prevalence and also that sexuality affects decision making because it is an integral part of men.

### Personal experience

Being some medical personnel, I have knowledge about prostate cancer as a disease but my knowledge about living with prostate cancer especially in men below 55years is limited. My being part of the medical fraternity has given me an opportunity to have physical several encounters with men who have prostate cancer but all the men that I have encountered are above 55 years of age, so I have not yet had an opportunity of encountering a man who is below 55 years with prostate cancer. And even for those above 55 years that I have diagnosed, I have not followed them up to know what happens in their social lives and how they cope with the disease. So, I would say that I know this disease, its presentation, treatment options and possible side effects but in terms what psychosocial implications it has on men’s lives and how they cope I am naïve.

## Appendix VII: Interview guide for men below 55 years with prostate cancer

Questions

- Tell me about what it was like for you on that day you were told you had prostate cancer?
- How was your encounter with the healthcare professionals?
- How has prostate cancer affected your life?
- How have your relatives and friends been affected?
- How has your outlook on life been affected?

## Appendix VIII: Interview guide for care givers.

- Tell me how (name) life has changed from the time he was diagnosed with prostate cancer
- How has (name) illness affected your family?

## Appendix IX:Ebinaagobererwa mu kubuuzibwa abajjanjabi

Ebibuzo

- Mbuliira engeri obulamu bwa (erinnya) gyebukyusemu okuva lwebamugamba nti ayina kokolo wa katungulu k'obusajja.
- Okulwala kwa (erinya) kukoseza kutya amaka gamwe?

## Appendix X: Examples of probes (Rubin, 2005)

Table 6 showing the types of probe

| TYPE OF PROBE | EXAMPLE |
|---|---|
| Continuation probes | “Mmm hmm.so…….’<br>“Then what….”<br>“And ….” |
| Slant probes | How do you feel about?<br>Describe how that felt |
| Evidence probes | “Can you give me an example”<br>“Are there specific instances when this happened?’ |
| Attention probes | “Ok I understand”<br>“That’s interesting” |
| Sequence probes | “Could you tell me what happened step by step’<br>“When did this happen?” |
| Elaboration probes | “Such as?”<br>“Can you give me an example?”<br>“Can you tell me more about that?” |
| Clarification probes | “Can you run that by me again”<br>“Can you explain that to me again in a bit more detail?” |

## Appendix XI: Reflection extracts

My first day of data collection, I arrive at the cancer institute very early, a little nervous, not sure of what the day will be like. Asking myself a few questions; will I get participants? Will they be willing to participate in the study? Will the staffs be friendly to me? It is 8am my contact person has not arrived, thinking whether I should call her or not to find out what time she will be arriving. I phoned her, she was calm and informed me that she will arrive at 9am.

I met [doctor's name] the one who attends to prostate cancer patients, was afraid to talk to him, became nervous but I stood up and introduced myself, he read through my introductory letter and was surprised that I was doing that research in relation to reproductive health, he told me it is more of surgery but he gave me a go ahead and wished me luck. I was not surprised by his thinking of it as a surgical discipline; it showed me that health workers do not care about the psychosocial impacts of this condition.

[Patient's name] was very receptive. Since he had waited for long in the queue before seeing a doctor I thought he would not want to be delayed any longer. So, I was not expecting a detailed conversation. I kept thinking; won't he let out his anger on me? We talked; surprisingly he was happy for having shared his experience with me. He was open about his sex life. I was afraid that he will not open up because of my age that he will not feel comfortable talking to someone who is like a daughter to him about such issues. Instead it is me who felt a bit ashamed hearing such issues, but I was glad that somebody was helping me get a glimpse of the world I will never be a part of. After the interview I kept thinking of how much men value their sexual function, they are willing to let go of so much for them to retain sexual activity. Yet it is something I do not value that much.

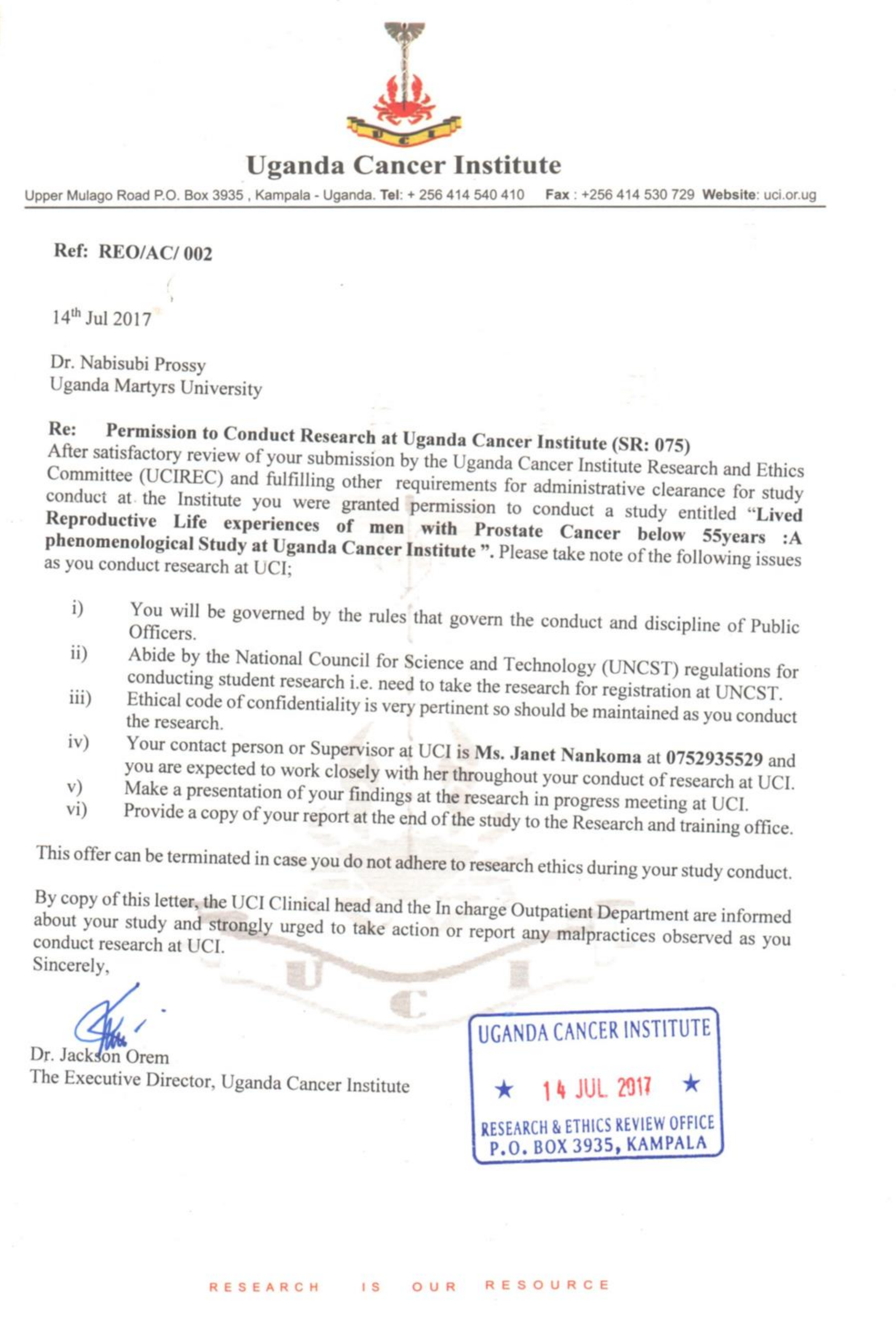
## Appendix XII: Plan for data collection

| Activity | Time frame | Person responsible |
|---|---|---|
| Designing tools | 01/January/2017 to 14th /January/2017 | Principal investigator |
| Pretesting tools | 03rd /March/2017 to 5th /March/2017 | Principal investigator |
| Data collection and cleaning | 1ST /June/2017 to 30th /June/2017 | Principal investigator |
| Analysis | 1st /July/2017 to 15th /July/2017 | Principal investigator |
| Report writing by principle investigator. | 15th /July/2017 to 22nd /July/2017 | Principal investigator |
| Report reviews and comments | 1st /August/2017 to 30th /August/2017 | Vivienne Laing (supervisor) |
| Presentation of results | 2nd /October/2017 to 5th/October/2017 | Principal investigator |
| Dissemination of results | | Principal investigator |

## Appendix XIII: Budget

| Activity/item | Quantity | Unit cost | Cost (shillings) | Source of funding |
|---|---|---|---|---|
| UCIREC fees | 1 | 180,000 | 180,000 | Principal investigator |
| Transport | 60 trips | 5,000 | 300,000 | Principal investigator |
| Stationary | 3 reams of papers.<br>1 box of pens<br>1 laptop | 15,000<br>5,000<br>1, 200,000 | 1,250,000 | Principal investigator |
| Printing and binding | 6 copies of the proposal<br>3 copies of the dissertation | 20,000<br>40,000 | 240,000 | Principal investigator |
| Airtime | 1000 minutes monthly | 30,000 | 300,000 | Principal investigator |
| Food | 2 meals /day | 5,000 | 300,000 | Principal investigator |
| Total | | | 2,570,000 | |

## Appendix X1V: Permission letter from UCIREC to conduct research at UCI



**Uganda Cancer Institute**
Upper Mulago Road P.O. Box 3935 , Kampala - Uganda. **Tel:** + 256 414 540 410 **Fax** : +256 414 530 729 **Website**: uci.or.ug

**Ref: REO/AC/ 002**

14th Jul 2017

Dr. Nabisubi Prossy
Uganda Martyrs University

**Re: Permission to Conduct Research at Uganda Cancer Institute (SR: 075)**

After satisfactory review of your submission by the Uganda Cancer Institute Research and Ethics Committee (UCIREC) and fulfilling other requirements for administrative clearance for study conduct at the Institute you were granted permission to conduct a study entitled "**Lived Reproductive Life experiences of men with Prostate Cancer below 55years :A phenomenological Study at Uganda Cancer Institute ".** Please take note of the following issues as you conduct research at UCI;

i) You will be governed by the rules that govern the conduct and discipline of Public Officers.
ii) Abide by the National Council for Science and Technology (UNCST) regulations for conducting student research i.e. need to take the research for registration at UNCST.
iii) Ethical code of confidentiality is very pertinent so should be maintained as you conduct the research.
iv) Your contact person or Supervisor at UCI is **Ms. Janet Nankoma** at **0752935529** and you are expected to work closely with her throughout your conduct of research at UCI.
v) Make a presentation of your findings at the research in progress meeting at UCI.
vi) Provide a copy of your report at the end of the study to the Research and training office.

This offer can be terminated in case you do not adhere to research ethics during your study conduct.

By copy of this letter, the UCI Clinical head and the In charge Outpatient Department are informed about your study and strongly urged to take action or report any malpractices observed as you conduct research at UCI.

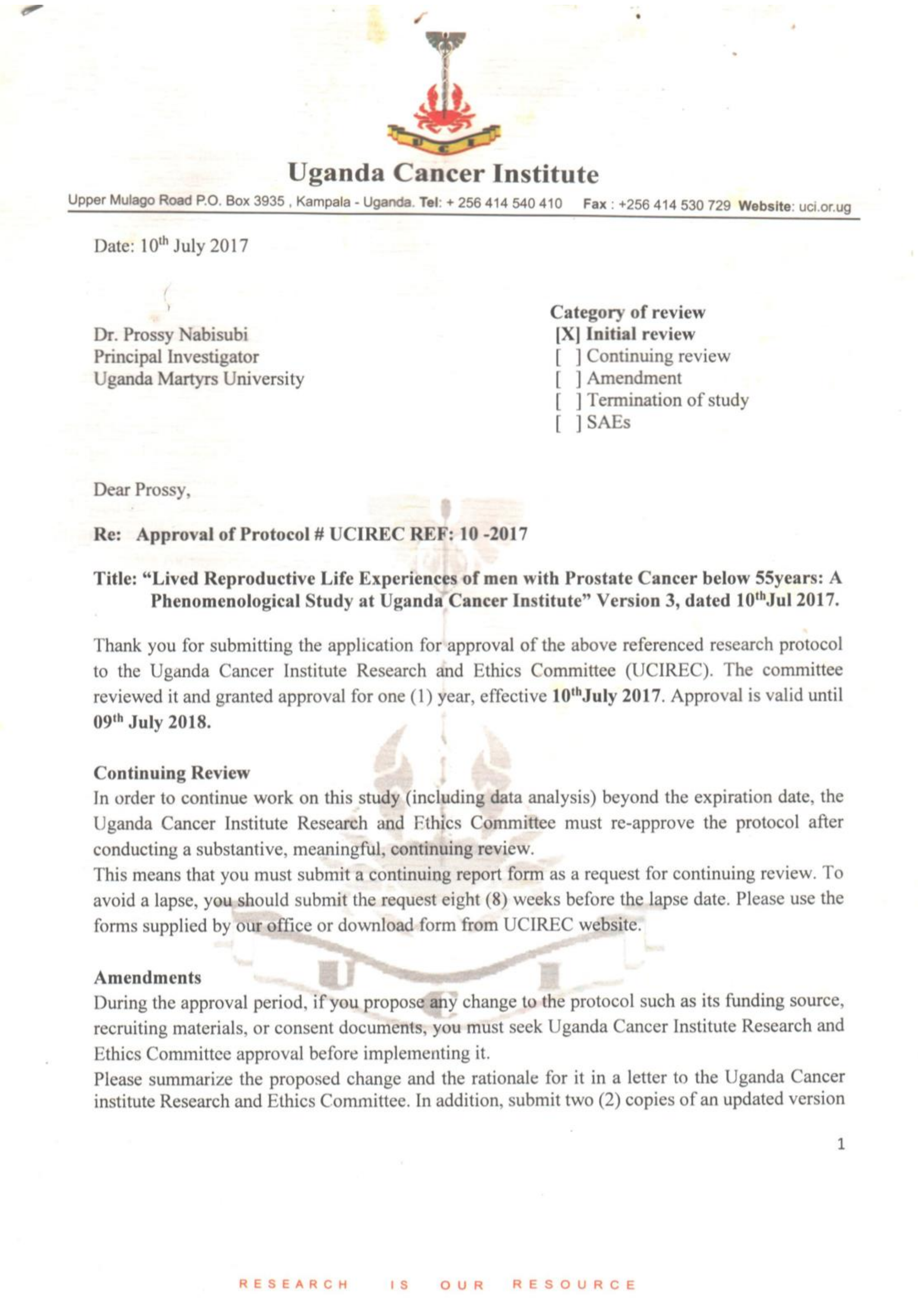
Sincerely,

Dr. Jackson Orem
The Executive Director, Uganda Cancer Institute

UGANDA CANCER INSTITUTE
★ 14 JUL 2017 ★
RESEARCH & ETHICS REVIEW OFFICE
P.O. BOX 3935, KAMPALA

RESEARCH IS OUR RESOURCE

## Appendix XV: Letter of protocol approval from UCIREC



**Uganda Cancer Institute**
Upper Mulago Road P.O. Box 3935 , Kampala - Uganda. **Tel:** + 256 414 540 410 **Fax** : +256 414 530 729 **Website**: uci.or.ug

Date: 10th July 2017

Dr. Prossy Nabisubi
Principal Investigator
Uganda Martyrs University

**Category of review**
**[X] Initial review**
[ ] Continuing review
[ ] Amendment
[ ] Termination of study
[ ] SAEs

Dear Prossy,

**Re: Approval of Protocol # UCIREC REF: 10 -2017**

**Title: "Lived Reproductive Life Experiences of men with Prostate Cancer below 55years: A Phenomenological Study at Uganda Cancer Institute" Version 3, dated 10thJul 2017.**

Thank you for submitting the application for approval of the above referenced research protocol to the Uganda Cancer Institute Research and Ethics Committee (UCIREC). The committee reviewed it and granted approval for one (1) year, effective **10thJuly 2017**. Approval is valid until **09th July 2018.**

**Continuing Review**

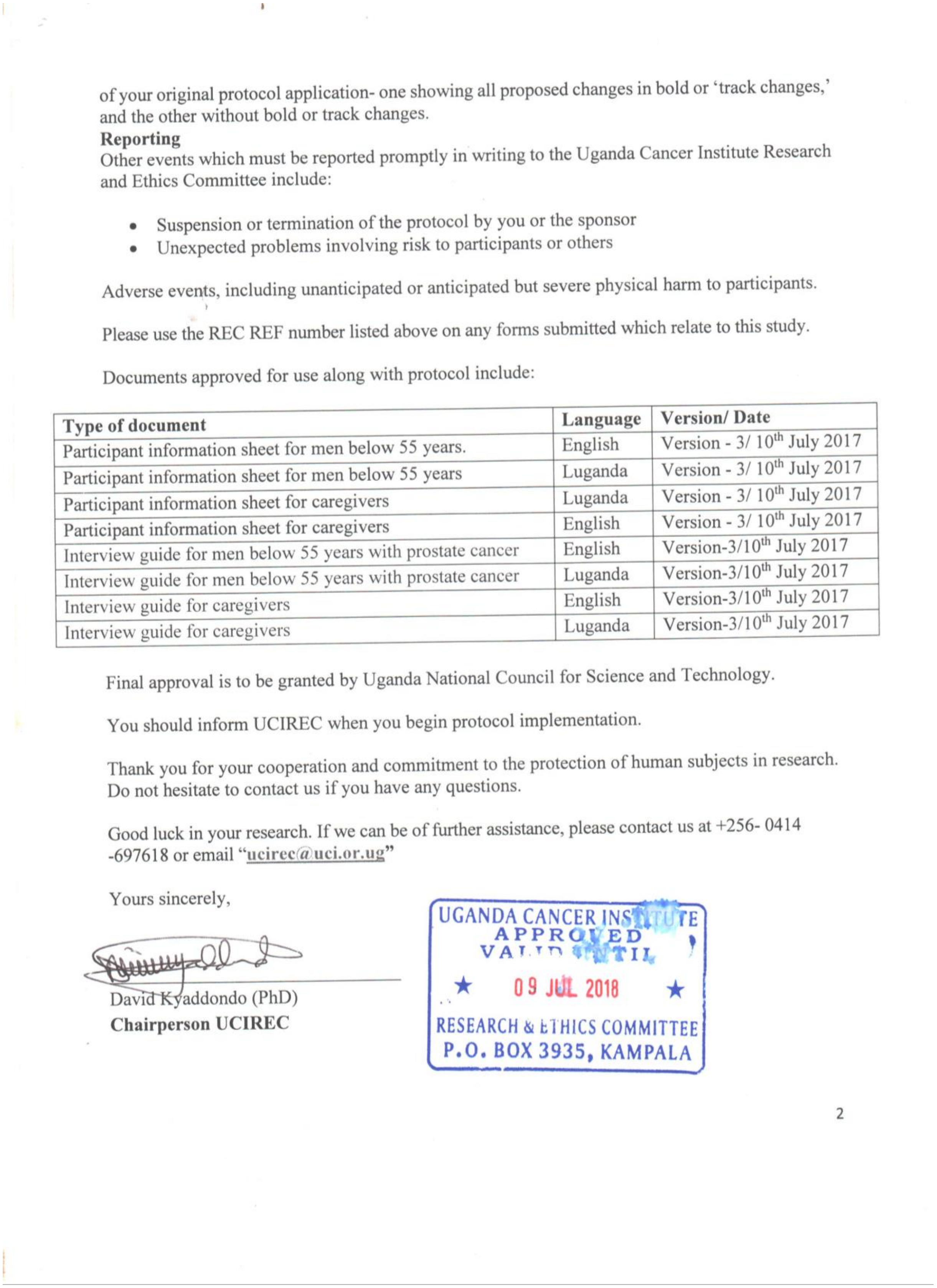
In order to continue work on this study (including data analysis) beyond the expiration date, the Uganda Cancer Institute Research and Ethics Committee must re-approve the protocol after conducting a substantive, meaningful, continuing review.

This means that you must submit a continuing report form as a request for continuing review. To avoid a lapse, you should submit the request eight (8) weeks before the lapse date. Please use the forms supplied by our office or download form from UCIREC website.

**Amendments**

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek Uganda Cancer Institute Research and Ethics Committee approval before implementing it.

Please summarize the proposed change and the rationale for it in a letter to the Uganda Cancer institute Research and Ethics Committee. In addition, submit two (2) copies of an updated version



of your original protocol application- one showing all proposed changes in bold or 'track changes,' and the other without bold or track changes.

**Reporting**

Other events which must be reported promptly in writing to the Uganda Cancer Institute Research and Ethics Committee include:

- Suspension or termination of the protocol by you or the sponsor
- Unexpected problems involving risk to participants or others

Adverse events, including unanticipated or anticipated but severe physical harm to participants.

Please use the REC REF number listed above on any forms submitted which relate to this study.

Documents approved for use along with protocol include:

| **Type of document** | **Language** | **Version/ Date** |
|---|---|---|
| Participant information sheet for men below 55 years. | English | Version - 3/ 10th July 2017 |
| Participant information sheet for men below 55 years | Luganda | Version - 3/ 10th July 2017 |
| Participant information sheet for caregivers | Luganda | Version - 3/ 10th July 2017 |
| Participant information sheet for caregivers | English | Version - 3/ 10th July 2017 |
| Interview guide for men below 55 years with prostate cancer | English | Version-3/10th July 2017 |
| Interview guide for men below 55 years with prostate cancer | Luganda | Version-3/10th July 2017 |
| Interview guide for caregivers | English | Version-3/10th July 2017 |
| Interview guide for caregivers | Luganda | Version-3/10th July 2017 |

Final approval is to be granted by Uganda National Council for Science and Technology.

You should inform UCIREC when you begin protocol implementation.

Thank you for your cooperation and commitment to the protection of human subjects in research. Do not hesitate to contact us if you have any questions.

Good luck in your research. If we can be of further assistance, please contact us at +256- 0414 -697618 or email "**ucirec@uci.or.ug**"

Yours sincerely,

David Kyaddondo (PhD)
**Chairperson UCIREC**

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09 JUL 2018
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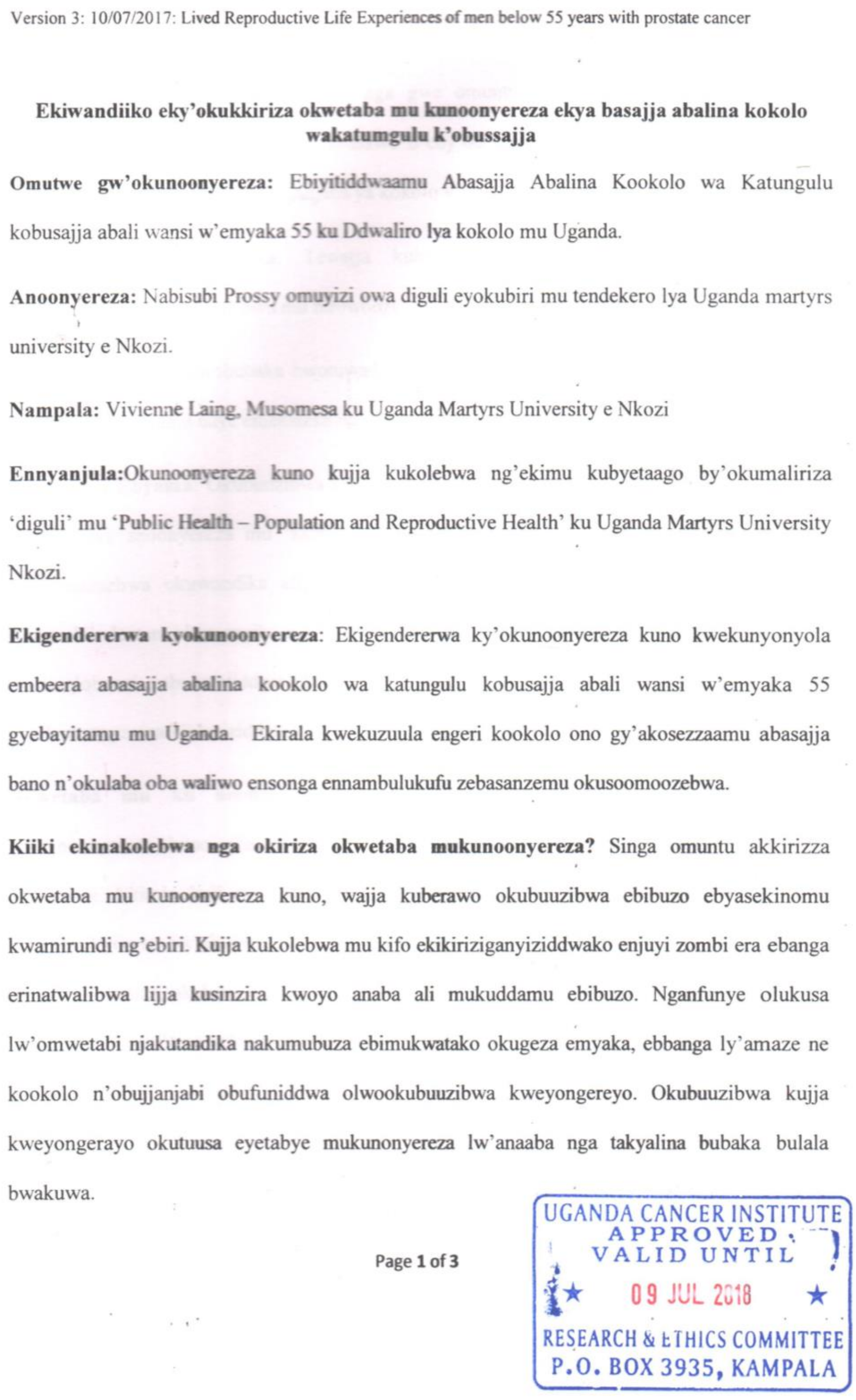
## Appendix XVI: Approved informed consent translated to Luganda



Version 3: 10/07/2017: Lived Reproductive Life Experiences of men below 55 years with prostate cancer

### Ekiwandiiko eky'okukkiriza okwetaba mu kunoonyereza ekya basajja abalina kokolo wakatumgulu k'obussajja

**Omutwe gw'okunoonyereza:** Ebiyitiddwaamu Abasajja Abalina Kookolo wa Katungulu kobusajja abali wansi w'emyaka 55 ku Ddwaliro lya kokolo mu Uganda.

**Anoonyereza:** Nabisubi Prossy omuyizi owa diguli eyokubiri mu tendekero lya Uganda martyrs university e Nkozi.

**Nampala:** Vivienne Laing, Musomesa ku Uganda Martyrs University e Nkozi

**Ennyanjula:**Okunoonyereza kuno kujja kukolebwa ng'ekimu kubyetaago by'okumaliriza 'diguli' mu 'Public Health – Population and Reproductive Health' ku Uganda Martyrs University Nkozi.

**Ekigendererwa kyokunoonyereza**: Ekigendererwa ky'okunoonyereza kuno kwekunyonyola embeera abasajja abalina kookolo wa katungulu kobusajja abali wansi w'emyaka 55 gyebayitamu mu Uganda. Ekirala kwekuzuula engeri kookolo ono gy'akosezzaamu abasajja bano n'okulaba oba waliwo ensonga ennambulukufu zebasanzemu okusoomoozebwa.

**Kiiki ekinakolebwa nga okiriza okwetaba mukunoonyereza?** Singa omuntu akkirizza okwetaba mu kunoonyereza kuno, wajja kuberawo okubuuzibwa ebibuzo ebyasekinomu kwamirundi ng'ebiri. Kujja kukolebwa mu kifo ekikiriziganyiziddwako enjuyi zombi era ebanga erinatwalibwa lijja kusinzira kwoyo anaba ali mukuddamu ebibuzo. Nganfunye olukusa lw'omwetabi njakutandika nakumubuza ebimukwatako okugeza emyaka, ebbanga ly'amaze ne kookolo n'obujjanjabi obufuniddwa olwookubuuzibwa kweyongereyo. Okubuuzibwa kujja kweyongerayo okutuusa eyetabye mukunonyereza lw'anaaba nga takyalina bubaka bulala bwakuwa.

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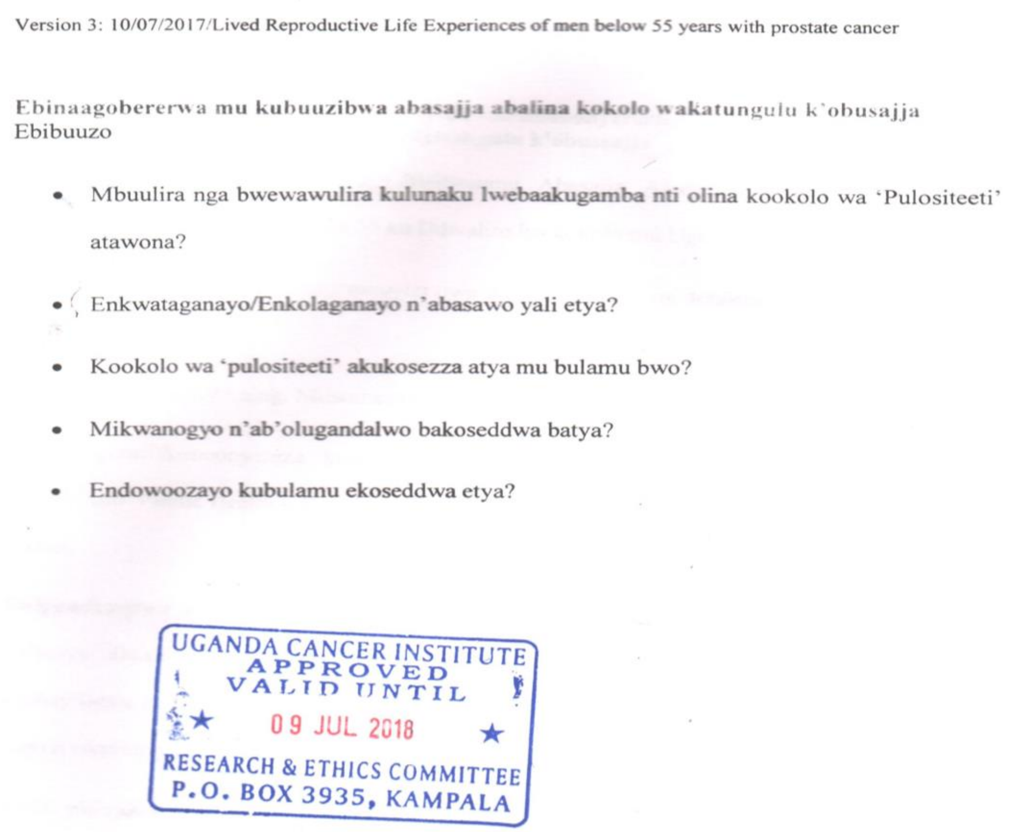
## Appendix XVI1: Approved interview guide for men below 55 years with Prostate cancer



Version 3: 10/07/2017/Lived Reproductive Life Experiences of men below 55 years with prostate cancer

Ebinaagobererwa mu kubuuzibwa abasajja abalina kokolo wakatungulu k'obusajja
Ebibuuzo

- Mbuulira nga bwewawulira kulunaku lwebaakugamba nti olina kookolo wa 'Pulositeeti' atawona?
- Enkwataganayo/Enkolaganayo n'abasawo yali etya?
- Kookolo wa 'pulositeeti' akukosezza atya mu bulamu bwo?
- Mikwanogyo n'ab'olugandalwo bakoseddwa batya?
- Endowoozayo kubulamu ekoseddwa etya?

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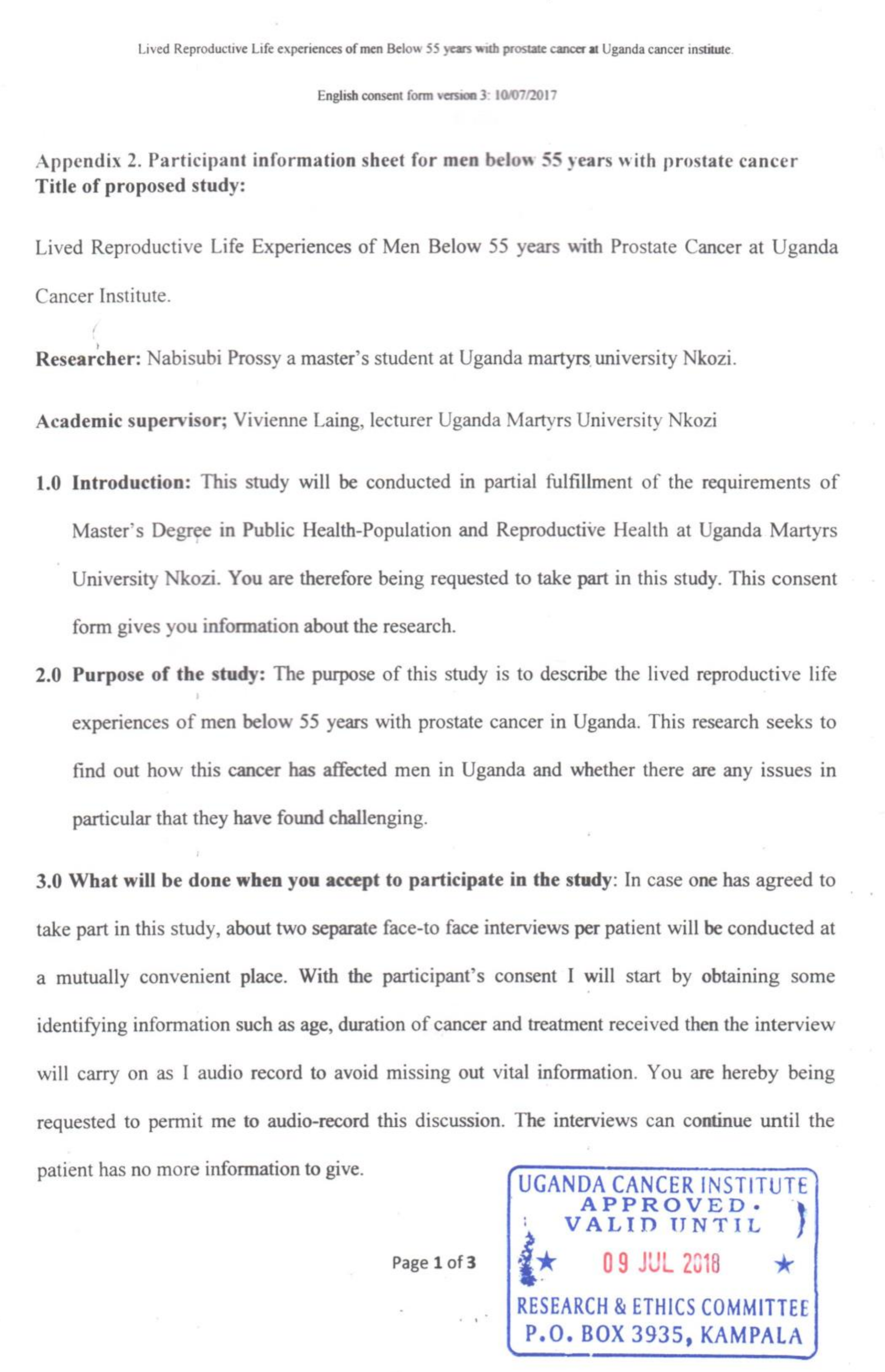
# Appendix XVIII: English consent form



Lived Reproductive Life experiences of men Below 55 years with prostate cancer at Uganda cancer institute.

English consent form version 3: 10/07/2017

## Appendix 2. Participant information sheet for men below 55 years with prostate cancer

**Title of proposed study:**

Lived Reproductive Life Experiences of Men Below 55 years with Prostate Cancer at Uganda Cancer Institute.

**Researcher:** Nabisubi Prossy a master's student at Uganda martyrs university Nkozi.

**Academic supervisor;** Vivienne Laing, lecturer Uganda Martyrs University Nkozi

**1.0 Introduction:** This study will be conducted in partial fulfillment of the requirements of Master's Degree in Public Health-Population and Reproductive Health at Uganda Martyrs University Nkozi. You are therefore being requested to take part in this study. This consent form gives you information about the research.

**2.0 Purpose of the study:** The purpose of this study is to describe the lived reproductive life experiences of men below 55 years with prostate cancer in Uganda. This research seeks to find out how this cancer has affected men in Uganda and whether there are any issues in particular that they have found challenging.

**3.0 What will be done when you accept to participate in the study**: In case one has agreed to take part in this study, about two separate face-to face interviews per patient will be conducted at a mutually convenient place. With the participant's consent I will start by obtaining some identifying information such as age, duration of cancer and treatment received then the interview will carry on as I audio record to avoid missing out vital information. You are hereby being requested to permit me to audio-record this discussion. The interviews can continue until the patient has no more information to give.

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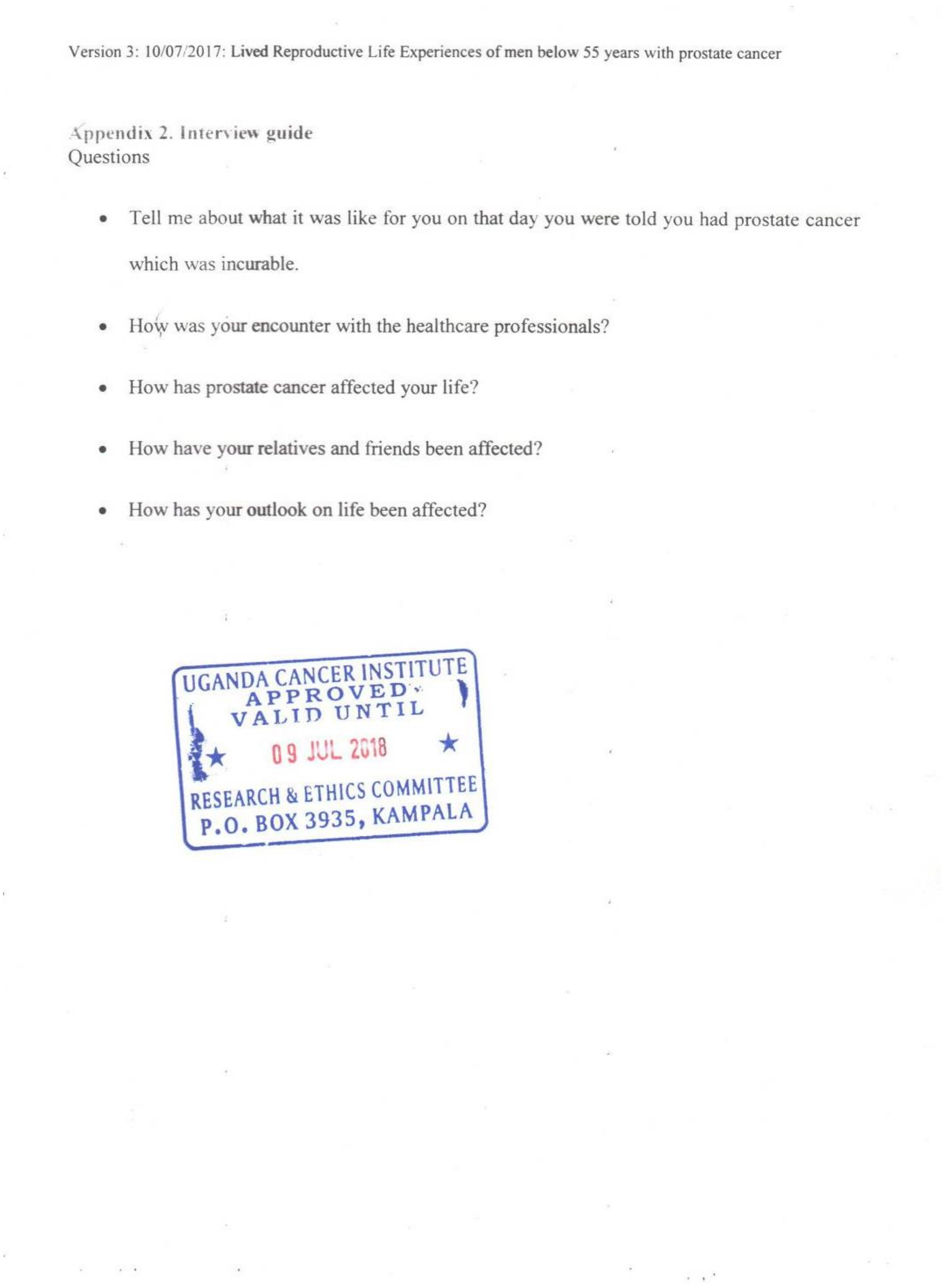
# Appendix XIX: Aproved interview guide for men below 55 years with prostate cancer



Version 3: 10/07/2017: Lived Reproductive Life Experiences of men below 55 years with prostate cancer

## Appendix 2. Interview guide

Questions

- Tell me about what it was like for you on that day you were told you had prostate cancer which was incurable.
- How was your encounter with the healthcare professionals?
- How has prostate cancer affected your life?
- How have your relatives and friends been affected?
- How has your outlook on life been affected?

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