

**EXPERIENCES OF MEN UNDERGOING PROSTATE CANCER SCREENING AT A
SPECIFIC HOSPITAL IN GAUTENG PROVINCE**

by

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submitted in accordance with the requirements for

the degree of

MASTER OF PUBLIC HEALTH

in the subject

HEALTH STUDIES

at the

UNIVERSITY OF SOUTH AFRICA

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July 2023

DECLARATION

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I declare that the dissertation above is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.



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ABSTRACT

Background

Prostate cancer is a worldwide problem affecting men globally. Prostate cancer screening is crucial to detect the disease early and in order to mitigate advanced disease and high-cost treatments. However, men are not well informed regarding the disease and not receiving the much-needed support during prostate cancer screening.

Purpose

The aim of the study was to explore the experiences of men undergoing prostate cancer screening at a tertiary hospital in Gauteng and how they would like to be supported while attending screening.

Research methods

A qualitative, exploratory research study was conducted to explore the experiences of men who attended prostate cancer screening and understanding how they wish to be supported. A convenience sampling procedure was conducted and a total of 19 participants took part in the in-depth interviews. Data were analysed using qualitative thematic analysis.

Findings

Six themes emerged from the study which were (1) prostate cancer knowledge, (2) screening influencers, (3) sources of information regarding prostate cancer, (4) barriers to screening, (5) symptoms experienced during screening, and (6) the support needs.

Conclusions

The study provided evidence that the lack of knowledge regarding prostate cancer was still a concern for men. Further, the study found that health care practitioners were not providing information regarding prostate cancer. Whilst some felt that doctors did not involve them much before embarking on screening procedure. It is also recommended that some mild analgesia be administered to patients while undergoing prostate cancer screening, as patient felt the experience might not encourage others to come for screening.

Key words

Cancer; experiences; men; prostate; screening; support.

ACKNOWLEDGEMENTS

I would like to thank God for giving me life and protection, wisdom, strength, and courage throughout my studies. "The Lord is my shepherd."

- A lot of thanks to my supervisor, Dr Anna Mosalo, for encouraging and guiding me throughout my studies. Her excellent work is highly appreciated.
- I extend my appreciation to my mother, Julia, for the love and support she provided for me all the way.
- I am indeed grateful to the CEO of Leratong Hospital, Dr Phanzu, for advising me to take the study setting to Chris Hani Baragwanath Academic Hospital.
- My special thanks go to the Chief Executive Officer, the head of urology, and the staff who assisted with this research at Chris Hani Baragwanath Academic Hospital.
- I am indeed grateful to the ethics review board at the Unisa Human Science College Ethics department.
- A lot of thanks to all the participants, who took off their busy schedules and participated in this study.
- I am grateful to National Research Foundation (NRF), for funding my studies and this project.
- My special thanks to Mr Pogiso Pule, who did follow-up to ensure smooth applications for the ethics review board at the specific tertiary hospital.
- I extent my appreciation to Mrs Ashley Ringane for assisting with coding and reviewing of transcripts.
- I am grateful towards Mrs Rina Coetzer for her excellent technical editing of the paper.

DEDICATION

In loving memory of my grandmother

Madibolo Magdalene Komane

1926-2002

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LIST OF ABBREVIATIONS

CREC	College Research Ethics Committee
DES	Diethylstilbesterol
DNA	Deoxyribonucleic Acid
DRE	Digital rectal examination
MRI	Magnetic Resonance Imaging
NHRD	National Health Research Database
PIA	Proliferative inflammatory atrophy
PIN	Prostatic intraepithelial neoplasia
PSA	Prostate specific antigen
TNM	Tumor Nodes and Metastases
UK	United Kingdom
US	United States

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION AND BACKGROUND

James, Wong, Graig, Hanson, Ju et al (2017:2), in a study to understand the perspectives of men regarding screening for prostate cancer, found that it is one of the leading causes of death among men worldwide. Whilst other studies found that prostate cancer is the 2nd leading cause of death among men worldwide accounting for 1.1 million cases and 300 000 deaths in 2012 alone (Khazaei, Sohrabivafa, Momenabadi, Moayed & Goodarzi 2019:245; Adeloye, David, Aderemi, Iseolorunkanmi, Oyedokun et al 2016:2). Further, Seraphin, Joko-Fru, Hämmerl, Griesel, Mezger et al (2021:4221), in a study to examine the patterns of prostate cancer in sub-Saharan Africa, found that the incidence was on the rise. Similar findings were reported in a study by Greenberg and Washington (2021:4131) to understand the state of prostate cancer in sub-Saharan Africa, where also the prevalence was found to be alarming.

Several studies shows that the burden of prostate cancer affects black men more than other ethnic populations. A study by Shenoy, Packianathan, Chen and Vijayakumar (2016:1), to reduce the burden of prostate cancer in the United States (US), found that the incidence was 60% higher and the mortality three times higher among African Americans than Caucasian men and remained constant for more than 20 years. Whilst a study to examine factors that influence men to not go for screening in Namibia reported that the burden of prostate cancer is expected to grow in Africa due to a change in lifestyle, diets, socioeconomic conditions, and aging population (Kangmennaang, Mkandawire & Lunginaah 2016:1). Le Roux, Urry, Sartorius and Aldous (2015:57) in KwaZulu-Natal, found that black men presented with an advanced and aggressive disease at a younger age of 40-50 years. Therefore, this highlight that prostate cancer is a problem in South Africa. Maphayi, Cassim, Bello, and George (2020:61), in a study to describe the testing of prostate specific antigen (PSA) in South Africa during 2013, revealed that a total of 20 365 PSA tests were performed and 79% of these were among black men. This is supported by the study conducted by Cassim, Ahmad, Wadee, Rebbeck, Glencross et al (2021:26), to describe Prostate cancer among men undergoing

biopsy in Gauteng who found the highest incidence were found among Black men in comparison to other racial groups.

Despite the high numbers of prostate cancer cases in sub-Saharan Africa, Bello, Buhari, Mohammed, Olanipekun, Egbuniwe et al (2019:1666), in a study to examine the uptake of PSA screening, found that there has not been much research done on the uptake of prostate cancer screening. The authors found that patients make decision to undergo screening for prostate cancer following the recommendation from a physician. The recommendation to screen men aged 40 years and above was largely supported by a study in a regional hospital of KwaZulu-Natal, South Africa that showed that men aged 40 years or older were more likely to develop prostate cancer (Le Roux et al 2015:57).

Baratedi, Tshiamo, Mogobe and McFarland (2020:89), in a study to understand barriers to prostate cancer screening among men in sub-Saharan Africa, found that health care workers were not providing support nor advising men to come back for their screening results. The authors further stated that there were no available programs to encourage men to go for prostate cancer screening. In Gauteng, South Africa, tertiary hospitals that caters for prostate care and treatment are Charlotte Maxeke Academic Hospital, Chris Hani Baragwanath Academic Hospital and Steve Biko Hospital. Patients need to access primary or secondary care to be screened and referred to any of the Tertiary care facilities.

The researcher who is the service user at one care facility was not sure what prostate screening services were available, and with an additional review of literature, noted that there is not much on studies regarding the support of men attending prostate cancer screening clinics. Hence, the researcher proposed to explore the experiences of men undergoing prostate cancer screening at a specific Hospital in Gauteng and understand how they wish to be supported.

1.2 RESEARCH PROBLEM

Prostate cancer screening is fundamental for early detection of disease as this will reduce the problems associated with late diagnosis such as high cost of treatment and advanced disease conditions. Adeloye et al (2016:2), in a study to determine the prevalence of prostate cancer in Africa, found that black men experience the burden of prostate cancer such as high death rate, advanced disease, aggressive disease, and occurrence of

disease at a younger age. Whilst James et al (2017:3), in a study to explore men's perspective of prostate cancer screening, found that men felt anxious whilst awaiting the results and left terrified with the possibility of positive results. Baratedi et al (2020:89), in a study to understand barriers to screening in sub-Saharan Africa, found that there is no support of men who undergo prostate cancer screening. The findings of Baratedi et al (2020:85) are consistent with that of Ugochukwu, Odukoya, Ajogwu and Ojewola (2019:168) conducted in Nigeria to assess the knowledge, attitudes, prevalence, and barriers to prostate cancer screening where it was reported that men felt loss of personal dignity by undressing and being inserted an object in the rectum. The authors also found that participants reported that the screening procedure was invading their privacy thus unwilling to undergo screening. It is therefore crucial that men are supported during screening for the disease. Conducting the study would therefore shed light on the experiences of men undergoing prostate cancer screening and understand how they wish to be supported.

1.3 PURPOSE OF THE STUDY

1.3.1 Research purpose

The study aims to explore the experiences of men undergoing prostate cancer screening at a tertiary care hospital and how they would like to be supported while attending screening.

1.3.2 Research objectives

The objectives of the study were:

- To explore men's knowledge and awareness regarding prostate cancer including screening at the specific tertiary care hospital.
- To explore the barriers towards prostate cancer screening among men attending a specific tertiary care hospital
- To explore the experiences of men undergoing prostate cancer screening at a specific tertiary care hospital in Gauteng.
- Explore how men undergoing prostate screening at the specific tertiary care hospital prefer to be supported.

1.3.3 Research questions

- What is the knowledge and awareness of men regarding prostate cancer and screening at the specific tertiary care hospital?
- What are the barriers towards screening among men attending prostate cancer screening at a specific tertiary care hospital?
- What are the experiences of men undergoing prostate cancer screening at a specific tertiary care hospital?
- What are the support needs of men attending prostate cancer screening at a specific tertiary hospital in Gauteng?

1.4 DEFINITION OF KEY CONCEPTS

1.4.1 Burden of disease

Burden of disease is the impact of a health problem and is measured by mortality, financial costs, and morbidity, and is often quantified as disability adjusted life years (Li, Zhou & Huang 2018:777). It is a measure of health in a population and aim to quantify the ideal of living in good health up to old age and the real situation in which life is shortened by premature death, injury, illness, and disability (Li et al 2018:777). In this study burden of disease is described by how prostate cancer impact the general quality of life and daily activities of a population globally and locally by prevalence, incidence, and mortality.

1.4.2 Experiences

Experiences represent the understanding of research participants regarding their choices, human experiences, options, and how their perception of knowledge is influenced by those factors (Chambers, Hyde, Laurie, Legg, Frydenberg et al 2018:1). In this study, experiences are defined as how the understanding of the study participants on prostate cancer screening and support needs are influenced by their experiences, choices, and knowledge while they are attending screening at a specific tertiary care hospital.

1.4.3 Prostate cancer

Aaron, Franco and Haywzrd (2016:279) define prostate cancer as the development of cancer in the prostate gland when the abnormal cells grow in an uncontrolled way and forming a tumour that is malignant. This definition is applicable in this study.

1.4.4 Prostate specific antigen (PSA)

Prostate specific antigen (PSA) is an enzyme that is produced by the epithelia cells of the prostate gland, and its function is to breakdown proteins in the semen into smaller molecules and improves the function of fertility and sperms by causing the semen to be less vicious as cited in Van Poppel, Roobol, Chapple, Catto, N'dow et al (2021:703). An elevated PSA is not necessarily a diagnosis of prostate cancer (O'Rourke 2007:165). However, high PSA levels of more than 4.0 ng/ml have been associated with a suspicion for prostate cancer due to its diffusion into the tissues and circulation. In this study a PSA screening test is a blood test which is used to investigate prostate cancer by measuring the amount of PSA in the blood (Ittmann 2018:1).

1.4.5 Risk factors

Sathianathen, Konety, Crook, Saad and Lawrentschuk (2018:627) define risk factors as factors that are associated with an increase occurrence of a disease. In this study, risk factors are the factors associated with an increase development of prostate cancer such as age, family history, lifestyle, and smoking.

1.4.6 Screening

Screening is the process of finding out the probability of people having a disease using a screening tool so that they can be offered early treatment or information to make informed choices or decision about their health and this can be administered to the entire healthy population or the targeted individuals (Duffy & Smith 2020:939). Screening does not directly decrease mortality but offer possibilities for early detection which is important for high-risk individuals (Jones, Steeves & Williams 2009:166). In this study, screening is

described as a process to examine prostate cancer among men who attended prostate screening at the specific tertiary care hospital using the PSA screening tool or the digital rectal exam procedure.

1.4.7 Staging and grading

Staging of prostate cancer is a process in which pathologist categorise the risk of the cancer to spread to other body parts beyond the prostate, and the probability of the cancer being successfully treated with therapies such as radiation or surgery (Buyyounouski, Choyke, Mckenney, Sartor, Sandler et al 2017:245). In this study the original meaning of staging is applied as is.

Grading is a process in which the cancer cells are investigated on how they compare to the normal prostate cells and helps identify how fast the cancer spread and grow (Castillejos-Molina & Gabilondo-Navarro 2016:282). Prostate cancer is graded based on cellular differentiation among biopsy specimen (O'Rourke 2007:167). The Gleason score is used for prostate grading to determine tumour grade through microscopic examination of biopsied tissue (Castillejos-Molina & Gabilondo-Navarro 2016:282; O'Rourke 2007:167). The original meaning of grading is applicable in this study as it is.

1.4.8 Support

Support is an instrumental, emotional, informational, and appraisal assistance (Clarke, Booth, Velikova & Hewison 2006:66). Support includes the social relationships through which individual needs are met and the resources that meet these needs (Clarke et al 2006:66). According to Clarke et al (2006:66), the system of support includes formal and informal relationships and groups which a person can receive emotional (love, security, and comfort), cognitive (advice, information, and knowledge), and material support that can be helpful in stressful situations. In this study the concept of support is applicable as per the description.

1.5 RESEARCH PARADIGM

A research paradigm is defined as a philosophical framework which form the bases of research (Zhang, Zhao, Kou, Li, Dong et al 2020:65; Kamal 2019:1386). The authors

further states that the research paradigm provides the understanding and patterns of beliefs whereby the research project practices and theories operate on.

The most common research paradigms include positivism, constructivism, and pragmatism. Although this research is based on constructivism, positivism and pragmatism are briefly described. Positivism mostly uses quantitative methods in the research as it believe in a single reality that is possible to understand and measured using statistical data analysis (Kaushik & Walsh 2019:1). Pragmatism believe that due to new or unpredictable situations, reality is renegotiated or continually interpreted and thus combining both positivism and constructivism to reach the needed results in the same study using both qualitative and quantitative methods to investigate a research problem (Kaushik & Walsh 2019:1).

Erdal, Mehmet and Bülent (2021:8) define constructivism as a philosophical paradigm or approach that indicates that people construct their knowledge and comprehension of the world through their own experiences and making reflections on those experiences. Constructivism which is applicable in this study, believe that there are multiple realities and that there is no single truth or reality (Park, Konge & Artino 2020:95). Constructivist researchers spend time to understand the meanings from data and interpreting them using qualitative research methods such as interviews to answer the “why’ questions (Park et al 2020:95). This study followed a constructivist paradigm by using qualitative exploratory research method particularly in-depth interviews with individual patients to explore the experiences of men undergoing prostate cancer screening and understanding how they wish to be supported.

1.6 RESEARCH DESIGN AND METHODS

A research design is described as a framework of techniques and research methods which the researcher chooses to tackle research questions through the collection of data, data analysis, and discussion of data (Huntington-Klein 2021:1). A research design allows the researcher to set up their studies for success by allowing them to hone in on the research methods that are suitable for the subject matter (Huntington-Klein 2021:1). Lê and Schmid (2020:308) described research design as the overall strategy chosen by the researcher to integrate different components of a study in a logical and coherent way and ensuring that the research problem is effectively addressed. The research design

constitutes data collection, measurements, and analysis of data (Huntington-Klein 2021:1). There are various types of research designs, however for the purpose of this research, an exploratory qualitative design was suitable to explore the experiences of men undergoing prostate cancer screening at a specific hospital in Gauteng.

Qualitative research provides the researcher with an allowance to understand and explore the phenomenon of the study (Levitt, Morrill, Collins & Rizo 2021:357). Busetto, Wick and Gumbinger (2020:1) indicated that one of the aims of the qualitative research is to provide an understanding of a research problem that goes in an everyday awareness detail, leading to more empathic, informed, and nuanced practice. One of the strengths of qualitative research is the ability to provide full complex description regarding the experiences of people pertaining to a health issue (Allan 2020:177). Qualitative research provides a comprehension regarding topics that relate to opposing views, beliefs, behaviours, emotions, and individual relationships, and thus endeavours a comprehension of the whole (Allan 2020:177; Busetto et al 2020:1). Intangible factors such as socioeconomic status, religion, ethnicity, social norms, and gender roles are effectively identified by qualitative (Levitt et al 2021:357).

Exploratory research design was applicable in this study as there was limited research conducted at the specific tertiary care hospital regarding the topic. Exploratory research design is conducted when there is little or insufficient information regarding a phenomenon or the problem of interest on which limited or no research has been done (Makri & Neely 2021:20; Boru 2018:3). The aim of exploratory research is not to answer the research questions conclusively or to provide a final answer, but to explore the topic of interest (Makri & Neely 2021:20; Boru 2018:3).

1.7 STUDY SETTING

The study setting is the social, physical and cultural site in which researchers conduct study activities (Majid 2018:3). The study was conducted at a specific tertiary institution in Gauteng. The specific tertiary care hospital is a large tertiary academic hospital situated in the Soweto area of Johannesburg. It is considered as one of the largest hospitals in South Africa. The hospital provides services including post-natal and ante-natal; gynaecology; plastic surgery; ear, nose, and throat services; ophthalmology; urology services; paediatric; orthopaedic; internal medicine; oncology; high care; intensive care

unit; and other services including radiology, speech therapy, pharmacy, and audiology. The hospital has a dedicated specialised urology department and a was suitable for this study. The urology department at the specific tertiary caters for men who present with prostate cancer, penile cancer, and other urological problems. Majority of men who come for treatment in this department are from the surrounding townships in the neighbouring areas and mostly from low socio-economic status group. The study was initially set out to be carried out at a secondary care facility. However, it turned out that prostate cancer patients at the secondary hospital were seen for initial consultation and then referred to specific tertiary hospital for screening and further management.

1.8 STUDY POPULATION

A population is a group of individuals that have the same characteristics (Fellows & Liu 2021:110). Study population is described as a subset of the target population from which the sample is drawn (Fellows & Liu 2021:110). The study population consisted of all men within the ages of 40 years and older who attended the urology clinic at the specific tertiary care hospital during February and July 2022.

1.9 SAMPLING

Sampling is defined as a process in the research methods which entails the recruitment of participants in a study (Fellows & Liu 2021:110; Hunter, Mccallum & Howes 2019:4). A convenient sampling procedure was followed to recruit participants for this study. Convenience sampling is a non-probability sampling procedure where the researcher selects a sample from the group of people who are easy to reach or contact (Elfin & Negida 2017:3). Participants in the study were conveniently present at the hospital for prostate cancer screening and were easy to reach and invited to take part in the study, and as such convenience sampling procedure was suitable for the study. The sample size was not pre-established, but it was informed by existing literature suggesting that a minimum of 12 participants would be adequate to achieve saturation in qualitative research (Vasileiou, Barnett, Thorpe & Young 2018:148). The researcher sought to interview 15 participants with contingency for those who may not be able to complete due to other issues such as excessive pain, or decision to abandon the study. Once the interviews were completed the researcher of the study later went for additional four interviews to ensure that saturation has been reached, when no new information emerged

from subsequent interviews. The sample size included a total of 19 men aged 40 years or older who came for prostate cancer screening at the specific tertiary hospital during February and June 2022.

Inclusion criteria

- Men ages of 40 years or older.
- Men referred for prostate cancer screening at specific Academic Hospital Urology clinic during the year 2022.
- Men willing to give informed consent.
- Men who received positive test results for PSA screening test.
- Men who are still at workup stage without confirmed prostate cancer.

Exclusion criteria

- Men below the age of 40 years.
- Men already receiving prostate cancer treatment.
- Men who were not able to give informed consent.
- Men who were too ill to participate in screening.
- Men already on prostate cancer treatment were not eligible to participate in the study as it was perceived that their treatment will bias their responses.

The main reason for excluding men below the age of 40 years was that evidence shows that men aged 40 years or older are more likely to develop prostate cancer (Rawla 2019:63), hence the study only focused on men aged 40 years or older.

1.10 DATA COLLECTION

Data collection is a process in which researchers gather and measure information in an established system on targeted variables, and this enables the researcher to evaluate a particular outcome and answer the relevant question (Fellows & Liu 2021:110). The purpose of data collection is to collect information in a manner that is systematic and measured to ensure that the information is accurate and facilitate analysis of data (Wei, Guo, Wang, Wang & Qiu 2021:404).

The process of data collection began after receiving ethical clearance from the College Research Ethics Committee (CREC). The research proposal of this study was submitted for ethic clearance at the University of South Africa CREC and permission was granted (Ethics reference number: 61263079_CRECHS_2021) (Annexure A). However, at the specific tertiary hospital the researcher was advised to submit an online application on the National Department of Health (DOH) before the head of the urology department could grant permission to conduct the study. Once the online application was completed the Head of Urology department at the specific tertiary hospital granted the permission (Annexure C).

Due to fact that data collection occurred during SARS-COVID-19 pandemic period, strict SARS-COVID-19 protocol measures as stipulated by WHO (2020:1), including UNISA COVID-19 Guidelines were followed. Such measures included hand hygiene, respiratory hygiene such as the wearing of clean face mask, physical distancing, environmental cleaning and management of COVID-19 patients (WHO 2020:1). The hospital was already adhering to these measures as such the researcher just ensured that these were properly followed for the purpose of this study.

The researcher developed an interview guide (Annexure D) which was guided by the existing literature that focused on questions related to experiences, knowledge, barriers, and support (Baratedi et al 2020:89; Adibe, Aluh, Isah & Anosike 2017:1962; James et 2017:2). The interview guide was validated by the Urology clinic staff working at the prostate clinic, as well as the study supervisor. The interview guide was tested on two patients to assess for easy comprehension and amendments of the questions if necessary.

Data collection took place during February to July 2022. Patients who undergo prostate cancer screening at the urology clinic at the hospital were seen only on Wednesdays, thus the researcher opted to interview two patients during these days per week. Participants were invited to participate in the study by the clinic staff while waiting for their screening results. The participants completed an informed consent prior to participating in the study and the audio recorded interviews. The researcher read aloud the information to participants to make sure they understand the study before they sign the consent form. The researcher requested permission to record the interview on an audio tape.

individual interviews were conducted in a private room specifically arranged with the registered nurse in charge to maintain privacy and confidentiality, as the tendency is to stigmatise the patients diagnosed or awaiting their results. In-depth interviews lasted for approximately an average of 30-40 minutes. Most of the languages spoken in the community are Zulu and Setswana. The researcher being a resident in a similar community being conversant in Zulu and Setswana languages conducted the interviews.

Most of the interviews were conducted in Setswana language as participants were not forced on a language they did not understand and only few were conducted in English and Zulu languages. Each interview began by the researcher welcoming the participant and then explaining purpose of the study and their role during the interview. The researcher requested participants to sign the informed concerned (Annexure E). The researcher requested permission to record the interview and asked the participants to sign the informed concerned for the audio recording (Annexure F) once they agreed. The recordings were done so that the researcher can transcribe the audio at a later stage. The researcher began by asking participants questions related to knowledge or understanding of prostate cancer followed by the reason that influenced them to come for screening, their experiences during screening and their support needs, and thus closing by asking questions related to screening procedures.

Initially, the researcher concluded the interviews after collecting data from 15 participants. However, to ensure that indeed data saturation was reached, additional 4 interviews were conducted. No new information emerged when compared with the data already collected. The researcher then closed the interviews with 19 participants, and this was determined when collection of further interviews had little or no impact to the data already collected.

1.11 DATA ANALYSIS

Data analysis is referred to as a process of cleansing, inspecting, modelling and transforming data with the goal of deriving useful information, conclusions and support of decision making (Taherdoost 2022:1; Fellows & Liu 2021:333). It is the process of applying statistical or logical techniques to illustrate, describe, recap, condense, and evaluate data (Taherdoost 2022:1). The researcher did verbatim transcription of all the interviews conducted in the study. The supervisor reviewed the first two transcripts for

the purpose of verification and comparison with the transcripts done by the researcher to ensure that no meaning was lost and codes captured what emerged from data sets.

Data analysis followed an iterative process and was done manually by the researcher. To elaborate on the objectives, a thematic analysis of the collected data was conducted to guide the analysis process (Lester, Cho & Lochmiller 2020:97). The researcher developed a codebook in which a list of codes and categories were identified, to develop themes. After analysing the data, a qualified intercoder reviewed a portion of the data sets to confirm that they conveyed the same meaning. Subsequently, a meeting was arranged between the intercoder and the researcher to discuss these findings and to reach a consensus. The Intercoder also signed a confidentiality declaration (Annexure I) to ensure that no information is shared outside the study. The study supervisor verified some of the themes to ensure that correct coding processes was followed. The process will be detailed in research and design section in chapter three.

1.12 ETHICAL CONSIDERATIONS

The ethical standards were appeased throughout the study by ensuring that all the principles of ethics were followed. The researcher ensured that the principle of beneficence was respected. Although there were no direct benefits for participating in the study, the researcher ensured that the findings of the study were used to increase the uptake of screening by making the findings available to public health, policy makers through journal publication and reporting on the study.

The principle of respect for persons was ensured by respecting the decisions of study participants even when participants withdrawn from the study. No harm aroused from taking part in the study and as such the principle of none-maleficent was respected. The principle of justice was ensured by making sure that all the study activities were not against the law. Participants were given opportunity to ask questions prior to making decisions on whether to participate in the study or not, while still retaining the benefits of accessing the health care.

The study was submitted for ethical clearance at Unisa College Research Ethics Committee (CREC) department for approval (Annexure A). Permission to conduct the study was received from the specific tertiary hospital (Annexure B). Participants were

provided with the details about the study and requested to sign consent to participate which detailed the terms of the participants' consent (Annexure E). Participants provided informed consent and participation was voluntary. Although there were no direct benefits for participating in the study; the participants were informed about the importance of sharing the findings to improve the screening uptake and services for the next men who come for screening. Participants were also informed about the anticipated potential psychological harm resulting from the interviews particularly from patients that had relatives that were previously affected by the disease, thus interviewing these men was anticipated to evoke emotional trauma. Counselling was arranged with the hospital counsellor and made available to the participants without incurring any costs.

Participants were advised to stop the interviews should they feel uncomfortable or any distress resulting from the interviews. It was expected that potential participants might know or relate to someone who suffered from prostate cancer, hence the experience led them to come for screening. However, none of the participants experienced any emotional trauma during the data collection. All the information collected was kept confidential. There are no names used in the dissertation or the manuscript and ultimately no identifying information is linked to the data.

1.13 SCOPE OF THE STUDY

The study was conducted at an Academic Hospital in Gauteng province of South Africa. The study presents the experiences of men undergoing prostate cancer screening and understanding how they wish to be supported.

1.14 STRUCTURE OF THE DISSERTATION

- Chapter 1: Discussed outline and orientation to the study
- Chapter 2: Literature review pertaining to burden of disease, risk factors, symptoms, diagnosis, staging, treatment, and support
- Chapter 3: The research methodology that guided the study
- Chapter 4: Analysis, presentation, and discussion of research findings

- Chapter 5: Conclusions and recommendations

1.15 SUMMARY

This chapter discussed information and background regarding the disease, research methods and design, and ethical considerations. In Chapter 2, the literature review pertaining to prostate cancer will be discussed.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 discussed information and background regarding the disease, research methods and design, and ethical considerations. In Chapter 2, the literature pertaining to prostate cancer will be discussed. Snyder (2019:334) reported that the aim of literature review is to compare findings from past studies, identify gaps in knowledge around the topic of interest and determine the possibility of contributing to existing knowledge. The search engines consulted were Medline, Ovid, and Science direct, Sage journals, PubMed and Tailor and Francis. Keywords used were “prostate cancer”, “prostate cancer screening”, “prostate cancer support”, and “experiences of men undergoing prostate screening.” The researcher selected published articles from 2016 to 2022 to ensure that the literature is current.

This following issues regarding prostate cancer will be discussed: the burden of prostate cancer, risk factors for developing the disease, prostate screening, diagnosis, prostate cancer signs and symptoms, types of prostate cancer, grading and staging of the disease, treatment options for prostate cancer, and the concept of support around prostate cancer screening.

2.2 BURDEN OF PROSTATE CANCER

Studies have reported that prostate cancer is a major public health problem and a second leading cause of death associated with cancer among men across the world (Hao, Östensson, Eklund, Grönberg, Nordström et al 2020:2; Enaworu & Khutan 2016:524). Pishgar, Ebrahimi, Moghaddam, Fitzmaurice and Amini (2018:1224,) in a study to provide worldwide prostate cancer estimates of mortality, incidence, and burden from 1990 to 2015, found an increase of prostate cancer incidence by 3-fold from 1990 to 2015. These findings are consistent with that of a study by Zhai, Zheng, Li, Deng, Zhou et al

(2020:1969) examining the global epidemiology of prostate cancer, by finding that the worldwide incidence of prostate cancer increased from 30 per 100 000 population in 1990 to 37 per 100 000 population in the year 2017.

Similar observations were noted in a study by Smith-Palmer, Takizawa, and Valentine (2019:1) to provide evidence on prostate cancer mortality in Europe and found that prostate cancer accounted for 23% of all male cancers and 10% of cancer deaths in Europe in 2012 alone. Accordingly, Smith-Palmer et al (2019:1) in their study reported that 1 in 8 men will develop prostate cancer during their lifetime.

Adeola, Blackburn, Rebbeck and Zerbini (2017:3791) in a study to assess the burden of prostate cancer in Africa reported that it is indeed a public health concern with the highest incidence, high number of deaths, and a high 5-year prevalence rate. The authors indicated that the high mortality rates, incidence rates and 5-year prevalence rates were similar in South Africa. However, the developed world differs with these observations by showing high incidence and low mortality, thus reflecting proper treatment and early diagnosis (Adeola et al 2017:3791).

However, Greenberg and Washington (2021:4131), in a study to understand the state of prostate cancer in sub-Saharan Africa, found that the burden of prostate cancer is not fully reported with large numbers of undiagnosed and unreported cases due to poor screening facilities, lack of knowledge among men regarding prostate, and unskilled staff. Further, Sharma (2019:137) in a study conducted to examine the patterns of prostate cancer burden, shown an increased mortality due to prostate cancer in sub-Saharan countries. In South Africa, the incidence of prostate cancer and the mortality rates were also reported to be high in a study assessing the burden of prostate cancer by Adeola et al (2017:3791). Whilst Culp, Soerjomataram, Efstathiou, Bray and Jemal (2020:38), in a study to assess the recent mortality, incident rates and trends of prostate cancer on the Globocan database, found that the incidence of prostate cancer in South Africa are similar to that of the Western Europe, North America and Australia.

Culp et al (2020:38), in a study to assess prostate cancer mortality and incidence rates, highlighted that South Africa have better health facilities to diagnose prostate cancer compared to majority of other sub-Saharan African countries. However, the authors noted that there is still shortage of resources and manpower, and thus led to complications

related to the management of the high burden of prostate cancer cases. This calls for intervention to bring forth means to inform men about risks of developing prostate cancer and encourage screening. It is assumed that empowering men at risk would promote better informed decisions and steps to reduce the burden of the disease on the health system.

2.3 RISK FACTORS FOR DEVELOPING PROSTATE CANCER

Sathianathen et al (2018:627) define risk factors as factors that are associated with an increase occurrence of a disease. Various factors such as age, ethnicity, family history, smoking and lifestyle have been implicated as risk factors for developing prostate cancer (Pernar, Ebot, Wilson & Mucci 2018:5; Adler, Friesen, Yeboah, Tettey, Biritwum et al 2019:71). The researcher conducted a thorough literature search regarding risk factors pertaining prostate cancer within the African context; however, there is limited research in this subject pertaining to risk factors as highlighted in a study by Hayes and Bornman (2018:1). Further Seraphin et al (2012:158) in a study conducted in Africa which analysed a registry data on 13170 cases of prostate cancer found that those aged 70 years or older were more likely to develop the disease (Seraphin et al 2012:158). The risk factors that have been identified as a possibility for developing prostate cancer are age, ethnicity, smoking, family history, and lifestyle.

2.3.1 Age

Pernar et al (2018:4), in a study to describe the epidemiology of prostate cancer globally, suggested that most of the prostate cancer cases are diagnosed during the 7th decade, followed by the ages of 70 and 79 years. These findings are similar to those of a study by Kimura and Egawa (2018:528) to assess the epidemiology of prostate cancer in Asian countries by finding that the incidence of prostate cancer increases drastically among those over the age of 55 years. The total risk of developing prostate cancer is strongly associated with age as supported by Freeland, Crowell, Giafaglione, Boutros and Goldstein (2021:28), who found that age was an important risk factor, with the incidence increasing from 1 in 45 men aged 40 to 59 years to 1 in 7 men aged 60 to 79 years. Pernar et al (2018:5) found that older men are more likely to have their prostate cell damaged due to aging, and as such put them at the high risk to developing prostate cancer. The authors further indicated that as men gets older, the adult tissue cells

gradually cause mutations and influences transformation in the prostate area thus influencing disease and damage the prostate cell Deoxyribonuclei Acid (DNA) which is a complex protein high molecular weight consisting of deoxyribose, phosphoric acid and four bases and cause cancer.

Other findings in a study to examine trends of prostate cancer incidence and mortality and net age from 1990 to 2017 in China found that prostate cancer cases increased by 2.7% among older men in that period (Liu, Yu, Bi & Zhang 2019:70). The study showed that older groups (50 to 79 years) had increased mortality compared to younger groups (15 to 49 years) (Liu et al 2019:70). Whilst age has played a role as a risk for prostate, ethnicity has also been found to contribute as risk for developing prostate cancer (Pernar et al 2018:5).

2.3.2 Ethnicity

Ethnicity relates to a state in which a group of individuals belong to a common culture or national tradition as reported in a study by Oskolkov (2022:155), the types of ethnicities were African American or Black, Aboriginal, Asian, European American, or White. Other studies cited highlighted an association between ethnicity and the development of prostate cancer. A study by Pernar et al (2018:5) to characterise the epidemiology of prostate cancer in American men indicated that 1 in 6 men of the African American descent developed prostate cancer. Similarly, Perdana, Mochtar, Umbas and Hamid (2017:230), in a study to determine the risk for developing prostate cancer in the US, found striking prostate cancer incidence and deaths differences across ethnic groups whereby black men had the highest mortality and incidence compared to their White counterparts.

Whilst Rawla (2019:67), in his study, suggested that the high incidence and mortality rates among African American men were associated with socioeconomic status, the environment, and diet. Rawla (2019:67), further reported that other ethnic groups such as Asian or Hispanic men were less likely to develop prostate cancer compared to African American, citing reasons such as different environment, socio-economic status, and diet as explanatory factors for these variations. These findings were also observed in a study by Perez-Cornago, Key, Allen, Fensom, Bradbury et al (2017:1563) to investigate the risk factors for prostate cancer in the United Kingdom (UK) and United States (US) cohort and

found that race predicted prostate cancer and indicated that, 50% of the cases occurred among the blacks, followed by whites and less among Asians. In addition, Noone, Cronin, Altekruse, Howlader, Lewis et al (2017:632), in a study to examine the survival and incidence of prostate cancer in the US men, found that black Americans were 2.4 times more likely to die from prostate cancer compared to white Americans, while other ethnic groups such as American Indian, Pacific Islanders, and Hispanic men had lower mortality rates. Similarly, Layne, Graubard, Ma, Mayne and Albanes (2019:92-95), in a study to determine the risk factors of prostate cancer among black and white men, found that smoking plays a significant role in the development of prostate cancer.

2.3.3 Smoking

Smoking has been found to increase the risk of developing prostate cancer due to increased circulating levels of cadmium cellular oxidation in the blood and or through exposure to carcinogens due to cigarette smoking (Foerster, Pozo, Abufaraj, Mari, Kimura et al 2018:953). Nettey, Walker, Keeter, Singal et al (2018:501), in a study to assess the risks factors for developing prostate cancer independent of socio-economic and clinical factors, found that smokers have a doubled risk of developing prostate cancer and dying from the disease.

Similarly, Malik, Batool, Masood and Yasmin (2018:337) in a study to evaluate risk factors for prostate cancer, found that smoking was significantly associated with prostate cancer in Pakistani men. Similar findings were also found by Brookman-May, Campi, Henríquez, Klatte, Langenhuijsen et al (2019:756) to evaluate evidence regarding the association between smoking and other modifiable risk factors on the risk for prostate cancer. The authors found that smoking was associated with development of aggressive prostate cancer and worse disease outcomes. Family history has also been implicated as a risk factor for prostate cancer.

2.3.4 Family history

Family history involves the passing on of traits among family members and as result people who have a relative or family member diagnosed with a health problem are more likely to develop that health problem. A number of studies have indicated that family history increases the risk of developing prostate cancer. Williams, Awasthi, Fink, Pow-

Sang, Park et al (2018:2165), in a study to investigate prostate cancer outcomes and factors contributing to the racial differences in the US, found a greater risk for developing prostate cancer among men with a family history of prostate cancer. The study further reported that the risk of prostate cancer were 2 to 3 times among men who had family member diagnosed with prostate cancer in the past.

Tse, Lee, Ho, Lam, Lee et al (2017:4), in a study to examine the risk factors for developing prostate cancer in Hong Kong, found that about 10% of prostate cancer cases were related to heredity. The authors highlighted that the risk of developing prostate cancer increased to 5-fold when a family member reported having prostate cancer. Whilst Rawla (2019:67) found that family history accounted for 20% of prostate cancer cases and inherited genetic materials were implicated in playing a significant role in the development of prostate cancer and increase the risk of disease. Lifestyle factors were also found to be risks for prostate cancer development.

2.3.5 Lifestyle

Lifestyle factors are described as the habits that can be modified and a way of living that can contribute to well-being and overall health. Lifestyle factors may include diet, alcohol consumption, tobacco use and physical activity. The risk of prostate cancer might be affected by diet such as consumption of food that have high fat and calcium, and lifestyle (Wilson & Mucci 2019:1). Overwhelming evidence on the lifestyle factors on the risk of developing prostate cancer has been found in numerous studies. A narrative review by Shephard (2017:1055) to update the information on the relationship between physical activity and prostate cancer found that men who were involved in moderate and vigorous physical activities had lower risk of prostate cancer compared to men who did not engage in recreational activity. Al Qadire, Alkhalailah and Albashtawy (2018:994), in a study to explore the association of lifestyle factors and development of prostate cancer, found that history of prostate infection, overweight and high fat intake increased the risk of developing prostate cancer.

Another retrospective cohort study by Kim, Kim, Joung, Kwon, Seo et al (2018:1194) to develop a risk prediction model among Korean and Japanese men, found that consumption of alcohol, physical activity, and frequency of meat consumption were significantly related to development of prostate cancer. Similarly, Brookman-May et al

(2019:756), in a systematic review to evaluate evidence on risk factors for prostate cancer, suggested that although physical activity was a useful factor to prevent prostate cancer, it was not clear under which conditions physical activity was protective for development of prostate cancer. In order that prostate cancer can be detected and reduced it is crucial that men are made aware of available screening processes.

2.4 PROSTATE CANCER SCREENING

Duffy and Smith (2020:939) define screening as the process in which unrecognised disease is likely to be identified in asymptomatic and healthy populations, however through utilisation of tests and other examinations that can easily be rapidly applied in the target population. Prostate cancer screening is the process used to examine and diagnose for prostate cancer before the development of symptoms in a target population (Force 2018:1901). Force (2018:1901) also suggest that prostate cancer can be found at an early stage of its development by screening and thus enabling the cancer to be successfully treated when found at early stage.

There are two commonly used tests for screening prostate cancer which are prostate specific antigen (PSA) and digital rectal examination (DRE). PSA is still the single best method for early diagnosis. PSA is a serine protease produced by malignant cell in the prostate as well by hyperplastic prostate (O'Rourke, 2007:165). PSA test is a test used to measure the amount of blood levels of PSA – a substance that is made in the prostate. Preston, Gerke, Carlsson, Signorello, Sjoberg et al (2019:399) in a case control study among black men of the Southeastern USA, found that men who have prostate cancer have higher levels of PSA in their blood.

Eastham (2017:218), in a study to examine prostate cancer screening, indicated that at least two measurements of PSA are recommended to be taken three weeks apart due to the possibilities of significant inter-individual variation. The limitation of PSA screening is that the test has high sensitivity (the ability of the test to identify true positives) and low specificity (the ability of the test to identify true negatives), and this may lead to false positive tests. The reference value was set at 2.5 ng/ml in in the past, and this resulted in many unnecessary prostate biopsies and overtreatment (Eastham 2017:218). Naji, Randhawa, Sohani, Dennis, Lautenback et al (2018:149) indicated that some of prostate cancers do not show high level of PSA in the blood and as such digital rectal exam is

suggested to be the most effective test for prostate screening in these instances. Naji et al (2018:149) also suggested that a combination of PSA set at a reference value greater than 4 ng/ml and a digital rectal examination are the most significant for screening prostate cancer.

Digital rectal examination (DRE) is a procedure in which a physician inserts a gloved finger or digital machine in the rectum in a male to feel any irregularities in the surface of the prostate through the bowel wall. In a meta-analysis which looked at DRE for prostate cancer in a primary care setting by Naji et al (2018:149), found that the method of DRE diagnose up to 18% of prostate cancer cases. Several studies have been conducted in relation to prostate screening by DRE. Ugochukwu et al (2019:168), in a study conducted in Nigeria to assess the knowledge, attitudes, prevalence, and barriers to prostate cancer screening, found that men felt loss of personal dignity by undressing and being inserted an object in the rectum. Other studies reported that the DRE procedure was painful (Ugochukwu et al 2019:168; Elhardello & MacFie 2018:579; Romero, Romero, Brenny Filho, Bark, Yamazaki et al 2008:850). Although screening is useful to identify potential cases, diagnosis is fundamental to confirm these cases.

2.5 PROSTATE CANCER DIAGNOSIS

Kasivisvanathan, Rannikko, Borghi, Panebianco, Mynderse et al (2018:1767), in a study to assess the standard diagnostic test for prostate cancer, indicated that the current gold standard diagnosis for prostate cancer is the prostate biopsy. Biopsy is a procedure that involve taking small tissues samples of the prostate to look for cancer under microscope. The main importance of biopsy is to obtain a sample that is representative for the entire prostate gland so that a pathologists may be able to accurately establish a histological diagnosis (Streicher, Meyerson, Karivedu & Sidana 2019:1).

The authors highlighted that patients need to fit two criteria to be considered as a candidate for biopsy which are a suspicious Digital rectal exam and a higher PSA measurement of 4 ng/mL. The results of the PSA are obtained and confirmed with separate results three weeks apart. The size of the prostate as measured by the ultrasound or digital rectal exam is important to consider (Streicher et al 2019:1). The possibilities of prostate cancer are high if the results show a high PSA in the blood and a small prostate. Similarly, the prostate cancer likelihood is 80% if the PSA values are

between 4 and 10 ng/ml and the prostate is large than 40 grams (Kasivisvanathan et al 1018:1768).

Ahdoot, Wilbur, Reese, Lebastchi, Mehralivand et al (2020:917), in a study to explore biopsy for prostate cancer, highlighted that all the steps related to the diagnosis procedures, implications related to the diagnostics and the related risks must be fully explained to the patients who undergo biopsy. It is further suggested that a patient be treated with broad spectrum of antibiotics prior to the procedure and that quinolones are the most common antibiotics.

The physician who performs the procedure calculate the volume of the prostate. The entire gland surface is punctured to obtain samples to obtain peripheral zone samples of which 75% of prostate cancer depends on. In total, twelve fragments are obtained of which six are collected from each lobe. It is crucial that men are informed about signs and symptoms of prostate cancer, so that men can be aware and seek help when these occur.

2.5.1 Signs and symptoms of prostate cancer

Patients with prostate cancer do not generally show symptoms of the disease, hence Prostate specific antigen screening is crucial to identify patients. However, some patients may present with symptoms at health care facilities. Tikkinen, Dahm, Lytvyn, Heen, Vernooij et al (2018:362), in a study to assess screening of prostate cancer by PSA, found that patients presented with symptoms such as decreased urinary output, urine blockage, urgency, and frequency of urination. The authors highlighted that symptom on advanced level of prostate cancer included renal failure, bone pain, bone fracture, weight loss, hematuria, and fatigue. Eldred-Evans, Burak, Connor, Day, Evans et al (2021:396) studied the diagnosis of prostate cancer using magnetic imaging (a technic used in radiology to form pictures of the body anatomy) and found that symptoms of prostate cancer generally appear 3 to 4 years after the diagnosis had been made. It is important that men are informed about early symptoms in order for them to can present themselves whilst the cancer is still in the early stage can respond to different treatment modalities.

2.5.2 Men's experiences regarding prostate cancer screening

Experiences in qualitative research refer to the interpretations, subjective perceptions, and the reflections of individuals or groups regarding a particular phenomenon. Receiving a cancer diagnosis have been found to generate various emotions and making understanding the disease and treatment difficult to understand. Gellerstedt, Langius-Eklöf, Kelmendi, Sundberg and Craftman (2022:2485) in a study conducted on the experiences of men after receiving diagnosis of prostate cancer following an opportunistic screening reported that men felt that screening was a life saver. Whilst others reported that they faced challenges such as having a lethal disease, loss of sexual function and the risk of incontinence.

Webb, Kronheim, Williams and Hartman (2006: 234) in a study found that men have multitude of apprehension towards prostate screening. However, the traditional DRE could be replaced by side lying to remedy feeling of vulnerability, and education to prepare younger males for the sensitive encounter.

Albaugh, Sufrin, Lapin, Petkewicz and Tenfelde (2017:1) in a study to explore men's experiences and their partners after surgical treatment or radiation found that men felt that they were not satisfactorily prepared with after treatment side effects such as sexual dysfunction and its impact on their intimate relationships. This makes it very important that men are provided with information to the best of their ability to adjust post treatment life.

Jägervall, Brüggemann and Johnson (2019:40) in a study conducted on the experiences of gay men after prostate cancer treatment in Sweden reported on physical changes, some of the men reported on weaker feeling of orgasms, while some felt that the prostate was an organ of pleasure during anal penetration, however that has disappeared. Relationships were impacted due to loss erection was voiced by the gay men partners. It is important that relationships are strengthened during such critical times. The issue of support should be emphasised in order to improve how patients navigate their situation.

2.5.3 Types of prostate cancer

Prostate cancer begins as pre-cancerous and can either be referred to as prostatic intraepithelial neoplasia (PIN) or proliferative inflammatory atrophy (PIA). Prostatic intraepithelial neoplasia can be classified as low grade (shows a normal appearance of the prostate cells pattern) and high-grade (display an abnormal appearance of the prostate cells) (Xin 2019:68). The man's risk to developing prostate cancer is not related to low grade PIN, whilst a high-grade PIN is a sign for developing prostate cancer in the long run (Xin 2019:68).

Proliferative inflammatory atrophy (PIA) is not classified as cancer but might lead to high grade PIN or direct to prostate cancer. The most common type of prostate cancer is adenocarcinomas- implying that cancer is manufactured by the gland cell which produces the fluid of the prostate called the semen (Xin 2019:67). Yang (2019:) indicated that the prostate has also been implicated in other cancers such as neuroendocrine tumours, small cell carcinomas, sarcomas, and transitional cell carcinomas: however, these cancers rarely occur. It is crucial to know the grading and staging of prostate cancer for better treatment plans.

2.6 STAGING AND GRADING FOR PROSTATE CANCER

The staging and grading of prostate cancer are crucial for treatment plans to determine how far the cancer has spread at the time of diagnosis. The staging and grading of prostate cancer are conducted with Gleason Score to define whether cancer has spread, and ultimately describe the progress of cancer (Montironi, Cheng, Cimadamore, Mazzucchelli, Scarpelli et al 2021:1530). More information regarding staging and what the Gleason score entails is presented.

2.6.1 Staging of prostate cancer

The process of staging describe the extent to which the cancer within the prostate and how far it has spread to other parts of the body (Buyyounouski et al 2017:245). Castillejos-Molina and Gabilondo-Navarro (2016:281) suggested that DRE and other special imaging tests such as Magnetic Resonance Imaging (MRI) scan and computer tomography may be used to stage prostate cancer. The system used for prostate cancer staging is the

Tumor, Nodes, and Metastases (TNM) system and is based on 5 key information: the extend of the main tumour (T category); whether the cancer has spread to nearby lymph node (N category); whether the cancer has metastasised (M category); the PSA level at diagnosis; the grade group. Prostate cancer has four stages often written as Roman numerals I to IV, and the more the cancer has spread is indicated by a higher stage.

2.6.2 Grading of prostate cancer

Grading of prostate cancer is a measure of how cells quickly grow or spread and the aggressiveness of the cells (Castillejos-Molina & Gabilondo-Navarro 2016:282). Gleason grading system is the most common system used for grading. Each piece of tissue in this grading system is given a grade of 3 or 5. According to Egevad, Delahunt, Berney, Bostwick, Chevillie et al (2018:8), in a study to assess the utility of image based for prostate cancer grade standardisation, indicated that a grade score of 1 or 2 was assigned in the past. A grade that is assigned less than 3 is regarded as normal, whilst a grade of 3 indicated a cancer that is growing slowly and a grade of 5 shows an aggressive form of prostate cancer (Castillejos-Molina & Gabilondo-Navarro 2016:282).

Ström, Kartasalo, Olsson, Solorzano, Delahunt et al (2020:222), in a population-based study on grading prostate cancer developed a score by Gleason system by combining two common grades, found in the biopsy sample. A low score was indicted by a score of grades 3+3 and a high score was indicated by a grade of 5+5 (Ström et al 2020:222). The Gleason score help the physician to understand whether the cancer is low, intermediate, or high-risk cancer (Schatten 2018:2). Both the grading and staging of prostate cancer help plan treatment options available for prostate cancer.

2.7 TREATMENT OPTIONS OF PROSTATE CANCER

The current study will not focus much on treatment options of prostate cancer for the purpose of this research. However, it is necessary to provide summary regarding possible treatments available for prostate cancer. There is treatment for localised disease and treatment for advanced disease. Localised disease or otherwise known as prostate cancer cases with low or intermediate risk with low tumour volume can either be actively or passively monitored. The goal of active monitoring is to detect those prostate cancers

which are aggressive and require complicated treatment modalities such as radiation (therapy that use ionization radiation to kill cancer cells) and radical prostatectomy (a procedure removing prostate gland and seminal vesicles) (Mohler, Antonarakis, Armstrong, D'amico, Davis et al 2019:479). Chemotherapy is required in some special cases (Steele & Holmes 2019:583).

Passive monitoring is an option for patients that have low risk and other comorbid conditions that allows them to have a life expectancy of less than 10 years, and this strategy focus on treating symptoms as they appear (Nuhn, De Bono, Fizazi, Freedland, Grilli et al 2019:88). Passive treatment options for localised disease include new technologies for surgical treatment of prostate cancer treatment such as robotic techniques and laparoscopy; radiotherapy; cryotherapy; highly intensive focused ultrasound and brachytherapy.

Advanced prostate cancer requires more sophisticated treatment types. Therapies such as androgen deprivation and salvage or adjuvant radiation are offered when there is biomedical recurrence of disease following radical surgery (Castillejos-Molina & Gabilondo-Navarro 2016:282). To treat recurrence diseases after radiation therapy, a hormone blockage is generally used as a palliative treatment. There is another option which is cheaper compared to hormonal blockage which is called diethylstilbesterol (DES) medication (Swami, Mcfarland, Nussenzveig & Agarwal 2020:702).

Undergoing treatment for prostate cancer can impact how men relate to their well being and masculinity before treatment. It is important that their experiences be acknowledged in order to support them. It also crucial that men experiences regarding screening and treatment made less painful and supportive.

2.8 SUPPORT

Most studies pertaining to support were conducted a while back. Support is an instrumental, emotional, informational, and appraisal assistance (Clarke et al 2006:66). Support includes the social relationships through which individual needs are met and the resources that meet these needs (Clarke et al 2006:66). According to Clarke et al (2006:66), the system of support includes formal and informal relationships and groups which a person can receive emotional (love, security, and comfort), cognitive (advice, information, and knowledge), and material support that can be helpful in stressful

situations. Accordingly, Maree, Mosalo and Wright (2013:459) in the study pertaining to women's experience of partner support reported that support can be provided by peers, family, partners, and network groups. Further, types of support include formal support- which is provided by health professionals, natural support system- provided by family and friendship networks, and social support- which can be linked to either formal or natural support (Maree et al 2013:459).

There is limited research on support for men who undergo prostate cancer screening especially within the African context. Chambers, Occhipinti, Foley, Clutton, Legg et al (2017:291) to determine whether cognitive therapy reduces stress in men with prostate cancer failed to prove its effectiveness. Support gaps among men with prostate cancer have been highlighted in studies in Canada and Scotland and suggested more qualitative studies to be conducted to develop interventions related to support (Paterson, Kata, Nandwani, Das Chaudhury & Nabi 2017:497; Carter, Bryant-Lukosius, Dicenso, Blythe & Neville 2011:189).

Carter et al (2011:189), in a study to explore supportive care needs among men with advanced prostate cancer, found that emotional distress, information needs, and functional issues were the main issues highlighted. In the study by Paterson et al (2017:497) in a study to understand the experiences of support of men diagnosed with prostate cancer in UK, found challenges with intimacy and interpersonal needs. Chambers et al (2018:1), in a study to explore lived experiences of Australian men diagnosed with advanced prostate cancer, found that men expressed a need for supportive care that is multimodal and taking into consideration their life course of illness experiences. The study further found that men felt that involvement of family/partner, peer support or sharing of experiences, communication, accessible care, and care coordination would be ideal.

The studies cited in the chapter emphasised gaps in information sharing and emotional support among men with prostate cancer; however, none explored support needs of men undergoing prostate cancer screening. It is crucial that support be discussed for the purpose of guiding this study. Limited studies could be traced addressing supportive care of men undergoing screening. The researcher is of the opinion that conducting further studies could shed light on the importance of provision of support to men undergoing screening especially in the African context.

2.9 SUMMARY

This chapter discussed the literature pertaining to prostate cancer, the burden of disease, risk factors, prostate cancer screening, staging and grading including different treatment options for prostate cancer, and support needs for patients undergoing screening.

CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

Chapter 2 discussed a literature review pertaining prostate cancer burden, risks, screening, treatment options, and support. This chapter will discuss the research design and methods employed in this study to answer the research questions. Research methods are described as the strategies, techniques, steps and procedures for collection and analysis of data in research (Huntington-Klein 2021:1; Lê & Schmid 2020:308). The research methods and design will be discussed, followed by the study setting, study population, sampling procedure, data collection, ethical consideration, and data analysis procedures.

3.2 RESEARCH DESIGN AND METHODS

Research design is an overall strategy chosen by researchers to integrate different research components in a logical and coherent way, and ensuring that the research question will be effectively addressed (Kazdin 2021:111; Lê & Schmid 2020:308). The research design constitutes the collection, measurement and analysis of data (Borusyak, Jaravel & Spiess 2021:1; Tobi & Kampen 2018:1211). A qualitative exploratory research design was conducted to explore the experiences of men undergoing prostate cancer screening at a specific tertiary care hospital in Gauteng province. The researcher used face-to-face interviews to understand the in-depth experiences of participants. The researcher used a qualitative approach to accomplish the research, as this approach is more concerned with understanding a problem rather than explaining it. It was critical to use qualitative approach to understand the reality as constructed by participants, as participants had different perceptions regarding prostate cancer, and different experiences towards screening.

Qualitative research generates non numerical data to understand people's experiences, beliefs, behaviour, attitudes, and interactions (Flick 2022:21; Cho, Grenier & Williams 2022:685). Qualitative research focuses on understanding and gaining insight about the

perceptions and circumstances of individuals regarding specific phenomena (Cho et al 2022:685; Flick 2022:21). Qualitative research explores and understand the participants' meanings as ascribed to their human or social problem (Wagner, Kawulich & Garner 2019:9). Qualitative research provides the researcher with an allowance to understand and explore the phenomenon of the study (Levitt et al 2021:3577; Kilicoglu 2018:949). Busetto et al (2020:1) indicated that one of the aims of the qualitative research is to provide an understanding of a research problem that goes in an everyday awareness detail, leading to more empathic, informed, and nuanced practice. One of the strengths of qualitative research is the ability to provide full complex description regarding the experiences of people pertaining to a health issue (Allan 2020:177). Qualitative research provides a comprehension regarding topics that relate to opposing views, beliefs, behaviours, emotions, and individual relationships, and thus endeavours a comprehension of the whole (Allan 2020:177; Busetto et al 2020:1). Intangible factors such as socioeconomic status, religion, ethnicity, social norms, and gender roles are effectively identified by qualitative research (Levitt et al 2021:357).

Researchers uses exploratory research design when there is scarce data or few studies to provide reference for a specified research problem (Peterson & Gricus 2022:1). According to Sawatsky, Ratelle and Beckman (2019:14) and Boru (2018:12), exploratory study design is conducted when there is little or insufficient information about the phenomenon or the problem of interest on which no research has been done. Exploratory research design explores why things occur when there is little information available on that topic (Gravlee 2022:67). Exploratory research can increase the researcher's understanding of the topic and help make predictions about future occurrences (Gravlee 2022:67). Exploratory research design in this study was suitable to the phenomena as there is little, or no studies of this nature conducted at the specific tertiary hospital.

3.3 STUDY SETTING

The study setting is described as the social, physical and cultural site in which researchers conduct study activities (Majid 2018:3). The natural setting is important in qualitative research and the focus is on making meanings as the researcher studies participants while they are in their natural setting (Maxwell 2021:111; Stenfors, Kajamaa & Bennett 2020:596). The initial setting chosen was a secondary care facility, however

because patients are seen for initial consultation then referred to the specific setting where the specialist doctors are present to manage the patients further.

The study was conducted at a specific tertiary academic hospital in Gauteng province. The specific academic hospital is a large tertiary academic hospital situated in the Soweto area of Gauteng. The hospital is one of the largest hospitals in South Africa. The hospital has 3 200 beds and caters for 150 000 inpatient and 500 000 outpatient cases annually. The hospital provides services including post-natal and antenatal care; gynaecology; plastic surgery; ear, nose, and throat services; ophthalmology; renal unit; paediatric; orthopaedic; internal medicine; oncology; high care; intensive care unit; and other services including radiology, speech therapy, pharmacy, and audiology. The hospital has a dedicated urology department and receive referrals from most hospitals in Gauteng province. The urology clinic at the specific tertiary hospital provides services such bladder care, kidney dialysis, penile cancer, prostate cancer, and other urological services affecting men. Patients who come to the urology clinic at the specific tertiary hospital have been referred by neighbouring secondary care facilities and some come as walk ins from the local Soweto area and the neighbouring townships. The majority of the patients are from middle- and low-income communities and does not have medical insurance to go for private hospital care.

3.4 STUDY POPULATION

A population is a group of individuals that have the same characteristics in terms of time and place (Fellows & Liu 2021:110; Asiamah, Mensah & Oteng-Abayie 2017:1607). Study population in research is described as a subset of the target population from which the sample is drawn (Fellows & Liu 2021:110; Asiamah et al 2017:1607). The population in the study consisted of all men around the ages of 40 years or older who came to the specific tertiary hospital during February to July 2022.

3.5 SAMPLING

Sampling is defined as a process in the research methods which entails the recruitment of participants in a study (Farrugia 2019:69; Majid 2018:3). There are several types of sampling procedures including probability and non-probability sampling (Farrugia 2019:69; Taherdoost 2016:20). Probability sampling is suited for quantitative approach

as it focus on random sampling of participants which is not applicable in this study, whilst non-probability sampling technique is suited for qualitative approach (Gentles, Charles, Ploeg & Mckibbon 2015:1772). A non-probability sampling was utilised for the purpose of this study. Non probability sampling techniques include convenient, snow ball, and purposive (Taherdoost 2016:22). The researcher followed a convenient sampling technique to recruit participants as they were readily available at the study setting and invited them to take part in the study.

3.5.1 Sampling procedure

Convenient sampling is described as a method of selecting participants who are readily available at the specific setting (Hennink & Kaiser 2021:1; Farrugia 2019:69; (Gentles et al 2015:1772). It is also defined as sampling procedure whereby the researcher selects a sample from the group of people who are easy to reach or contact (Farrugia 2019:69; Elfil & Negida 2017:3). The participants were sourced from the hospital urology clinic as they were already attending at the site. The researcher sourced assistance of the professional nurses working in the clinic to invite participants who were referred for screening in the hospital.

3.5.2 Sample size

Sample sizes in qualitative research are usually small so that the depth of the case-oriented analysis can be supported (Vasileiou et al 2018:148). Qualitative samples are selected by their capacity to provide rich data relevant to the phenomenon being studied. Due to the nature of qualitative study, it was not feasible to interview every individual who met the selection criteria, however the researcher made efforts to invite participants who met the inclusion criteria(3.5.3). According to Vasileiou et al (2018:148), qualitative researchers typically conduct sample size of at least 12 participants particularly in qualitative exploratory research to establish data saturation. However, the researcher planned to interview 15 participants to make contingency for those who may not be able to go through the entire interview due to excess pain or withdrawal from the study. The researcher interviewed four additional participants, bringing the total number of participants to 19, thereby ensuring that data saturation has been reached.

3.5.3 Inclusion and exclusion criteria

Inclusion criteria relates to all the characteristics that potential study participants must have in order to be included in the study while exclusion criteria relate to the factors that make participants ineligible to be included in the study (Patino & Ferreira 2018:84). The inclusion and exclusion criteria for the study are discussed below.

Inclusion criteria

The criteria for inclusion were based on the researcher recruiting patients who come for prostate cancer screening at the specific tertiary hospital during February and July 2022 who had the following characteristics:

- Men ages of 40 years or older.
- Men referred for prostate cancer screening at specific Academic Hospital Urology clinic during the year 2022.
- Men with family history of prostate cancer.
- Men who were able to give informed consent.
- Men who received positive test results for prostate screening.
- Men who are still at workup stage without confirmed prostate cancer.

Exclusion criteria

Men who have the following characteristics were excluded in the study:

- Men below the age of 40 years attending for other urologic conditions.
- Men already on prostate cancer treatment.
- Men who were not able to provide informed consent.
- Men who were above age 40 years but too ill to participate.
- Men who may present with other psycho-emotional problems.

Men below the ages of 40 years were excluded as they have been cited to less likely to present with prostate cancer (Rawla 2019:63),

3.6 DATA COLLECTION

Data collection is a process in which researchers gather and measure information in an established system on targeted variables, and this enables the researcher to evaluate outcomes and answer the relevant question (Fellows & Liu 2021:110; Li, Higgins & Deeks 2019:109; Nguyen 2019:195).

The researcher was solely responsible for data collection and soon began once the ethical clearance was obtained from the Unisa College Research Ethics Committee (CREC) (Annexure A). A letter requesting permission to conduct the study was communicated to the CEO at the tertiary academic care hospital (Annexure B), however was advised to apply for an online permission at the National Department of Health (DOH) which is mandatory for researchers to utilise health facilities for research purposes. Once an application was submitted on the National Health Research Database (NHRD), the researcher received communication from the head of urology department at the specific tertiary hospital and permission to conduct the study at the facility was granted (Annexure C).

Due to the global SARS Covid-19 pandemic, the researcher observed all Covid-19 protocol measures as stipulated by (WHO 2020:) and followed Unisa Guidelines for SARS-Covid-19 as well. Such measures included hand hygiene, respiratory hygiene (use of clean safe facial mask), physical distancing, environmental cleaning and management of Covid-19 patients (WHO 2020:1). The hospital was already adhering to the SARS-Covid-19 guidelines. The researcher requested permission to utilise one of the private rooms in the Urology department, which was already disinfected, to conduct the interviews. The researcher provided hand sanitiser and disposable masks to accommodate participants who did not have face masks and requested them to wear a mask before commencing the interviews.

Once facility permission was granted at the urology clinic at specific tertiary hospital, the researcher scheduled a meeting to visit the urology clinic. The agenda was to familiarise himself with the clinic and to meet with the staff working at the urology clinic to explain regarding the study. The researcher planned with the staff about the suitable days on which data collection can take place. The suggested days for collecting data were Wednesdays as participants for this study were available only these days. The researcher

under the guidance of the supervisor planned with the urology staff about the number of participants to interview per day. A decision was made to recruit a maximum number of two participants per day to allow for subsequent transcription of data.

A self-developed semi-structured interview guide was used to collect data by the researcher (Annexure D). The interview guide was informed by other studies regarding the choice of questions (Baratedi et al 2020:89; Adibe et al 2017:1962; James et al 2017:2). The questions in the interview guide focused on prostate cancer experiences, perceptions, support needs, and the screening measures. The interview guide was validated by colleagues working in a similar setting, as well as the staff working in a day-to-day care at the urology clinic and the head of the department of the urology at the specific tertiary care hospital, including the supervisor. Prior to the actual interviews, the interview guide was tested on two participants who shared similar characteristics with the prospective participants to check their ability to understand the questions.

Each interview began by the researcher welcoming participants followed by the researcher explaining their role during the interview (Annexure H). The researcher explained about the study to participants to make sure they understood the study before they signed the consent forms. The researcher assisted participants to complete the informed consent (Annexure E) and the informed consent for the recording (Annexure F) for a smooth administration prior to take part in the study. The rationale for recording the interview was that the researcher might not be in position to remember the entire discussion during the interview. Also, that the conversation can be replayed and transcribed later for analysis as this cannot be performed simultaneously. Participants were also given copies to take home in case they might want someone to read for them at their homes (Annexure G). The researcher obtained participants demographics (Annexure D) and asked the participants about their experiences, perceptions, support needs and screening measures.

Most of the languages spoken in the community are Zulu and Setswana. The researcher being a resident in a similar community being conversant in Zulu and Setswana languages conducted the interviews. Most of the interviews were conducted in Setswana language as participants were not forced on a language they did not understand and only few were conducted in English and Zulu languages. The researcher initially completed the interviews with 15 participants as there was no new information coming up, however

additional 4 interviews were conducted to ensure data saturation, totalling to 19 interviews for the study. Data saturation is the process where there is no new information emerging in the interview conversations (Guest, Namey & Chen 2020:2).

3.7 DATA ANALYSIS

Data analysis is a process of cleansing, inspecting, modelling and transforming data with the goal of deriving useful information, conclusions and support of decision making (Fellows & Liu 2021:333; Taherdoost 2022:1; Mihas 2019). It is the process of applying statistical or logical techniques to illustrate, describe, recap, condense, and evaluate data (Taherdoost 2022:1; Mihas 2019:26).

The recorded audio interviews were played several times and transcribed verbatim by the researcher to ensure that no meaning was lost during transcription. The researcher transcribed each interview immediately after the interview to ensure that it captured the information as shared by the participants. Data analysis followed an iterative process i.e., the researcher immersed himself in the data and read through the transcripts several times to search for meanings. The transcriptions were checked for quality by the researcher comparing them against the original interviews to ensure meaning of the interviews were retained. To maintain consistency in codes and meaning, the intercoder also coded a select number of transcripts as a means of verification. The researcher submitted two transcripts to the supervisor to verify and check if there are any errors, as well as consistency of the codes developed.

To elaborate on the objectives, a thematic analysis of the collected data was conducted to guide the analysis process. Thematic analysis is a process for analysing qualitative data which entails searching through the data to identify, analyse and report repeated observed patterns (Lester et al 2020:97). This method was suitable as it relied on similarity principle that entailed looking for information that has similar content, meanings or symbols and a contrast principle that entailed looking for content that disrupted the emerging themes (Kiger & Varpio 2020:846). The researcher also used thematic analysis to reduce bias in the study as themes were produced from the data and not invented by the researcher.

The researcher developed a codebook in which a list of codes and categories, and themes were identified. The codebook consisted of themes and categories that were used in data analysis (Lester et al 2020:97), including developing codes (Annexure J). Coding is a process of identifying passage in texts, searching concepts and making relations between the texts (Lester et al 2020:97). Themes were developed inductively from the qualitative data itself and were classified as themes and categories (Akinyode & Khan 2018:171). The researcher coded the data manually in Microsoft word using highlighters to group codes to search for meanings.

The data were stored electronically and encrypted on drop box and will be discarded after a period of 6 years to allow sufficient time if one might need to redo the analysis and to share the de-identified transcriptions if the study is submitted to a peer review journal. Only the researcher, the intercoder, and the supervisor had access to these data.

3.8 ETHICAL CONSIDERATIONS

It is mandatory for researchers to adhere to all ethical standards, exercise care and ensure that they protect the rights of participants when conducting research that involves humans as participants (Newman, Guta & Black 2021:1; Hasan, Rana, Chowdhury, Dola, Rony et al 2012:1). The ethical standards were appeased throughout the study by ensuring that all the principles of ethics were followed.

3.8.1 Permissions of the study activities

The research proposal for the study was submitted for ethical clearance at Unisa College Research Ethics Committee (CREC) for approval, and permission was granted (Ethics reference number: 61263079_CRECHS_2021) (Annexure A). Permission to conduct the study at the study site was sought from the specific tertiary hospital and permission was granted (Annexure C). To seek permission from the study site, initially a letter requesting permission was communicated to the hospital management (Annexure B) and the researcher was advised to submit the application at NHRD. Participants in the study signed informed consent for agreeing to participate before participating in the study (Annexure E). Participants signed the informed consent that allowed the researcher to record the audio interviews (Annexure F).

3.8.2 Informed consent

An informed consent is described as the process in which a researcher informs participants about the risks and benefits of participating in a research study (Manti & Licari 2018:145). Participants were conversant with the information pertaining to the study to make a voluntary decision to take part in the study. Informed consent obliges researchers to ensure that participants are fully engaged in making decisions to participate in the study and avoid making participants to feel that they are forced to participate (Biros 2018:72). Informed consent obliges researchers both ethically and legally (Manti & Licari 2018:146).

The participants in this study were provided with an information sheet (Annexure G) which details the terms of the participants' consent and explain the aim of the study. The researcher had an opportunity to explain the purpose of study, emphasised voluntary participation and explained what it means to take part in the study to participants in a face-to-face encounter in a private room. To participate in the study, participants provided an informed consent. Participation was strictly voluntary, and potential participants were fully informed that they can withdraw participation at any time during the study and this would not be used against them in any way. Participants who consented to in the study provided signatures for agreeing to be interviewed and audio recorded (Annexures E & F). The researcher provided contact details including those of the supervisor in case participants had questions that need clarity.

Participants were informed that all the information collected during the study will be kept confidential and password protected on drop-box. Only the supervisor and the researcher have access to the information collected, including intercoder who had to code some of the transcripts to ensure that it captured participants statements (Annexure I). Confidentiality was ensured as the participants personal information would not be linked to the interviews. Also, would be used in the dissertation or the manuscript. However, the demographic characteristics of the participants was reported in the dissertation and the manuscript.

3.8.3 Ethical principles

The researcher in the study ensured that the research ethics principles practiced in the study are in accordance with those highlighted in Kemparaj and Kadalur (2018:822) such

as are respect for persons, beneficence, non-maleficence, and justice. The following Ethical principles were upheld in the study: respect for persons, beneficence, non-maleficence, and justice.

3.8.3.1 Respect for persons

Respect for persons is the principle of autonomy which is a Latin word for “self-rule.” Researchers are obliged to respect the autonomy of participants (Armond, Gordijn, Lewis, Hosseini, Bodnár et al 2021:1; Bitter, Ngabirano, Simon & Taylor 2020:1). The researcher must respect the decision made by participants concerning their lives and or the study (Armond et al 2021:1; Bitter et al 2020:1). It is also referred to as the principle of human dignity (Kemparaj & Kadalur 2018:822). It provides researchers with the duty of not interfering with decisions made by competent persons and to empower them (Armond et al 2021:1). The researcher in this study respected the decisions made by participants and assured them that withdrawing from participating in the study will not have any negative consequences towards them. Participants were not coerced to take part in the study.

3.8.3.2 Beneficence

The principle of beneficence obliges researchers to do good for participants (Armond et al 2021:1; Bitter et al 2020:1). It is the moral of doing good to others (Armond et al 2021:1; Kemparaj & Kadalur 2018:822). It promotes doing the best for the participants. Although there were no direct benefits to the participants, the findings will be crucial to guide future support provided towards men who undergo prostate cancer screening in clinical settings and increase the uptake of prostate cancer screening among men.

3.8.3.3 non-maleficence

Non-maleficence is the principle of doing no harm (Armond et al 2021:1; Kemparaj & Kadalur 2018:822). It is the opposite of beneficence and states that no harm should be done to participants (Armond et al 2021:1; Bitter et al 2020). Initially, the researcher anticipated potential psychological harm resulting from the interviews. Preparations were made to address the anticipated harm which included notes of the researcher advising participants to stop the interviews should they feel uncomfortable or any distress. It was expected that potential participants might know or relate to someone who suffered from

prostate cancer, hence the experience led them to come for screening. Interviewing these patients was expected to unfold psychological trauma. The researcher made the hospital management aware that there might be a need to utilise the hospital counselling service. The researcher together with management arranged on standby counselling should it be needed. However, there was no harm resulted from participating in this study.

3.8.3.4 Justice

The principle of justice has four components including respect for law, distributive justice, retributive and rights justice (Armond et al 2021:1; Bitter et al 2020:1). Kemparaj and Kadalur (2018:822) reported that respect for law is the obligation of the research activity to not be against the law; distributive justice is equal allocation of resources; retributive justice is the correction of wrongs when they occur; and then rights justice is the special advantages accompanied by related duties (Armond et al 2021:1; Kemparaj & Kadalur 2018:822). To accomplish these, all the research activities in this study were not against the law. Participants' rights were always respected throughout the study period. The researcher took measures to ensure that participants did not experience any emotional harm during the interviews. However, as a precautionary measure, counselling sessions were arranged with the hospital counsellor at no cost to the participants, in the event of any potential emotional distress. None of the participants experienced any emotional harm or took decisions to withdraw from the study.

3.9 RIGOUR OR TRUSTWORTHINESS

The criterion for assessing qualitative studies is trustworthiness. Trustworthiness is the confidence in the collected data, the research methods applied, and interpretation of the study findings to ensure that the study is of high quality (Kumar, Capraro & Perc 2020:20200491; Kyngäs, Kääriäinen & Elo 2020:41). Trustworthiness is a key concept as researchers are allowed to describe the qualities of the qualitative terms from the outside restrictions (Kumar et al 2020:20200491; Kyngäs et al 2020:41). The value of truth, consistency, neutrality, and applicability are necessitated by quality of the research (Kumar et al 2020:20200491; Kyngäs et al 2020:41). The quality of data was maintained by field notes, effective communication, quality recorder, and comfortable environment. Prolonged engagement in the field with participants at the specific tertiary hospital allowed

the researcher to build rapport with participants, and this helped obtain rich, useful, and accurate data.

A qualitative researcher should go out in the field and personally be involved in every step of the research and find the “truth” to understand the social reality of participants (Kumar et al 2020:20200491; Kyngäs et al 2020:41). For a qualitative study to be accepted as trustworthy, the researcher must demonstrate a precise, exhaustive and consistent manner through recoding, and full disclosure of analysis methods to enable the reader to assess if the process is credible (Rose & Johnson 2020:432). Guba and Lincoln (1989) as cited in Maher, Hadfield, Hutchings and De Eyto (2018:3) indicated that the research process should satisfy four criteria in order to ensure trustworthiness. These criteria are credibility, transferability, dependability, and conformability.

3.9.1 Credibility

Credibility is the confidence in the collected data and the interpretations. Credibility ensures the measurement of the original intent of the study and researchers strive for saturation of data to establish credibility by continually collecting and analysing data and comparing it to see if new themes, ideas and constructs emerge or to see if there is reemergence of the same notion. (Kyngäs et al 2020:44). The researcher collected data in the languages that the participants understood and there were no language barriers as the researcher is conversant with languages spoken in the communities utilising the specific tertiary hospital. The researcher conducted multiple visits at the urology clinic at the tertiary care hospital and collected data until saturation was reached. It helped to collect data from different participants at different times, as this provided data from a diverse pool. The researcher maintained accurate analysis and truthful reporting of findings.

3.9.2 Transferability

Transferability refers to how the findings of the study can be replicated to other settings or context, and a full description of the phenomenon being studied (Kyngäs et al 2020:44). The researcher gave a thick description of the results to enable the reader to evaluate whether the study can be replicated to their context. The collected data contained rich data and the study findings and conclusions were supported by detailed participants' responses, and this will allow the reader to decide if the finding can be transferred to other

settings taking into consideration the characteristics shared by the participants and the study setting.

3.9.3 Dependability

Dependability ensures that the work is described fully in such a way that another researcher will be able to repeat the process, and provide evidence that the study findings are stable and consistent over time (Thirsk 2021:328; Kyngäs et al 2020:45). Dependability refers to an extent that other researchers may repeat the research process and find similar findings. The researcher took detailed notes in the field, and audio recorded the interviews, then transcribed the interviews and cross checked with the filed notes to check if the information corresponds. However, the study approach and interpretations may be influenced by the study researcher's past experiences, biases, and prejudices (Kyngäs et al 2020:41). One method of resolving this was bracketing in which researchers uses this to separate their own experiences with what is being studied. The researcher wrote memos throughout data collection and analysis and reflected on his engagement with the data.

3.9.4 Conformability

Conformability try to minimise the researcher bias and it is the degree of the neutrality of the findings of the study (Kyngäs et al 2020:45). The researcher acknowledged any predisposition on the topic. Audit trail is the most popular technique to establish conformability in qualitative research which include a detailed description of the data collection process, data analysis and the interpretation of results (Jamie & Rathbone 2022:11; Forero, Nahidi, De Costa, Mohsin, Fitzgerald et al 2018:120). To achieve this, the researcher fully described the data collection process, analysis, and interpretation of results for this study. The researcher interpreted the findings as close as possible based on the analysis to reflect the views of the participants and compared the findings with the literature.

3.10 SUMMARY

This chapter discussed the research design and methods that guided the study. The study setting, population, sampling procedures, data collection process, rigor of the study, data analysis and management, and the ethical considerations of the study were also discussed.

CHAPTER 4

ANALYSIS, PRESENTATION AND DISCUSSION OF THE RESEARCH FINDINGS

4.1 INTRODUCTION

Chapter 3 presented the research design and methods of this study. This chapter presents the analysis, findings including literature control, and discussion of the study.

4.2 CHARACTERISTICS OF STUDY PARTICIPANTS

This section reports the characteristics of the study participants. A total of 19 participants between the ages of 54 and 84 years participated in the study. Most of the participants were Zulu (n=6), followed by South Sotho (n=4), Swazi (n=2), Tsonga (n=2), Coloured (n=1), Ndebele (n=1), North Sotho (n=1), Xhosa (n=1), and other (n=1). Most of the participants (n=15) came from urban region while four came from rural areas and was referred to the hospital. Most of study participants were married (n=14) while few were either culturally married (n=2), cohabiting (n=1), in a stable relationship (n=1), or single (n=1). Most of the participants completed their tertiary education (n=10) while 7 participants completed grade 11-12 and only 2 men completed grade 8-10. The majority were on state pensioners grant (n=15), receiving a monthly pension income of +R2000 (n=15). The other four participants were unemployed, however, of these, two were receiving a monthly income of +R2000 while the other two did not have any monthly income.

4.3 THEMES AND CATEGORIES THAT EMERGED FROM THE DATA

The study explored the experiences of men attending prostate cancer screening at a specific tertiary care hospital in Gauteng, and how they wish to be supported during screening period. Six themes emerged which were: (1) prostate cancer knowledge, (2) screening influencers, (3) sources of information regarding prostate cancer, (4) barriers to screening, (5) symptoms experienced during screening, and (6) the support needs (Annexure J). Once themes emerged from data, categories were developed from codes

and were representing similar issues. A summary of themes and categories is presented below (Table 4.1).

Table 4.1 Summary of themes and categories

Themes	Categories
1 Prostate cancer knowledge	1.1 Lack of knowledge of the disease
	1.2 Partial knowledge of the disease
2 Screening influencers	2.1 Referrals by a health care practitioner and having other comorbidities
	2.2 Family history of prostate cancer and knowing someone affected by the disease
	2.3 Symptoms experienced prior to diagnosis
3 Sources of information regarding the disease	3.1 Media
	3.2 Pamphlets
4 Barriers to screening	4.1 Fear, shyness, and embarrassment
	4.2 Lack of information regarding the disease
5 Symptoms experienced during screening	5.1 Pain
	5.2 Discomfort
6 Support needs	6.1 Provision with information pertaining the disease
	6.2 Provision of counselling before and during screening
	6.3 Provision of good pain control and treatment
	6.4 Reduction of waiting time
	6.5 Support person present during screening

4.3.1 Theme 1: Prostate cancer knowledge

The first theme that emerged was knowledge of prostate cancer. Participants were asked to explain their knowledge regarding prostate cancer. Two categories emerged which were (1) lack of knowledge of the disease, and (2) partial knowledge of the disease.

4.3.1.1 Category 1.1: Lack of knowledge of the disease

Most of the participants in the study lacked the knowledge regarding prostate cancer and as a result they did not go for screening. The study revealed that majority of the participants did not have any knowledge of prostate cancer, whilst others indicated that they have heard about prostate cancer however they do not know much about the disease. The following are participants narratives:

“Nothing! only ... I hear of it, but I don’t know anything about it.” P1.

“I do not want to lie, truly speaking I do not know anything about it. It is only when I was attending the clinic, this year, then they send me here (implying the academic hospital), saying it looks like I have cancer. So, I do not know anything, even what causes it I do not know!.” P3

“I am beginning to hear the word prostate cancer here at the hospital. The time I started being ill.” P4

“Well truth be told I know nothing, which is why I am here, I’ve been referred to here and all that, so I know nothing.” P5

“And then the other thing sir you have a believe, our fathers and grandfathers we have never had thing of a person having prostate cancer, so our knowledge of this condition is not well.” P16

“Hmm prostate cancer for me I don’t know how I will explain it, because I only feel it in my body that it is painful. So, I don’t know how I can explain how I am feeling so that you can understand.” P14

Although some participants alluded to not knowing about the disease, even those who stated that they know it was only partial.

4.3.1.2 Category 1.2: Partial knowledge of the disease

Partial knowledge is defined as either the knowledge that is used consistently but have errors or when the knowledge is used inconsistently (Ugochukwu et al 2019:168). Although some of the participants lacked the knowledge regarding the disease, some had form of information, though it was not wholly true pertaining to the disease. Participants described prostate cancer as follows:

“They say something close up (pausing and pointing” down” on their trousers and the penis) ... of swollen down there, close-up of down there.” P1.

“Uhm one thing I know about prostate cancer is that it grows in the pubic area. And it is giving problems with urinating. And then sometimes it can extend to the spine.”

P6

“I hear that they say a person have difficulties with urinating. Some says the urine just goes off.” (Meaning uncontrollably). P3:

” Uhm! it can even go to the extend if not being detected at an early stage you can even lose your mind, forgetting that you are undressed just going out.” P8

“Actually, err! I don’t know much about prostate cancer, but I know about prostate enlargement because I have gone under prostate enlargement. And they did two twice biopsies, but they found that it was negative, so they want to do another biopsy; again, because the prostate is enlarging. Yea that’s why they want me to go to biopsy again.” P16

Others had these to say:

“Well not much. But when you go to a local clinic the nurses always talk about prostate cancer and they advise that at the age of 40 you must go and test.” P12

“Uhm for me as far as prostate cancer is concerned, I know that black men, I know that prostate cancer usually affects black men. And then men, especially over the age of 40, yeah! are the ones who suffer from prostate cancer most of the time.”

P15

“So far this is something that I’ve always knew it is there and the result is that us men we should always come to check it especially when we reach certain age and check your state of it.” P18

4.3.2 Theme 2: Screening influencers

Another theme that emerged from the data was screening influencers. Studies conducted regarding screening influencers found that referrals by health care practitioners, old age and experiencing symptoms of the disease prompted participants to go for screening (Shungu & Sterba 2021:925; James et al 2017:1). The finding from the study found the factors that influenced participant’s decisions to come for screening at the specific tertiary

care hospital were (1) referrals by a health care practitioner and having other comorbidities (2) family history of prostate cancer and knowing someone affected by the disease, and (3) symptoms experienced prior to diagnosis.

4.3.2.1 Category 2.1: Referrals by a health care practitioner and having other comorbidities

Health care practitioners plays an important role in advising or recommending screening to older men who have other ailments and comorbidities such as high blood pressure and diabetes to go for prostate cancer screening (Shungu & Sterba 2021:925; Enaworu & Khutan 2016:525).

Some of participants in the study were referred by the health care practitioners, which influenced their decision to go for screening. Other participants reported that they usually go to the local clinics for other medical reasons such as other comorbidities such as going for follow up for diabetes and high blood pressure and were then referred for screening. The participants had this to say:

“I was attending the clinic for high blood pressure. I have high blood, so when I was attending the clinic. Then when they took our blood ... the results came then they told me that it looks like you have prostate, then the sister (registered nurse) gave me a referral letter and said I should go to the hospital.” P3

“I have been referred here from the clinic in Kagiso (one of the satellite primary care clinics). I have been attending treatment for high blood pressure there. So, they found out that my BP (blood pressure) was not good, so they decided to refer me here at Bara. That’s what I know, the problem was BP.” P5

The participant had this to say further:

“When I arrived at the clinic, they told me that the results are back, so when the results are back, they show that I have cancer. That is when they gave me a referral letter to the hospital.” P5

“So, as I am attending the clinic, they took blood tests and they told me that they suspect it (prostate cancer), so they took the bloods for tests and all that. So, when

the blood came back, they said to me nah! you have got prostate cancer and they... that clinic (keyarona) they referred me straight here to Bara.” P9

“Yea! so usually I go to the clinic. I am attending the clinic to get HIV treatment so every year I take blood for the tests... But apart from that I enquire about it (prostate screening) because I know I am long due, so I have been checking since the age of 50 and they been telling me that there is no problem. But when I checked the last time when they referred me for cancer, prostate cancer, they found that my PSA was high. Yea! (emphasising)!.” P10

“Yea I have high blood pressure, and diabetes; So, every after 3 months I go to the clinic for checkups. So that they can see if my blood pressure is up or the sugar level.” P8

Participant further said:

“They refer you here at Urology! they told me that the condition that I have is very dangerous and as such you should go to urology so that you can find help.” P8

4.3.2.2 Category 2.2: Family history of prostate cancer and knowing someone affected by the disease

Previous studies indicated that family history is one of the major risk factors for developing prostate cancer (Williams et al 2018:2165; James et al 2017:1; O’Rourke 2007:165).

Rawla (2019:63) defines family history as the record of medical history and the relationships among family members. Laynet et al (2019:91) indicated that family history consists of information regarding diseases among blood relatives of patients.

Some of the participants cited reasons for accessing health care was because they witnessed a family member or relative having the disease. Participants reported that they feared going through the same path that their family member went through. The narratives were as follows:

“Uhm prostate cancer my father actually had one and he passed on so, even my brother. But after my brother passing on, I started taking blood from the clinic telling them to make thorough check, whatever kind of disease, they must just do.” P2

“As I was saying my father had one and my brother had one, so I didn’t want to end up in a situation I saw happening to them. So, I wanted it to be detected as early as possible.” P4

The participant further said:

“So that I can be able to deal with it because if one thing has jumped number 1 and 2 and then you know by 3 its going to be a dead thing. Yes! so, I didn’t want to be there.” P4.

Others had these to say:

“Yes, in a family there’s one in my family, my cousin. We discuss about prostate and even share ideas and everything. I also make sure that within the family circles, friends or people who are close to me.” P11

“My father died; he had prostate cancer. my father is the only person I know who had prostate cancer. But I don’t think it is only prostate cancer because he had other issues, you see yeah.” P15

4.3.2.3 Category 2.3: Symptoms experienced prior to diagnosis

Accordingly common symptoms presenting prior to diagnosis of prostate cancer are erectile dysfunction, urinary incontinence, and urine blockage (Tikkinen et al 2018:362). This confirms what was reported in the study:

“The thing that took me to the clinic, I was at a shop a hardware shop, I just realised that I was not able to hold my urine. I just noticed late when I have wet my pants. Then from there (laughing) (embarrassed) I went to a doctor.” P13

“At respiratory I asked the doctor, after attending me he asked me what else is bothering me. And then I told the doctor that when I sleep with my woman, I no

longer get strong you know my “4 5” (South African slang ‘for penis’) becomes soft, so I asked if I will never get help. That’s when he sent me here at Urology.” P4

“I can feel that my urine is hot but I can sit for two months while the urine is burning me until I discuss this with another man, maybe while we are chilling somewhere and we have a conversation and he says maybe this thing is caused by 1 2 3 (other causes) that’s when I will go to the hospital when I am already sick and feeling pains things like that.” P15

“Since I had a problem with urine blockage last year in April, then I came here after 4 days. I had a blockage urine for 4 days and then I could not even relieve myself, so I came to the clinic.” P19

“I did not feel well in my body, I can say I was sick because the pains started while I was at work and then I had to drive, it was hard. I felt my urine wanting to come out, but it didn’t come out.” P18

“I felt not right in my body, yea! (emphasising) Well, I must come to check up. And so, they caught it. I was dizzy. I came to trauma. They referred me to this other woman somewhere here, and they referred me to H4 that is where they found the results.” (Supposedly PSA).” P6

“From nowhere I experience urinary problems. And I said maybe it is because I don’t drink lots of water!! that is the cause I ran to buy soda and I drank it and I find out that it is not helping. After that I realise that this thing is quite serious. When I tried to pass urine, I felt like am doing number 2 (implying excretion of solid waste or poop) when I am doing number 1 (passing urine).” P16

“Normally I transport school children ... so this thing happened in the morning just after I dropped them at the primary school. So, the doctor told me that it could be an infection because I have never had any sign before. So, the doctor gave me an injection and told me then I will be able to pass urine but then for an hour nothing happened until he said to me that I need to go to see urologist doctor for this kind of problem.” P10

4.3.3 Theme 3: Sources of information regarding prostate cancer

The third theme that emerged from the data was information sources regarding prostate cancer. The information sources were (1) media, and (2) pamphlets from the health facility.

4.3.3.1 Category 3.1: Media

The media plays a major in communicating health in the public as most people are exposed to the media (Chhatre, Wittink, Gallo & Jayadevappa 2020:1). Accordingly, the media types were identified as source of information regarding prostate cancer among three study participants. The following information was shared:

“I have seen this on media as well, internet as well because I have been perusing it to even understand what I am going through, so I have been doing my own research as well.” P17

“From the radio and newspapers, they always say this, I am a person who hear the news a lot, I also read a lot, so I sometimes come across these things.” P16

“My understanding due to the research I conducted on Google about prostate, I know that prostate cancer usually affects black men.” P12

4.3.3.2 Category 3.2: Pamphlets

The participants reported that the health facility distributed pamphlets as a way of passing knowledge or rather communicating health information to patients. One participant reported that they received a pamphlet from the local clinic while others indicted that the pamphlet was provided at the specific tertiary care hospital. Their narratives were as follows:

“At the clinic most of the time they encourage men that they must go for prostate screening, especially in the townships they have notes, (implying pamphlets), there are pamphlets, and they encourage men that at the age of 40 you must go and check-up for cancer.” P19

“I only got a pamphlet today ... yea and I read it.” P14

“They showed me that book about prostate cancer. That lady” Mosa” she showed us that book about prostate, and that’s when I started to hear that I have prostate.”

P9

4.3.4 Theme 4: Barriers to screening

Yeboah-Asiamah, Yirenya-Tawiah, Baafi and Ackumey (2017:184) in a study conducted in Ghana reported that barriers may discourage a patient to take part in the screening of prostate cancer. Further, other barriers cited towards prostate cancer screening were fear, lack of information, and embarrassment (Baratedi et al 2020:87).

The categories that emerged from screening barriers were (1) fear, shyness, and embarrassment, and (2) lack of information regarding the disease.

4.3.4.1 Category 4.1: Fear, shyness, and embarrassment

Fear and embarrassment have been implicated as barriers to screening in other studies of prostate cancer screening (Yeboah-Asiamah et al 2017:184). Participants in the study reported that fear, shyness, and embarrassment were barriers to prostate cancer screening. Theirs responses were as follows:

“Maybe they are scared, so they don’t come to check their prostate.” P1.

“I sometimes feel like maybe men know about this thing and what it is going to be done to them. Sometimes you find that I am a man my age ne! (emphasising) I am scared to be inserted those fingers or sometimes.” P13

“I also think it is little knowledge that we have especially concerning our health. You see yeah. For me when I have pain, I just keep quiet thinking it is a small thing I do not attend to it.” P15

Whilst others had this to say:

“They are shy. Yea! they are shy ... This is how I see it. Some it is because they are shy! like hai people will say I have prostate cancer you see.” P3

“Well men if you check they are embarrassed when it comes to these things. They have this thing that this is my life, this is my privacy, then to be checked by other people I will never be a man enough, well I am going to be disrespected. Do you get me. so that is why sometimes some of them refuse.” P5

“You find that another man is embarrassed that at his age he will have to undress for a younger child (implying young doctors) (the participant was embarrassment as he reported).” P7

“There is nothing except that I am scared of being inserted finger, I am scared of it.” P12

“For me it is my first-time meeting something like this, I sometimes feel like maybe men know about this thing and what it is going to be done to them. Sometimes you find that I am a man my age ne, I am scared to be inserted those fingers.” P13

“Some of them do not want to be castrated, they don't want to be cut and that is why they do not come.” P8

“Most men have doubt or fright. So, when you have doubt, and they also like to listen what other people are saying. Just like me when I went to test if there a person and I told them about the pain that I felt they might decide not to go there anymore.” P10

“It is scary first and foremost. It's a procedure whereby you have never done it before, you hear people and other patients talking about it.” P11

4.3.4.2 Category 4.2: Lack of information regarding the disease

Lack of information has been identified as a barrier to screening in previous research by Awosan, Yunusa, Agwu and Taofiq (2018:51). The participants revealed that lack of

information about prostate cancer screening was a barrier to screening for prostate cancer, as evidenced by the responses shared:

“Most of the time it is lack of knowledge you get my point! It is lack of Knowledge! With me I just discovered that, I am 68 years now, I think I was 63 or 64, when I Googled. If I knew before that at the age of 40, I should start checking I would do that and then those younger than me I would tell them that at the age of 40 you should test.” P18

“I think you know what, I don’t know how I can put it... an un-educational behaviour (implying people with low level education). I mean some people they just want to act ignorant! You see if I say ignorant it’s that they know that it is there, but they want to put themselves on a side that ah! I will see it when it comes. And that thing of ah ... I will see it when it comes, that time when it comes maybe it comes on stage 4.” P2.

Another of the participants expressed that men do not just care about life:

“Sometimes I feel like these people do not care about their life too much. It looks like they do not care about their lives so much.” P3

Others had these to say:

“This should start from the community. Because the community, if you tell the community what prostate cancer is, how it happens then people will be able to know and go to the hospital and start to test prostate cancer early before it is too late!! (emphasising). Yea!! it should start from the community not here at the hospital. Because if it starts from here, it means you are suffering already (implying by then definite cancer has being diagnosed!).” P13

“Us black people, I am sorry to talk like this, but we have our own believe, we don’t believe in these things. But honestly not knowing what you trust because you have to go to find help. For me there is nothing that I am scared of when I go to the doctor, I know the doctor will help me. It could be that I have wrong knowledge about something (laughing)appears embarrassed.” P15

“So, we also like to go see traditional healers to make us some medications what is the use of going to the hospital because the traditional healer is like a jack of all traits, and only to find out that the person knows nothing about this particular disease that you have and he cannot even understand!.” P16

4.3.5 Theme 5: Symptoms experienced during screening.

Elhardello and MacFie (2018:579) reported that most of the time patients experience pain and discomfort during the process of prostate cancer screening. Participants were asked about their experiences regarding the screening procedure at the specific tertiary care hospital. Two categories emerged which were: (1) pain, and (2) discomfort.

4.3.5.1 Category 5.1: Pain

The study revealed that majority of the patients experienced pain during screening. Mostly severe pain reported were associated with the digital rectal exam procedure. They report that the pain came when the health practitioner inserted an object in their rectum in a search for the prostate cancer. Their narratives were as follows:

“Eish pains, it is very painful (laughing- patient (embarrassed!!). But he (the doctor) told us before the procedure that it is painful, but as this is the normal procedure you must tolerate the pain. And indeed! I did tolerate.” P3

“When they insert that thing, it was difficult getting in and it was painful (loudly emphasising this!!). Yea! it is very painful! And the time he was removing that thing then I was even able to breath now.” (getting a sense of relief). P4

“Yo! it is very painful. Yea it is really very painful. But if you want to live you will just tolerate the pain so that you can live.” P10

Further another participant described pain followed by bleeding as follows:

“Nah!! (emphasising), that one is the worse pain you can experience in your lifetime! I don't think there is any other pain more than that, anything more than that then it is death. That was really close to death yeah!” P17

Other participants further said:

“It is not nice at all because it is like someone is shooting you straight at the prostate with a needle 12 times ... you pass blood. Yes, it is not blood mixed with urine, you only pass blood.” P15

“I felt so dizzy! I felt dizzy!! (emphasising), and he said (the doctor) nah! you must sit. I felt dizzy and a lot of pain (emphasising!). Then after 10 minutes then I felt the dizziness coming to an end, then he put me on a chair and said I should sit there for half an hour.” P3

4.3.5.2 Category 5.2: Discomfort

Despite that some reported pain, few others took this in a lighter side. Their narratives were as follows:

“I don't know the name of the instrument that was inserted at the back because they had inserted it at the back something that grasp a bit, you see. That is the only thing I felt but just a little bit.” P5

“Well, when they started, I felt uncomfortable. When they started to insert the finger to feel anything at the back of me because he wants to feel any irregularities you just feel uncomfortable. Yeah! because usually, there is nothing that enters there at the back yah that's it.” P15

“I mean anything they stuck in your body it makes you uncomfortable.” P12

“I am going to speak the truth. I did not like it when he inserted a finger inside of me. But then I just accepted it because this person is a doctor. So, I must accept what he says we should do.” P7

Despite that some participants had their experiences regarding the digital rectal exam, others had something positive to say. The participants expressed excitement knowing that they were going to receive help in this regard. The narratives follow:

“Am no ... What can I say (seem unsure!) I can't mention how I felt. I was just happy that I am getting treatment and that I am going to be strong again (referring to penis).” P4

“Oh, yea it was not too bad. It was not too bad because I knew they are working yea (implying its part of the process).” P13

“Nah because I want life, I did not have a problem with the process... yea I agreed, and I said they should check everything that they need to check.” P8

“I don't have any problem, not at all. That's why I am saying I am happy that I came here and found out that it is starting and go along with it, that's it.” P2

4.3.6 Theme 6: Support needs

Research on support date a while back. According to Clarke et al (2006:66) the system of support includes formal and informal relationships and groups which a person can receive emotional (love, security, and comfort), cognitive (advice, information, and knowledge), and material support that can be helpful in stressful situations. Maree et al (2013:459) reported that support can be provided by peers, family, partners, and network groups. Further, types of support include formal support- which is provided by health professionals, natural support system- provided by family and friendship networks, and social support which can be linked to either formal or natural support (Maree et al 2013:459).

There seem to be limited research on support directly targeting men who undergo prostate cancer screening. The need for support emerged as a last theme with five categories: (1) provision with information regarding the disease (2) providing counselling before and during screening (3) provision with good pain control and treatment (4) reduction of waiting time, and (5) support person present during screening.

4.3.6.1 Category 6.1: Provision of information pertaining to the disease

The study findings revealed that participants needed to be the provided with information pertaining to prostate cancer. Some of the participants expressed the information needs as follows:

“And anything that they should tell me to handle myself well, things like that. I need information to know how far the cancer is and, also to know if it is growing or what, I just want the support to know about treatment.” P18

“The doctor should tell me how long that thing is on me, how do I feel, such question like when you pass urine what you feel and all those things ... this process sometime when you are embarking on this journey of prostate cancer, you have to be informed what is going to take place and what is going to happen.” P15

“In our churches they don’t preach about this prostate cancer of which maybe even the priest should preach and educate people, and it should just be there even in family gatherings ... even in the social gathering wherever we are we should just talk about it. Like at church when I have time, I do talk about it.” P19

Another participant voiced out that health care practitioners should provide health information at the specific hospital as follows:

“Well, I think sometimes you have to call a spade a spade. But this thing of saying this is a disease that cannot be cured, I don’t think it is a good thing to say to a patient; even though it is such situation because everything there is research, TB was there on research, quite a lot of sickness has been there on research and eventually they get there. But to say this treatment is just for nothing, you gonna live and die with this disease I don’t think it is nice or it is alright or the right thing to say.” P17

4.3.6.2 Category 6.2: Provision of counselling before and during screening

Prashar, Schartau and Murray (2022:1), in their study reported that pre and post counselling were very crucial to ease the emotional stress associated with a health problem among patients in health care settings. Most participants reported that there was no counselling offered during the process of screening and felt that it would be ideal if it was offered. In this study the participants reported that health practitioners at the specific hospital do not provide information but just proceed to do the examination. Participants had these to say:

“No, you don’t have that kind of counselling. You see the doctor, you don’t talk. If you don’t ask questions the doctor also doesn’t, the doctor just write and then give you the next appointment date that’s it ... I was feeling that eer ..., when I arrive here at the hospital, I should get one on one with the doctor (implying the need for counselling session).” P15

“No, they didn’t give me any information about prostate cancer here at the hospital! when I arrived here, they just examined me. No there is no counselling that I received.” P18

“The world health organisation they should take action against Baragwanath. They must retrain them, some of them they need to retrain them. People need some of us need counselling, I don’t really need it, but lawyers will do anything for.” P19

“Nah (no), they have not counselled us, they only briefed us that we are going to go through this about biopsy; it is a bit painful, but it is worth it, then from there onwards no counselling nothing.” P17

“No, there was no counselling. It is a challenge. Currently I am by myself, as I am saying the news were delivered and I have to accept it and sometimes you feel like sitting down and talking to someone. like I am talking to you right now but if you are by yourself you need to stomach (just take it), accept it, and move forward you have no choice.” P11

One participant expressed the need for encouragement. The participant had this to say:

“This thing I wish like you can find someone who can encourage you. Because always when something comes up, at the back of your mind you think you are going to die. So, like, I wish when it is like that then someone should give you the support that even if it is like that things are going to be okay.” P3

Participant further reported:

“But with me even the woman I am staying with I told her that the doctor is checking me for prostate cancer. And she said please take care of that treatment (implying more support was offered by her partner!).” P3

4.3.6.3 Category 6.3: Provision with good pain control and treatment

The study findings revealed that some participants were anxious to get treated and be better. Some of participants were concerned with whether they can be cured or treated. They had these to say:

“Let’s say maybe cancer treatment, when they give people medication, when they have diagnosed how advanced the cancer is, they should give medication that can treat the cancer.” P5

“Okay you see now I have only one worry, which I do not know if I might find it on the doctors or what. Is that, is this thing cured or what.” P3

If I can just get support. Is there a support that can make me a man so that I can raise up (implying cure for erectile dysfunction), you can’t just live without a woman.” P4

“Oh, for the support that I want is for this cancer to go down or cured. The way the doctors can do it. That is the kind of support I want. I want them to help me in any way they may be able to help me.” P10

Other participants expressed the need for provision with good pain control. The participants expressed as follows:

“They didn’t inject anything to neutralise pain ... Maybe before they do biopsy maybe they should give someone an injection just to relief or to reduce the pain.” P17

“Eish!! I felt a lot of pain, I even told the doctor that you are hurting me. And then the doctor said to me nah! this is the procedure.” P8

“Yea you see this time I have got this ... you see this thing (showing the interviewer a urine bag) (I am urinating from this bag. So, which means (laughing) I am feeling pain (however this could relate to sadness).” P13

4.3.6.4 Category 6.4: Reduction of waiting time

Reduction of hospital waiting is significant to improve efficiency in patient care, however studies showed that hospital waiting time is still a concern (Patel, Markatia, Sridhar & Cavuoto 2022:551; Tsandila Kalakou, Aase, Kjosavik & Husebø 2021:1).

The study findings revealed that service delivery was poor as some patients were served after a long waiting time in the hospital queue. Some of the participants reported that the waiting time was long and felt like this should be shortened. The responses are recorded below:

“But there is a system in this hospital, particularly here at the hospital you come in and then you queue with those people (referring to other patients). That is the worst thing! Earlier we used to have our own window to get treatment. Most of the time is wasted at the chemistry (implying pharmacy), that’s where we need, I wish we could have our own section that gets you tested and get you your medicine and go. Like before, I don’t know why they changed, that is the worst thing they ever did.” P12

“Yeah, the only thing that is of a concern to me that to come here it is a public hospital I know, I have to be patient I have to wait there is nothing I can do; but the treatment like our appointments to see the doctor, before you are seriously attended it takes a very... long time. Yeah, it takes a lot of time because it takes two years then you do biopsy to check if you have cancer but two years while you arrived earlier from the clinic that you are sick.” P15

“So, I never had any problem unless if maybe time of write your card (admission), then you wait for an hour or two. I am impatient just to wait and do nothing I just to do something you see.” P2

When we come here sometimes, we wait for a long time. And sometimes we feel pain you know (from waiting in the long queue the whole day).” P13

The participants further had this to say:

But otherwise, everything is fine ... so you feel like they should shorten the waiting time.” P13

4.3.6.5 Category 6.5: Support of person present during screening

Although there are not many studies regarding support person in the screening room, previous studies have indicated the significance of family member, friend, and spouse as crucial to provide support among patients diagnosed with prostate cancer (Prashar et al 2022:1; Maree et al 2013:459).

Some participants expressed the need for a support person in the screening room. This person can either be a nurse or a family member present in the screening room during screening. The responses of the participants are recorded below:

“There was only one doctor, a female doctor ... nah she was just alone.” P19

“It was only me and the doctor. there was no nurse.” P18

“Fortunate enough one of my family members is a nurse, I spoke to him about this procedure, he was very much aware of what is happening because I was with him in there and said that this blood in the urine will disappear after some couple of days and that’s what really happened.” P11

“It was me and the doctor who was busy with me., it was only me and the doctor who was helping me with this.” P9

Two other participants expressed the need for provision of privacy in the room. Participants reported invasion of privacy, as evidenced below:

“There was a white doctor and another patient.” P7

“On the side of the urine (referring to other screening room) that is where there is another doctor with their patient and then there it is me the other patient, you see.”
P15

4.4 DISCUSSION OF THE STUDY FINDINGS

The study revealed that knowledge of prostate cancer was still a concern, as this was noted from narratives shared. This finding from the study support what was found by Baratedi et al (2020:87) to understand screening barriers in sub- Saharan Africa and found that men lacked knowledge regarding prostate cancer. Furthermore, the finding in the study also support Ugochukwu et al (2019:168) and Ojewola, Oridota, Balogun, Ogundare, Alabi et al (2017:151) who found that majority of the participants had poor knowledge of prostate cancer. The study findings revealed that few participants had partial knowledge of prostate cancer. This finding was also confirmed by Matshela, Maree and Van Belkum (2014:189) in a study to pilot test an intervention to detect prostate cancer case in Tshwane a community of SA, where some of the participants had little knowledge regarding prostate cancer.

Most of the participants were referred for prostate cancer screening through health care practitioner, having a family history or knowing someone affected by the disease, as well as symptoms experienced prior to presenting themselves at a health facility. This finding was confirmed by Shungu and Sterba (2021:925) and James et al (2017:1) in a study reported that health care professionals were influential for participants to decide to screen for prostate cancer. Similarly, these findings from the study asserts what was found by Enaworu and Khutan (2016:525) where participants were influenced by a relative or family member to screen for prostate cancer.

Most of the patients went for follow up at hospital for check-up when they experience symptoms such as urine blockage and incontinence as found in the study. This finding was consistent with the findings by Enaworu and Khutan (2016:525) in which they found that the main factor that influenced Nigerian men to screen for prostate cancer was experience with symptoms. However, Gellerstedt, Langius-Eklöf, Kelmendi, Sundberg and Craftman (2022:2485) found participants in their study came for prostate cancer screening despite not having any symptoms.

The present study found that media was the most source of information regarding prostate cancer, with none citing health care practitioners as their source of information for prostate cancer. Only few participants in the study reported that the sources of information were information pamphlets. In a study to assess information sources in

patients with localised prostate cancer, Chhatre et al (2020:1) reported that half of the participants identified the media as a source of information. Although this study did not identify health providers as a source of information, participants in a study by Chhatre et al (2020:1) identified health care providers as useful in communicating decision making and treatments for prostate cancer. Another study by Blanch-Hartigan and Viswanath (2015:204) recognised health care providers, media, family or friends, and support groups as sources of information. These findings indicate that there is a gap in communication between health practitioners and patients on the provision of information at the specific tertiary care hospital.

Barriers regarding screening in the study were fear, shyness, and embarrassment, and lack of provision of information pertaining to the disease. Similar findings were found by Ocho and Green (2013:1) regarding perceptions of men about screening in communities of Trinidad and Tobago who reported that screening was an invasion of privacy and the fear of being inserted a finger in the rectum. This finding contradicts what was reported by Yeboah-Asiamah et al (2017:184) in Ghana who reported that majority of the participants disagreed that prostate cancer screening was embarrassing. As evidenced by the present study lack of information was a barrier to screening. This is also affirmed by Awosan et al (2018:51) in a study conducted in Nigeria who also found that lack of information was a barrier to screening.

The findings of the study revealed that a substantial proportion of participants reported a lack of communication from healthcare providers regarding prostate cancer screening. This noteworthy observation underscores the prevailing lack of awareness among men within their respective communities regarding prostate cancer. The lack of awareness regarding prostate cancer among men points to their reluctance to undergo screening, as they perceive themselves to be in good health and less risk of developing the disease.

Further, the study found that the symptoms experienced during the screening procedure were pain and discomfort as reported in other studies (Ugochukwu et al 2019:168; Elhardello & MacFie 2018:579; Romero et al 2008:850). However, Yeboah-Asiamah et al (2017:184) highlighted that few of their study participants disagreed that the screening of prostate cancer was painful. The present study found some positives regarding the screening whereby some participants expressed excitement towards the screening citing that the screening provided an opportunity for early treatment of the disease. Similar

findings were reported in a study by Gellerstedt et al (2022:2485) who found that the study participants regarded screening as a life saver.

Smith and Koehlmoos (2011:1) reported that provision with information is critical for good health, as found in the present study whereby participants felt the need to provide with information regarding the disease. Similar findings were reported by Eibich and Goldzahl (2020:1) who found that health knowledge among European women was improved by the provision of health information. Participants in the current study reported a need for counselling before and during screening as this was not provided. However, it is crucial that participants are afforded some form of counselling to gain co-operation during screening. These findings confirm what was reported by Al-Omari, Al-Rawashdeh, Damsees, Ammar, Alananzeh et al (2022:1) who found that counselling was needed by men in their study. Lintz, Moynihan, Steginga, Norman, Eeles et al (2003:769) in a study to investigate the support needs among men also found that 48% of their study participants desired one-on-one counselling as a support service.

Pain is one of the common symptoms experienced by cancer patients. The study found that participants needed to be provided with good pain control and treatment. The same findings were found by Cockle-Hearne, Charnay-Sonnek, Denis, Fairbanks, Kelly et al (2013:2121) who found that 81% of participants had unmet supportive care needs such as treatment for prostate cancer. These findings are similar to what was found in a study by Tsandila Kalakou et al (2021:1) who found that treatment support was needed by men. In addition, management of pain showed a significant improvement on pain relieve among patients dignosed with cancer in Taiwan (Su, Chuang, Chen, Tsai, Huang et al 2021:1903).

Participants in the present study reported the need for reduction of hospital waiting time. Participants in a study by Patel et al (2022:551) also reported that the hospital waiting time was long. This highlights the need for health facilities to maximise efficiency in patient care by reducing waiting time. Tsandila Kalakou et al (2021:1) in a study found the need for structured health care process to improve waiting time, confriming what was found in the study regarding the reduction of hospital waiting time.

Support of a person in the screening room was also reported as a support needed by participants in the current study. Although no studies reporting support person during

screening were found, many participants in a literature review of qualitative studies described the support of a person such as family, friend, or partners as a key source of emotional support during the journey of prostate cancer (Prashar et al 2022:1).

4.5 SUMMARY

This chapter presented the analysis, findings and literature control, and discussion of this study. Six main themes that emerged from the study were presented and controlled with literature including a discussion section pertaining to these.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The study findings, analysis, and discussion were presented in Chapter 4. This chapter will discuss justification, limitations, recommendations, as well as the conclusions.

5.2 JUSTIFICATION OF THE STUDY

The researcher noted from the literature that there is little, or no research conducted around experiences of prostate cancer screening in an African context, however had interest regarding what support is available as well as the experiences of men undergoing screening, particularly at the specific tertiary hospital.

In Chapter 3 the methods and design that guided the study were discussed. Chapter 4 discussed the findings and literature control including discussion of the study. Based on the findings the study was achieved.

The study shed light on the extend of prostate cancer knowledge and uptake of screening among men attending a specific tertiary Hospital, as well as concerned experiences during screening.

5.3 LIMITATIONS OF THE STUDY

- Due to qualitative nature of the study, the sample size was small and could not be generalised to all men attending the specific Tertiary hospital. However, data saturation was reached with 19 participants despite the small sample.
- Social desired responses might have been given by participants due to individual face to face in-depth interviews, or even having discussed with others as interviews were conducted on alternate days. Some participants might have shared some questions.

- Information bias might have been introduced in the study when participants were asked to recall what made them to come to the hospital as older people tend to forget easily.
- Some of the participants did not like the idea of recording conversations, they mentioned that the recording makes them uncomfortable and fear that they might be in trouble in a later stage.
- Some of the participants were not fully engaged when responding to questions citing reasons such as fear of being left behind as they utilised hospital transport.

5.4 RECOMMENDATIONS

Recommendation arising from the study are as follows:

5.4.1 Recommendations to practice

- It is crucial that perhaps screening procedures could be accessible from primary care facilities due to participants having to travel to access screening, making it a challenge to travel to referral sites.
- It is recommended that designated health care members be available especially in men's clinics to inform them about the basic symptoms of the disease to assist with early access and reporting.
- Sharing of information regarding prostate screening should be made widely available in areas where most men are accessible such as sports arena, churches, taverns, etc.
- It is also important that patient have a health practitioner to support them whilst doctors are busy conducting screening.
- Maintaining privacy during screening should be practiced at all costs as some of men felt that having other patients in the cubicle invaded their privacy.
- Whilst it is expected that patient be given mild analgesic during the procedure this was reportedly not practised with all patients and could deter others to recommend screening to their friends.
- It is recommended that men attending prostate screening be offered counselling before and after the procedure as most of them mentioned that counselling was not provided.

5.4.2 Recommendations to the Department of Health

- The Department of Health in Gauteng province should ensure that as many platforms such as media, health information sessions are created to raise awareness about prostate cancer, through mass media campaigns. The ministry can implement TV and radio shows or programs which discusses prostate cancer on a weekly or monthly basis.
- Perhaps it could assist if DOH makes it mandatory that men from ages 40> be offered prostate screening even if they are at the health facilities for other reasons to try and promote early screening.

5.5 CONCLUSIONS

The study provided evidence that lack of knowledge regarding prostate cancer was still a challenge especially in sub-Saharan countries. It is therefore crucial that men be targeted at their favourite spots such as churches or taverns and be provided with prostate cancer information. Several barriers added to poor screening uptake such as having been in contact with health practitioners and failing to recommend screening.

Poor pain control was also an issue. It is crucial that doctors provide mild analgesic during screening and provide counselling before and throughout the process. Long waiting times especially with ill patients was raised as a matter of concern. Perhaps having a health practitioner check on patients' and prioritise them to access the doctors could reduce unnecessary long waiting periods.

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ANNEXURES

ANNEXURE A: Ethical Clearance Certificate from the University of South Africa



COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

23 April 2021

Dear Boitumelo Mapale Komane

Decision:
Ethics Approval from 23 April 2021
to 23 April 2024

NHREC Registration # :
Rec-240816-052
CREC Reference # :
61263079_CREC_CHS_2021

Researcher(s): Name: Boitumelo Mapale Komane
Contact details: 61263079@mylife.unisa.ac.za

Supervisor(s): A. Mosala
Contact details: 0124296647

Title: Experiences of men undergoing Prostate cancer Screening at a Specific Hospital in Gauteng Province

Purpose: MA

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for three years.

The *Low risk application* was reviewed on the 23 April 2021 by College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the



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confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date (23 April 2024). Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

The reference number 61263079_CREC_CHS_2021 should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.

Yours sincerely,

Signature : pp

Prof. KB Khan
CHS Ethics Chairperson
Email: khankb@unisa.ac.za
Tel: (012) 429 8210

Signature : PP

Prof K. Masemola
Executive Dean : CHS
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ANNEXURE B: Letter requesting permission at Chris Hani Baragwanath Academic Hospital

Hospital CEO

Chris Hani Baragwanath Academic Hospital

28 Chris Hani Rd, Diepkloof 319-Iq,

Johannesburg, 1864

Phone: [011 933 0967](tel:0119330967)

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

My name is Boitumelo Komane, registered for a master's in public health at the University of South Africa (UNISA). As part of the requirements for the program, I am undertaking a study titled *Experiences of men undergoing Prostate cancer Screening at a Specific Hospital in Gauteng Province*. Your hospital has been selected as the study site for data collection aspect of this study, as the facility provide prostate cancer screening service.

The study aims to explore the experiences of Men undergoing prostate cancer screening at a secondary care hospital. Furthermore, it is important to enquire what kind of support would encourage men to go for screening. The attached proposal outlines the specific research objectives. Data collection will take approximately 4 months period. During this time, the researcher will interview up to 15 men who come for prostate cancer screening. The information will be collected by means of in-depth interviews and will be audio recorded (see attached interview guide).

The study has received Ethical clearance from the UNISA College Research Ethics Committee. The study proposal and the interview guide are attached for your perusal should you need further information on the study. These documents have also been submitted to the UNISA research ethics committee and ethical clearance has been granted.

There is also a foreseeable risk for participating in the in-depths interviews. It is anticipated that potential participants might know or relate to someone who had

experienced prostate cancer. Interviewing these men might trigger a psychological trauma. Therefore, the researcher would kindly like to request the hospital management to give permission to utilise the counselling service that is already in place in the hospital should it be needed during the interviews.

Due to the global pandemic of covid-19, the researcher will follow covid-19 preventative measures as stipulated by (WHO, 2020). Such measures include hand hygiene, respiratory hygiene, physical distancing, environmental cleaning and management of covid-19 patients (WHO, 2020). It is expected that the hospital is already adhering to these measures, hence the researcher would like to request to utilise one of the private rooms in the hospital, which is already disinfected, to conduct the interviews. The researcher will however be in possession of a sanitizer and will request participants to wear a mask before entering the premise. In addition, the researcher will have extra masks which can be given to those participants who do not have a mask.

Should you require further clarity, kindly feel free to contact me on the details below.

Yours sincerely

Boitumelo Komane

Masters student

61263079@mylife.unisa.ac.za /079 423 3772 from 08h00-15:30h00

Supervisor: Mrs Annah Mosalo. mosala@unisa.ac.za / 012 429 6213 from 08h00-15h00

Mon to Friday

ANNEXURE C: Facility permission from Chris Hani Baragwanath Academic Hospital



ANNEXURE D: Interview guide

Title of study: Experiences of men undergoing Prostate Cancer Screening at a Specific Hospital in Gauteng Province

Names of researcher: Boitumelo Mapale Komane

Supervisor: Dr Annah Mosalo

SECTION A: DEMOGRAPHIC DETAILS					
A.1.	CULTURAL GROUP	Coloured	1	Q1=	
		Ndebele	2		
		North Sotho	3		
		South Sotho	4		
		Swazi	5		
		Tsonga	6		
		Venda	7		
		Xhosa	8		
		Zulu	9		
		White	10		
		Other	11		
A.3.	REGION	Rural	1	Q3=	
		Urban	2		
A.4.	AGE			Q4=	
A.5.	MARITAL STATUS	Married	1	Q5=	
		Co-habiting	2		
		Culturally Married	3		
		Stable relationship	4		

		Single	5		
A.6.	NUMBER OF CHILDREN				
		0-1		Q=6	
		2-3			
		4 >5			
A.7.	EDUCATIONAL LEVEL OF PARTICIPANT	Never went to school		Q7=	
		Up to Grade 7			
		Grade 8-10			
		Grade 11- 12			
		Tertiary			
A.8.	EMPLOYMENT STATUS OF PARTICIPANT	A day worker	1	Q8=	
		A pensioner	2		
		Disability grant	3		
		Employment	4		
		Unemployed	5		
A.9.	MONTHLY INCOME OF PARTICIPANT	None	1	Q9=	
		R1- R2000	2		
		R2001-R2500	3		
		R2501 -R4000	4		
		R4001- R8000	5		
		R8001>	6		

Section B: Scope of questions:

1. Can you briefly explain what you know about prostate cancer? Probe.
2. Where did you get information about prostate cancer? Probe.
3. Is there someone you know who have/ had prostate cancer, in your family or relatives? Probe.
4. Can you explain what influenced your decision to come for prostate cancer screening? Probe.
5. Did you receive counselling at the hospital? Probe.
6. Who was in the room with you during the screening procedure? Was a nurse present? Probe.
7. Can you explain your experience of the whole prostate cancer screening procedure? probe
8. What do you think are the barriers to prostate cancer screening? Probe.
9. Can you tell me in what way can we support you to make the experience better and less traumatic/ invasive? Probe.
10. Can you explain what do you think can be done to improve the participation in prostate cancer screening? Probe.

ANNEXURE E: Informed consent

Researcher: Boitumelo Mapale Komane

I, [print full name], give consent to take part in this interview. I understand what it means to be involved in this study and that the study has been fully explained to me. Please tick the appropriate option below.

	Yes	No
I understand that at any time without any consequences I can withdraw from the research		
I agree that it will remain anonymous to other members except for the researcher that I participated in this study		
I agree that anonymous quotes may be used in the report or publication by the researcher		
I agree that there will be a recording of the interview		
I have been provided with contact information of the researcher or study supervisor should I need further information about the study		

Contacts:

Researcher: Mr Boitumelo Mapale Komane. 61263079@mylife.unisa.ac.za / 079 423 3772 from 08H00-15:30H00

Supervisor: Dr Annah Mosalo. mosala@unisa.ac.za/ 012 429 6447 from 08h00-15h00 mon to Friday

CONSENT

..... (signature)

..... (name of participant)

..... (date)

ANNEXURE F: Informed consent for audio recordings

Informed consent for audio-recording

- I agree that the researcher informed me about the study and also to record the interview of the audio during the interview.
- I agree that I have received the information sheet and signed informed consent and that I understand what the study entail.
- I agree that my audio recording will be anonymously used to generate a report and a publication and be kept on a file otherwise for 2 years.
- I agree that my audio recording can be transcribed and coded for analysis of results.
- I therefore agree that my inputs be audio recorded.

PARTICIPANT:

Signature

Name

Date and Time

I, _____, confirm that the participant mentioned have been fully informed of the nature, risk and conduct of the study. •

RESEARCHER:

Signature

Name

Date and Time

ANNEXURE G: Information sheet

REQUEST TO PARTICIPATE IN THE STUDY

Ethics clearance reference number:

Research permission reference number (if applicable):

<date>

Title: Experiences of men undergoing Prostate cancer Screening at a Specific Hospital in Gauteng Province

Dear Prospective Participant

Student research project

My name is Boitumelo Mapale Komane and I am doing research with Dr Anna Mosalo a lecturer in the Department of health studies towards a MA Public Health at the University of South Africa. We have funding from National Research Foundation for the purpose of this research. We are inviting you to participate in a study entitled Experiences of men undergoing Prostate screening at a specific hospital in Gauteng province.

WHAT IS THE PURPOSE OF THE STUDY?

The study aims to explore the experiences of Men undergoing prostate cancer screening at a secondary care hospital and what kind of support would encourage men to go for screening.

WHY AM I BEING INVITED TO PARTICIPATE?

Chris Hani Baragwanath Academic Hospital (CHBAH) has been chosen as the study setting for this research. In addition to this, the study focus mainly on men over the age of 40 years who come for prostate cancer screening at the facility as research has shown that this age group of men are more likely to develop prostate cancer. Consequently you are requested to take part in this study as you are the service user at CHBAH, specifically for prostate cancer screening. You have been invited to take part in the study through the assistance of the nurse responsible for prostate cancer screening at the facility. At least 12 participants will be required to take part in this research.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

You have been selected as a potential participant in the study because you are the service user at CHBAH which has been selected as a study setting for this research. You are requested to take part in an In-depth interview which will be conducted in a private room specifically arranged to maintain privacy and confidentiality. The interview will be conducted in a language that you understand and will be audio recorded. The interview will take approximately 45-60 min. Your demographic information will be recorded and you will also be asked questions related to your knowledge of prostate cancer, and your experiences pertaining to the screening procedure of prostate cancer.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

You will be able to withdraw from this study even after having agreed to participate. Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

You will not directly benefit from participating in the study. However, there would be indirect benefits such as gaining knowledge on the support of men undergoing prostate cancer screening. The knowledge gained will be used to provide evidence to support the health system and to implement the necessary care for men attending prostate cancer screening. In addition, the health practitioners responsible for providing care for these men will be equipped with knowledge that can be used to provide better support for future patients that come for prostate cancer screening.

ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

There are no negative consequences for participating in the study. However, the nature of the study involves only face to face interviews, which means you will not be given any form of drug for testing. You will only be expected to share your views and or experience

on a topic deemed sensitive. Hence the only anticipated risk will be associated with the psychological trauma associated with topic (prostate cancer).

To mitigate the potential risks, the researcher will ask you to take your time when answering questions. In situation whereby you become emotional, the researcher will stop the interview and refer you for counselling. You will be asked if it is okay to follow up on questions that are sensitive. You will be referred for counselling in the hospital if it is needed. The researcher will also alert the nurse working in the clinic to observe you on your successive visits to assess the state of your psychological trauma that may need further referral.

[A description for arrangement for indemnity and/or insurance coverage for participants if applicable]. The researcher will not be held responsible for any loss of item that you might bring to the interview. You are advised to look after your items. However, in case there is a loss the researcher will assist to report the matter to relevant department in the institution and or help look for the lost item.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

You have the right to insist that your name will not be recorder anywhere and that no one, apart from the researcher and identified members of the research team, will know about your involvement in this research. Your name will not be recorded anywhere and no one will be able to connect you to the answers you give *[this measure refers to anonymity]*. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

The study findings will be used to generate a report for dissertation and a manuscript for publication. All the information collected throughout the study will be kept confidential. There will be no names used in the dissertation or the manuscript and ultimately no identifying information will be linked to the data. However, the demographic characteristics of the participants and the views will be reported in the dissertation or the manuscript.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard/filing cabinet *[at the researcher's place]* for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. Hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not receive any form of incentives for taking part in the study. You will also not incur any financial costs by participating in the study.

HAS THE STUDY RECEIVED ETHICS APPROVAL

The study has been submitted for ethical clearance at the Unisa college of Human science ethics department. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Boitumelo Komane on 073 939 9836 or 61263079@mylife.unisa.ac.za

The findings are accessible for 2 years after the publication.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact 073 939 9836 or 61263079@mylife.unisa.ac.za

Should you have concerns about the way in which the research has been conducted, you may contact mosala@unisa.ac.za / 012 429 6213 from 08h00-15h00 mon to Friday. Contact the research ethics chairperson of the CREC, Dr KJ Malesa, maleskj@unisa.ac.za, 012 429 6054/ 4296447 if you have any ethical concerns.

Thank you for taking time to read this information sheet. If you are willing to participate in this study, kindly complete the consent form below.

Kind regards

Boitumelo Komane

A handwritten signature in black ink, appearing to be 'BK' or similar initials, written in a cursive style.

Researcher

ANNEXURE H: Example of interview

Interviewer: my name is boitumelo komane and I come from Unisa. I am doing research with dr Annah Mosalo, and the topic for our research is "the experiences of men undergoing prostate cancer screening and also understanding how they wish to be supported. So now I am recording our conversation when I ask you questions, do you agree that I should record this conversation?"

Respondent: no problem

Interviewer: okay. The first question that I want to ask you is that I need you to explain to me what you know about prostate cancer.

Respondent: uhm for me as far as prostate cancer is concerned, I know that black men, my understanding due to the research I conducted on Google about prostate, I know that prostate cancer usually affects black men. And then men, especially over the age of 40, yeah are the ones who suffer from prostate cancer most of the time.

Interviewer: so the time you went to the clinic did they ever explain to you about prostate cancer?

Respondent: no the clinic they don't explain anything they just suspect after the tests the blood tests that it is... they only talk about PSA. That the PSA it looks like it is high so you need to go see the urologists.

Interviewer: so at home is there anyone who have prostate cancer?

Respondent: I think my father died, he had prostate cancer.

Interviewer; is there any other person you know who had prostate cancer?

Respondent: no

Interviewer: he is the only one

Respondent: my father is the only person I know who had prostate cancer. But I don't think it is only prostate cancer because he other issues, you see yeah.

Interviewer: oh okay. So tell me how did you end up coming here at the hospital (Bara) to test for prostate cancer?

Respondent: yea so usually I go to the clinic. I am attending the clinic to get HIV treatment so every year I take blood for the tests. But apart from that I enquire about it because I know I am long due, so I have been checking since the age of 50 and they been telling me that there is no problem. But when I checked the last time when they referred me for cancer, prostate cancer, they found that my PSA was high. Yea

Interviewer: so they said you should come here at Bara

Respondent: they referred me here at Bara

Interviewer: which clinic was that?

Respondent; the clinic in Krugersdorp

Interviewer: oh okay. So the time you arrived here at the hospital at Bara, did you receive counselling for prostate cancer?

Respondent: no you don't have that kind of counselling. You see the doctor, you don't talk. If you don't ask questions the doctor also doesn't, the doctor just write and then give you the next appointment date that's it.

Interviewer; so this doctor was he with a nurse or it was just only the doctor?

Respondent; nah the doctor was the only one

Interviewer: so I want you to explain to me about the step by step process that happened when they tested you for prostate cancer

Respondent: uhm if I still remember well. It is not for the first time as I already told you that I started early to check but I was not checking here at Bara. I was still working by then

Interviewer; I want you to explain to me how they checked you here at Bara

Respondent; oh here at Bara?

Interviewer: yes

Respondent: okay well here at Bara when I arrived I saw the doctor, the doctor asked me to undress from behind and checked with a finger to feel if my prostate is enlarged or what, you see. So they checked with a finger then after that that test for urine to see if the urine is passing normally or not. Then they wrote down the results, their findings.

Interviewer: the time they were testing you like that, who was in the room?

Respondent; no it was only me and the doctor, but when I went to test for urine, it is separate, that's when there were other people who came to pass urine, It looks like it is only one machine to do that or it is two.

Interviewer: in the same room?

Respondent; in the same room yeah.

Interviewer: so you were being tested by a male or female doctor?

Respondent; it was a male doctor

Interviewer; oh okay. It was only this doctor when they were inserting you things at your back
respondent; nah there it was only me and the doctor. On the side of the urine that is where there is another doctor with their patient and then there it is me the other patient, you see

Interviewer: hmmm, so now I need you to please explain to me how were you feeling the time they were testing you like that

Rspondnet: pains or?

Interviewer; yes anything you felt

Respondent; anything that I felt or me as a person

Interviewer: everything, including you as a person or pain or how you experienced the test, anything that you experienced when they were testing you for prostate cancer

Respondent: well when they started I felt uncomfortable. When they started to insert the finger to feel anything at the back of me because he wants to feel any irregularities you just feel

uncomfortable. Yeah because usually there is nothing that enters there at the back yah that's it, that's the only thing

Interviewer; so they never inserted any machine at the back

Respondent: nah they did not insert any machine. Then there is this thing. Sorry. There is this thing they apply on your (pointing the stomach) that looks like mucus, they apply it and they check on the screening I don't know what they are checking, whether the prostate has got problems or if he's checking the bladder if it has got enough urine or whatever, but he was using that thing for screen.

Interviewer: ohk. So I need you to explain to me what kind of support you wish to get from the hospital.

Respondent: no the hospital I was feeling that I, when I arrive here at the hospital I should get one on one with the doctor. That communication, that the doctor should tell me how long that thing is on me, how do I feel, such question like when you pass urine what do you feel and all those things. You see. Not that me I have to initiate them, you see. There should be a conversation that the doctor is aware that this patient is aware of their condition and all the other things that cause them to have prostate cancer.

Interviewer: yea I understand you. Alright according to you what do you think it is the reason that older men are not coming to the hospital to test for prostate cancer?

Respondent: uhm men not to come here at the hospital I think us men, we take things for granted thinking it is just a minor thing it will go away. I also think it is little knowledge that we have especially concerning our health. You see yeah. For me when I have pain I just keep quiet thinking it is a small thing I do not attend to it. I can feel that my urine is hot but I can sit for two months while the urine is burning me until I discuss this with another man, maybe while we are chilling somewhere and we have a conversation and he says maybe this thing is caused by 1 2 3 (other causes) that's when I will go to the hospital when I am already sick and feeling pains things like that.

Interviewer: alright I understand. I think we have arrived to the end of our discussion. Is there anything else that you would like to talk about maybe?

Respondent: concerning this thing?

Interviewer: yeah anything

Respondent: uhm I don't think I have much but I was saying this process sometime when you are embarking on this journey of prostate cancer, you have to be informed what is going to take place and what is going to happen. It should not be that only on the day you come to the hospital then it is the only time you know what is going to happen, because when I go for treatment of biopsy that is the only time I get information that they are going to do 1 2 3, and then after that I feel uncomfortable, I need tissues because I was bleeding, these other thing I don't have them because I should be prepared and have these things or I should ask someone to accompany me, because you come here driving but when you done you are no longer 100%, you see so information should always be available so that you know what is going to take place.

Interviewer: alright, this is the only thing you wanted to tell me?

Respondent: yeah this is the only thing that is of a concern to me that to come here it is a public hospital I know I have to be patient I have to wait there is nothing I can do but the treatment like our appointments to see the doctor, before you are seriously attended it takes a very long time. Yeah it takes a lot of time because it take two years then you do biopsy to check if you have cancer but two years while you arrived earlier from the clinic that you are sick you have this condition, you see.

Interviewer: okay if it is like that then thank you so much for your time and also for agreeing to be part of my study I really appreciate all you time. Thank you so much.

Respondent okay thank you so much doc

Interviewer: tanki

ANNEXURE I: Confidentiality pledge with inter-coder

Confidentiality pledge

I, Mrs Ashley Ringane, a researcher at Perinatal HIV Research Unit (PHRU), a division of wits health consortium, confirm that I am an experienced qualitative researcher, and I assisted Boitumelo Komane, a masters (Public Health- MPH) student at the University of South Africa, with coding and reviewing the transcripts for his project. I confirm that I will abide by all the conditions of data sharing, and in particular I will not make the data available to any third party.

Signed: 

Date: 23 January 2023

ANNEXURE J: Codebook

Themes	Categories	Quotes
1 Prostate cancer knowledge	1.1 Lack of knowledge of the disease	<p>“Nothing ... I hear of it, but I don’t know anything about it.” P1.</p> <p>“I do not want to lie, truly speaking I do not know anything about it. It is only when I was attending the clinic, this year then they send me here saying it looks like I have cancer. So, I do not know anything, even what causes it I do not know.” P3</p> <p>“I am beginning to hear the word prostate cancer hear at the hospital. The time I started being ill.” P4</p> <p>“Well truth be told I know nothing, which is why I am here, I’ve been referred to here and all that, so I know nothing.” P5</p> <p>“Hmm prostate cancer for me I don’t know how I will explain it because I only feel it in my body that it is painful. So, I don’t know how I can explain how I am feeling so that you can understand.” P14</p>
	1.2 Partial knowledge of the disease	<p>“They say something close up (pausing and pointing their trouser and the penis ... of swollen down there, close up of down there.” P1.</p> <p>“Uhm one thing I know about prostate cancer is that it grows in the pubic area. And it is giving problems with urinating. And then sometimes it can extend to the spine.” P2.</p> <p>“I hear that they say a person have difficulties with urinating. Some says the urine just goes off” (meaning uncontrollably).” P3</p> <p>Well not much. But when you go to a local clinic the nurses always talk about prostate cancer and they advise that at the age of 40 you must go and test.” P12</p> <p>“Uhm for me as far as prostate cancer is concerned, I know that black men, I know that prostate cancer usually affects black men. And then men, especially over the age of 40, yeah</p>

Themes	Categories	Quotes
		<p>are the ones who suffer from prostate cancer most of the time.” P15</p> <p>“So far this is something that I’ve always knew it is there and the result is that us men we should always come to check it especially when we reach certain age and check your state of it.” P16</p>
2 Screening influencers	2.1 Referrals by health care practitioner and having other comorbidities	<p>“I was attending the clinic for high blood pressure. I have high blood, so when I was attending the clinic. Then when they took our blood ... the results came then they told me that it looks like you have prostate, then the sister (registered nurse) gave me a referral letter and said I should go to the hospital.” P3</p> <p>“I have been referred here from the clinic in Kagiso. I have been attending treatment for high blood pressure there. So, they found out that my BP (blood pressure) was not good, so they decided to refer me here at Bara. That’s what I know, the problem was BP.” P5</p> <p>“When I arrived at the clinic, they told me that the results are back, so when the results are back, they show that I have cancer. That is when they gave me a referral letter to the hospital.” P7</p> <p>“So, as I am attending the clinic, they took blood tests and they told me that they suspect it (prostate cancer), so they took the bloods for research and all that. So when the blood came back they said to me nah you have got prostate cancer and they ... that clinic (keyarona) they referred me straight here to Bara.” P9</p> <p>“Nah I did not come straight here I came to the local hospital, yea the clinic the local clinic. From there they sent me here.” P13</p>
	2.2 Family history of prostate cancer and knowing someone affected	<p>“As I was saying my father had one and my brother had one, so I didn’t want to end up in a situation I saw happening to them. So, I wanted it to be detected as early as possible. So that I can be able to deal with it because if one thing has jumped number 1 and 2 and then you know by 3 its going to be a dead thing. Yes! so, I didn’t want to be there.” P2.</p>

Themes	Categories	Quotes
		<p>“My father died; he had prostate cancer. my father is the only person I know who had prostate cancer. But I don’t think it is only prostate cancer because he had other issues, you see yeah.” P15</p>
	<p>2.3 Symptoms experienced prior to diagnosis</p>	<p>“At respiratory I asked the doctor, and the doctor after attending me he asked me what else is bothering me. And then I told the doctor that when I sleep with my woman, I no longer get strong you know my 4 5 (South African slang ‘for penis’) becomes soft, so I asked if I will never get help. That’s when he sent me here at Urology.” P4</p> <p>“Since I had a problem with urine blockage last year in April, then I came here after 4 days. I had a blockage urine for 4 days and then I could not even relieve myself, so I came to the clinic.” P19</p> <p>“I did not feel well in my body, I can say I was sick because the pains started while I was at work and then I had to drive, it was hard. I felt my urine wanting to come out, but it didn’t come out.” P18</p> <p>“I felt not right in my body, yea! (emphasizing) Well, I must come to check up. And so, they caught it. I was dizzy. I came to trauma. They referred me to this other woman somewhere here, and they referred me to H4 that is where they found the results.” P6</p> <p>“From nowhere I experience urinary problems. And I said maybe it is because I don’t drink lots of water that is the cause I ran to buy soda and I drank it and I find out that it is not helping. After that I realise that this thing is quite serious. When I tried to pass urine, I felt like am doing number 2 (implying excretion of solid waste or poop) when I am doing number 1 (passing urine).” P16</p>

Themes	Categories	Quotes
3 Source of information regarding the disease	3.1 Media types	<p>“I have seen this on media as well, internet as well because I have been perusing it to even understand what I am going through, so I have been doing my own research as well.” P17</p> <p>“From the radio and newspapers, they always say this, I am a person who hear the news a lot, I also read a lot, so I sometimes come across these things.” P16</p> <p>“My understanding due to the research I conducted on Google about prostate, I know that prostate cancer usually affects black men.” P15</p>
	3.2 Pamphlets	<p>“At the clinic most of the time they encourage men that they must go for prostate screening, especially in the townships they have notes, (implying pamphlets), there are pamphlets, and they encourage men that at the age of 40 you must go and check-up for cancer.” P19</p> <p>“I only got a pamphlet today ... yea and I read it.” P14</p> <p>“They showed me that book about prostate cancer. That lady” Mosa” she showed us that book about prostate, and that’s when I started to hear that I have prostate.” P9</p>
4 Barriers to screening	4.1 Fear, shyness, and embarrassment	<p>“Maybe they are scared, so they don’t come to check their prostate.” P1.</p> <p>“I sometimes feel like maybe men know about this thing and what it is going to be done to them. Sometimes you find that I am a man my age ne, I am scared to be inserted those fingers or sometimes.” P7</p> <p>“I sometimes feel like maybe men know about this thing and what it is going to be done to them. Sometimes you find that I am a man my age ne! (emphasising) I am scared to be inserted those fingers or sometimes.” P13</p> <p>They are shy. Yea they are shy ... This is how I see it. Some it is because they are shy like hai people will say I have prostate cancer you see.” P3</p>

Themes	Categories	Quotes
		<p>“Well men if you check they are embarrassed when it comes to these things. They have this thing that this is my life, this is my privacy, then to be checked by other people I will never be a man enough, well I am going to be disrespected. Do you get me. so that is why sometimes some of them refuse.” P5</p> <p>“You find that another man is embarrassed that at his age he will have to undress for a younger child (implying young doctors) (the participant was embarrassment as he reported).” P7</p>
	4.2 Lack of information regarding the disease	<p>“Most of the time it is lack of knowledge you get my point! It is lack of Knowledge! With me I just discovered that, I am 68 years now, I think I was 63 or 64, when I Googled. If I knew before that at the age of 40, I should start checking I would do that and then those younger than me I would tell them that at the age of 40 you should test.” P18</p> <p>“I think you know what, I don’t know how I can put it ... an un-educational behavior (implying people with low level education). I mean some people they just want to act ignorant! You see if I say ignorant it’s that they know that it is there, but they want to put themselves on a side that ah! I will see it when it comes. And that thing of ah ... I will see it when it comes, that time when it comes maybe it comes on stage 4.” P2.</p> <p>“Sometimes I feel like these people do not care about their life too much. It looks like they do not care about their lives so much.” P3</p>
5 Symptoms experienced during screening	5.1 Pain	<p>“Eish pains, it is very painful (laughing- patient was being embarrassed!). But he told us before the procedure that it is painful, but as this is the normal procedure you must tolerate the pain. And indeed! I did tolerate.” P3</p> <p>“When they insert that thing, it was difficult getting in and it was painful (loudly emphasizing this!!). Yea! it is very painful! And the time he was removing that thing then I was even able to breath now.” P4</p>

Themes	Categories	Quotes
		<p>“Yo! it is very painful. Yea it is really very painful. But if you want to live you will just tolerate the pain so that you can live.” P10</p> <p>“Nah!! that one is the worse pain you can experience in your lifetime. I don’t think there is any other pain more than that, anything more than that then it is death. That was really close to death yeah! P17” “I felt so dizzy! I felt dizzy. and he said (the doctor) nah! you must sit. I felt dizzy and a lot of pain (emphasizing!). Then after 10 minutes then I felt the dizziness coming to an end, then he put me on a chair and said I should sit there for half an hour.” P3</p>
	5.2 Discomfort	<p>“I don’t know the name of the instrument that was inserted at the back because they had inserted it at the back something that grasp a bit, you see. That is the only thing I felt but just a little bit.” P5</p> <p>“Well, when they started, I felt uncomfortable. When they started to insert the finger to feel anything at the back of me because he wants to feel any irregularities you just feel uncomfortable. Yeah! because usually, there is nothing that enters there at the back yah that’s it.” P15</p> <p>“I mean anything they stuck in your body it makes you uncomfortable.” P12</p> <p>“I am going to speak the truth. I did not like it when he inserted a finger inside of me. But then I just accepted it because this person is a doctor. So, I must accept what he says we should do.” P7</p>
	5.3 Positives regarding screening	<p>“Am no. What can I say, I can’t mention how I felt. I was just happy that I am getting treatment and that I am going to be strong again (referring to penis).” P4</p> <p>“Oh, yea it was not too bad. It was not too bad because I knew they are working yea.” P13</p> <p>“Nah because I want life, I did not have a problem with the process ... yea I agreed, and I said they should check everything that they need to check.” P8</p>

Themes	Categories	Quotes
		<p>“I don’t have any problem, not at all. That’s why I am saying I am happy that I came here and found out that it is starting and go along with it, that’s it.” P2</p>
6 Support needs	6.1 Provision with information pertaining the disease	<p>“In our churches they don’t preach about this prostate cancer of which maybe even the priest should preach and educate people, and it should just be there even in family gatherings ... even in the social gathering wherever we are we should just talk about it. Like at church when I have time, I do talk about it.” P19</p> <p>“And anything that they should tell me to handle myself well, things like that. I need information to know how far the cancer is and, also to know if it is growing or what, I just want the support to know about treatment.” P18</p> <p>“The doctor should tell me how long that thing is on me, how do I feel, such question like when you pass urine what you feel and all those things ... this process sometime when you are embarking on this journey of prostate cancer, you have to be informed what is going to take place and what is going to happen.” P15</p>
	6.2 Provision of Counselling before and after screening	<p>“No, you don’t have that kind of counselling. You see the doctor, you don’t talk. If you don’t ask questions the doctor also doesn’t, the doctor just write and then give you the next appointment date that’s it ... I was feeling that I, when I arrive here at the hospital, I should get one on one with the doctor (implying the need for counselling session).” P15</p> <p>“No, they didn’t give me any information about prostate cancer here at Bara, when I arrived here, they just examined me. No there is no counselling that I received.” P18</p> <p>“People need some of us need counselling.” P19</p> <p>“Nah they have not counselled us, they only briefed us that we are going to go through this about biopsy it is a bit painful, but it is worth it, then from there onwards no counselling nothing.” P17</p>

Themes	Categories	Quotes
		<p>“No, there was no counselling. It is a challenge. Currently I am by myself, as I am saying the news were delivered and I have to accept it and sometimes you feel like sitting down and talking to someone like I am talking to you right now but if you are by yourself you need to stomach it, accept it and move forward you have no choice.” P11 “This thing I wish like you can find someone who can encourage you. Because always when something comes up, at the back of your mind you think you are going to die. So, like, I wish when it is like that then someone should give you the support that even if it is like that things are going to be okay.” P3</p>
	<p>6.3 Cure, treatment, and provision of good pain control</p>	<p>“let’s say maybe cancer treatment, when they give people medication, when they have diagnosed how advanced the cancer is, they should give medication that can treat the cancer.” P5</p> <p>“Okay you see now I have only one worry, which I do not know if I might find it on the doctors or what. Is that, is this thing cured or what.” P3</p> <p>“If I can just get support. Is there a support that can make me a man so that I can raise up (implying cure for erectile dysfunction), you can’t just live without a woman.” P4</p> <p>“Cancer to go down or cured. The way the doctors can do it. That is the kind of support I want. I want them to help me in any way they may be able to help me.” P10</p> <p>“They didn’t inject anything to neutralise pain ... nah! maybe before they do biopsy maybe they should give someone an injection just to relief or to reduce the pain.” P17</p>
	<p>6.4 Reduction of waiting time</p>	<p>“But there is a system in this hospital, particularly here at the hospital you come in and then you queue with those people. That is the worst thing! Earlier we used to have our own window to get treatment. Most of the time is wasted at the chemistry (implying pharmacy), that’s where we need, I wish we could have our own section that gets you tested and get you your medicine and go. Like before,</p>

Themes	Categories	Quotes
		<p>I don't know why they changed, that is the worst thing they ever did." P12</p> <p>"So, I never had any problem unless if maybe time of write your card, then you wait for an hour or two. I am impatient just to wait and do nothing I just to do something you see." P2</p> <p>"When we come here sometimes, we wait for a long time. And sometimes we feel pain you know (from waiting in the long queue the whole day). P13But otherwise, everything is fine... so you feel like they should shorten the waiting time." P13</p>
	<p>6.5 Support person in the screening room</p>	<p>"There was only one doctor, a female doctor.... nah she was just alone." P19</p> <p>"It was only me and the doctor. there was no nurse." P18</p> <p>"Fortunate enough one of my family members is a nurse, I spoke to him about this procedure, he was very much aware of what is happening because I was with him in there and said that this blood in the urine will disappear after some couple of days and that's what really happened." P11</p> <p>"It was me and the doctor who was busy with me., it was only me and the doctor who was helping me with this." P9" There was a white doctor and another patient." P7</p> <p>"On the side of the urine that is where there is another doctor with their patient and then there it is me the other patient, you see." P15</p>

ANNEXURE K: Turnitin report

Boitumelo Mapale student number: 61263079 Dissertation

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