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Exploring Primary Care Providers' and Patients' Perspectives on Barriers and Enablers to Cervical Precancerous Lesion Detection in Primary Care Clinic Settings in Soweto

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EXPLORING PRIMARY CARE PROVIDERS' AND PATIENTS' PERSPECTIVES ON BARRIERS AND ENABLERS TO CERVICAL PRECANCEROUS LESION DETECTION IN PRIMARY CARE CLINIC SETTINGS IN SOWETO



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A dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg in fulfilment of the requirements for the degree of Master of Science

Johannesburg, South Africa
2025

DECLARATION

I Gugulethu Tshabalala, student number 1354725 hereby declare that this Dissertation is my own, unaided work. It is being submitted for the Degree of Master of Science in the Department of Internal Medicine at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



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08 August 2025

DEDICATION

To my mother, Teressia Nomalanga Tshabalala, thank you for your strength, resilience, and unwavering support. To my siblings, Siphiwe Gift and Busisiwe, your encouragement has carried me through. To my son, Sibusiso, you are my greatest motivation and source of pride. This achievement is for all of you –my foundation and inspiration.

PRESENTATIONS ARISING FROM THIS RESEARCH PROJECT

1. **Professional Hunters' Association of South Africa (PHASA) 2023**
   10–13 September 2023
   Cape Town

2. **14th African Organisation for Research and Training in Cancer AORTIC International Conference on Cancer in Africa**
   2–6 November 2023
   Dakar

3. **Johannesburg Health District Research Day**
   23 November 2023
   University of the Witwatersrand, School of Public Health

PUBLICATIONS ARISING FROM THIS RESEARCH PROJECT

1. Tshabalala, G., Blanchard, G., Mmoledi, K., Malope, D., O'Neil, D.S., Norris, S.A., Joffe, M. & Dietrich, J.J. A qualitative study to explore healthcare providers' perspectives on barriers and enablers to early detection of breast and cervical cancers among women attending primary healthcare clinics in Johannesburg, South Africa. *PLOS Glob Public Health*. 2023;3(5): e0001826. doi: 10.1371/journal.pgph.0001826

ABSTRACT

Background

Cervical cancer remains a major public health concern, ranking as the fourth most common cause of cancer incidence and mortality in women worldwide. Sub-Saharan Africa has the highest cervical cancer incidence and mortality rates globally, and it remains the leading cause of mortality among women in the region, mainly due to delayed diagnosis. This study explored primary care providers' and patients' perspectives on barriers and enablers to early detection of cervical cancer at primary healthcare clinics in Soweto.

Methods

Using a qualitative approach, semi-structured in-depth interviews were conducted with 22 healthcare providers (nurses, doctors, and facility managers) from 8 healthcare facilities in Orange Farm and Soweto and 15 women patients (9 screened and 6 not screened for cervical cancer). The in-depth interviews were audio-recorded and transcribed verbatim. The data were then input into NVivo for framework analysis. Healthcare provider and patient findings were analysed separately, focusing on barriers and enablers for early detection and treatment of cervical cancer. The results were framed using the Socio-Ecological Model for providers and a combination of the Socio-Ecological Model and Health Belief Model for patients.

Results

Healthcare providers reported that the South African National Department of Health provides inadequate cancer training and support, and that staff rotations led to gaps in cancer and screening knowledge. Healthcare providers perceived that patients had limited awareness of cancer and of screening services, consequently reducing demand. Providers highlighted resource shortages – staff, facilities, supplies, and access to lab results – limiting screening provision. They perceived that many women preferred self-medication, accessed traditional health practitioners' services, and often sought primary healthcare services when in critical condition. Interviews with women showed that they were generally aware of cervical cancer and screening procedures. Their perceived barriers to access included fear of diagnosis, perceived discomfort and pain with the procedure, and limited provider and equipment

resources. Patients cited long waiting times, delays in obtaining screening results, and missing results as additional barriers to screening access.

Conclusion

The findings reveal discordance between provider and patient perceptions of women's knowledge and awareness of cervical cancer and screening services. However, both groups identified substantial barriers to effective cervical cancer screening service provision and uptake that are amenable to interventions.

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TABLE OF CONTENTS

DECLARATION ii

DEDICATION iii

PRESENTATIONS ARISING FROM THIS RESEARCH PROJECT iv

PUBLICATIONS ARISING FROM THIS RESEARCH PROJECT v

ABSTRACT vi

ACKNOWLEDGEMENTS viii

FUNDING AND SUPPORT ix

LIST OF FIGURES xv

LIST OF TABLES xvi

CHAPTER 1: INTRODUCTION – CANCER AND CERVICAL CANCER BURDEN AND MANAGEMENT 1

1.1 Global Burden of Non-Communicable Diseases 1

1.2 Cancer Burden 2

1.3 The Cancer Epidemic in Sub-Saharan Africa and South Africa 3

1.4 Global Burden of Cervical Cancer 4

1.5 Burden of Cervical Cancer in Sub-Saharan Africa 5

1.6 Burden of Cervical Cancer in South Africa 6

1.7 Treatment and Management of Cervical Cancer in South Africa 7

1.8 Structure of the Dissertation 8

CHAPTER 2: LITERATURE REVIEW 10

2.1 Introduction 10

2.2 Cause and Strains of Cervical Cancer 10

2.3 Cervical Cancer Risk Factors and Prevention 11

2.4 Diagnosis and Staging of Cervical Cancer 11

2.5 South African Guidelines for Prevention and Early Detection of Cervical Cancer 12

2.6 Barriers to Cervical Cancer Screening and Pre-Cancerous Lesion Treatment in Sub-Saharan Africa 13

2.7 Rationale for the Study 13

2.8 Research Aims and Objectives 14

CHAPTER 3: CONCEPTUAL FRAMEWORK 15

3.1 Introduction 15
3.2 Socio-Ecological Model 16
3.3 Health Belief Model 17
3.4 The Capability, Opportunity, Motivation-Behaviour Model 18
CHAPTER 4: RESEARCH METHODOLOGY 20
4.1 Introduction 20
4.2 Research Design 20
4.3 Research Setting 20
4.3.1 Primary healthcare clinic 22
4.3.2 Community healthcare centre 22
4.3.3 Soweto 22
4.3.4 Orange Farm 23
4.4 Ethics Statement 24
4.5 Study Participants and Sampling 24
4.5.1 Healthcare providers (Objective 1) 25
4.5.2 Women routinely attending HIV clinics (Objective 2) 25
4.6 Data Collection Procedures 25
4.6.1 Transcription, coding, and assessment of data saturation 26
4.6.2 Interviewer training 26
4.7 Measures 27
4.7.1 Socio-demographic questionnaire 27
4.7.2 Interview guide 1: facility managers and healthcare providers 27
4.7.3 Interview guide 2: Women in HIV clinics 27
4.8 Data Management 27
4.9 Data Analysis 28
4.10 Reflexivity 28
4.11 Personal Positionality 29
4.12 Trustworthiness of the Research 30
CHAPTER 5: FINDINGS – PERSPECTIVES FROM HEALTHCARE PROVIDERS 31
5.1 Introduction 31
5.2 Participants' Characteristics 31
5.3 Individual Level 32

5.3.1 Perceived barriers to early detection of cervical cancer 32
5.3.2 Provider perceptions of patient barriers to cervical cancer screening .. 35
5.4 Interpersonal Level 37
5.5 Organisational Level 38
5.5.1 Healthcare providers barriers 38
5.6 Community Level 41
5.6.1 Healthcare provider perceptions of community barriers to cervical cancer screening demand 41
5.7 Policy Level 43
5.7.1 Policy barriers to adequate provision of cervical cancer screening services 43
5.8 Provider suggestions for enablers to early detection of precancerous and cancerous cervical lesions 43
CHAPTER 6: FINDINGS – WOMEN ATTENDING HIV CLINICS 47
6.1 Introduction 47
6.2 Participants' Characteristics 47
6.3 Overview of Results 48
6.4 Individual Level 48
6.4.1 Socio-Ecological Model 48
6.4.2 Patients' perceptions (Attitudes) 52
6.4.3 Cues to action 53
6.4.4 Negative cues to action regarding disclosure of possible cervical cancer symptoms and accessing screening services 55
6.4.5 Traditional health practitioner use 57
6.5 Family Level Influences on Screening Behaviour 59
6.5.1 Positive cues to action 59
6.5.2 Self-efficacy 60
6.6 Organisational Level Perspectives on the health system: Perceived barriers to screening access 61
6.6.1 Negative cues to action 61
6.6.2 Staff attitude 62
6.6.3 Barriers to continuity of healthcare: Clinic hopping 63
6.7 Community Level 64
6.7.1 Cues to action 64

6.7.2 Community knowledge of cancer 65
6.7.3 Role of religion in health-seeking behaviour – community religious resources as a cue to action 65
6.8 Motivators/Enablers for Cervical Cancer Screening in the Healthcare System 66
6.8.1 Health system positive cues to action 66
6.9 Facilitators to Cervical Cancer Education 66
6.9.1 Community education 66
6.9.2 In-clinic education 67
6.9.3 Media 67
CHAPTER 7: DISCUSSION 69
7.1 Introduction 69
7.1.1 Objective 1: Healthcare providers perspectives 69
7.1.2 Objective 2: Women patients' perspectives 72
7.2 Triangulation of Healthcare Provider and Clinic Women Findings 75
7.2.1 Common findings 76
7.2.2 Unique findings 77
7.3 Implications for Policy Intervention 77
7.4 Study Strengths and Limitations 78
REFERENCES 80
APPENDICES 91
APPENDIX A1: Information leaflet and informed consent form for individual in-depth interviews FOR managers/healthcare providers 91
APPENDIX A2: Information leaflet for individual in-depth interviews for patients 96
APPENDIX B1: Informed consent form signature page 100
APPENDIX B2: Informed consent form signature page 101
APPENDIX C: Participant sociodemographic data collection form 103
APPENDIX D1: In-depth interview guide for healthcare providers 104
APPENDIX D2: In-depth interview guide for healthcare facility managers 108
APPENDIX D3: Women patient interview guide 110
APPENDIX E: Faculty approval 113
APPENDIX F: Ethics clearance 114
APPENDIX G: Research committee of Johannesburg Health District approval 115

ACRONYMS AND ABBREVIATIONS

ART	Antiretroviral therapy
ASIR	Age-standardised incidence rate
CC	Cervical cancer
CCRT	Chemoradiation therapy
CHBAH	Chris Hani Baragwanath Academic Hospital
CHC	Community healthcare centre
CIN	Cervical intraepithelial neoplasia
COM-B	Capability, Opportunity, Motivation-Behaviour
FIGO	International Federation of Gynaecology and Obstetrics
GLOBOCAN	Global Cancer Observatory
HIC	High-income-country
HBM	Health Belief Model
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
IDI	In-depth interview
LMIC	Low- or middle-income country
NCD	Non-communicable diseases
NDoH	National Department of Health
PHC	Primary healthcare clinic
SEM	Socio-Ecological Model
TB	Tuberculosis
VIA	Visual inspection of the cervix with acetic acid
WHO	World Health Organization

LIST OF FIGURES

Figure 1.1: Global trends in cancer incidence and mortality 1

Figure 1.2: Global trends in cancer mortality 2

Figure 3.1: The Socio-Ecological and adapted Health Belief Model incorporated for determinants of screening uptake 16

Figure 4.1: Location of community members referred from primary healthcare facilities to the tertiary Chris Hani Baragwanath Academic Hospital in Soweto and Orange Farm 23

Figure 7.1a: Healthcare providers' perspectives and their complex interaction 70

Figure 7.1b: Women patients' perspectives and their complex interaction 73

LIST OF TABLES

Table 1.1: 2022 Age-standardised incidence of the most common adult cancers in South Africa 4

Table 2.1: 2018 FIGO staging classification for cervical cancer 11

Table 5.1: Healthcare providers' characteristics 32

Table 6.1: Sociodemographic characteristics of participants screened and not screened for cervical cancer 47

CHAPTER 1: INTRODUCTION – CANCER AND CERVICAL CANCER BURDEN AND MANAGEMENT

This chapter provides the background and rationale for the dissertation. It introduces the research questions and describes the research aims and objectives. It concludes with an outline of the dissertation structure, giving a brief description of each chapter.

1.1 GLOBAL BURDEN OF NON-COMMUNICABLE DISEASES

Non-communicable diseases (NCDs) are the foremost public health challenge globally, resulting in morbidity, mortality, economic loss, diminished quality of life, and poor social development across high- and low-resource countries [1]. Each year, more than 40% of the 38 million deaths from NCDs were premature and preventable [2]. These diseases accounted for an estimated 74% of global deaths between 1990-2019, with cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes classified as the four major NCDs [3]. The highest risks of dying from NCDs were observed in low-and middle-income countries (LMICs), particularly in sub-Saharan Africa [4].

Some 77% of these NCD deaths, including those from cancer, occurred prematurely between the ages of 30–69 years, with 86% of these younger deaths occurring in LMICs, including those in sub-Saharan Africa [5–7]. This is attributed to a surge in the burden of NCDs in sub-Saharan Africa over the past two decades, driven by increasing incidences of cardiovascular diseases and cancer risk factors such as hypertension, obesity, diabetes, and dyslipidaemia, caused by unhealthy diets, reduced physical activity, and air pollution (see Figure 1.1).

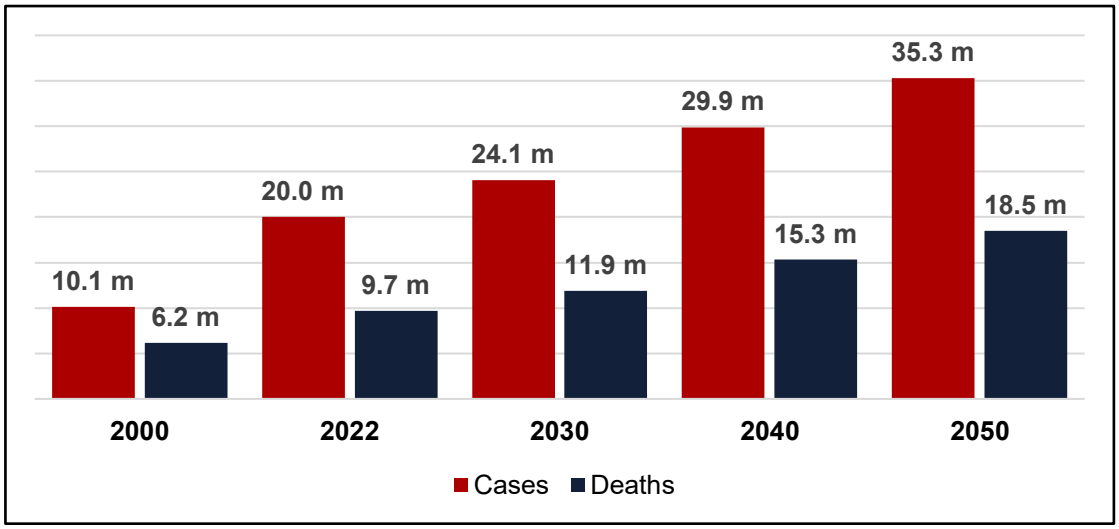


Figure 1.1: Global trends in cancer incidence and mortality [8]

In sub-Saharan Africa – including in South Africa, where the public health system serves 85% of the population – health systems are under-resourced to adequately cope with this epidemic [9].

1.2 CANCER BURDEN

Cancer ranks as a leading cause of death and a significant barrier to increasing life expectancy across the world [10]. In very high-income countries (HICs), because of the much older age distribution of their populations, cancer incidence is substantially higher than that of LMICs, and is the leading cause of death. As life expectancy continues to increase in LMICs, however, cancer incidence is steadily increasing [6]. This trend reflects ageing driven by increasing life expectancy and socio-economic development, continued population growth in LMICs, and rising lifestyle-related cancer risk factors [7] (see Figure 1.1). Based on projected population ageing and growth, the global burden of cancer is set to increase by more than 60% by 2040, from 18.1 million new cases in 2018 to a predicted 29.4 million cases in 2040, and LMICs will bear the brunt of the mortality burden, as shown in Figure 1.2.

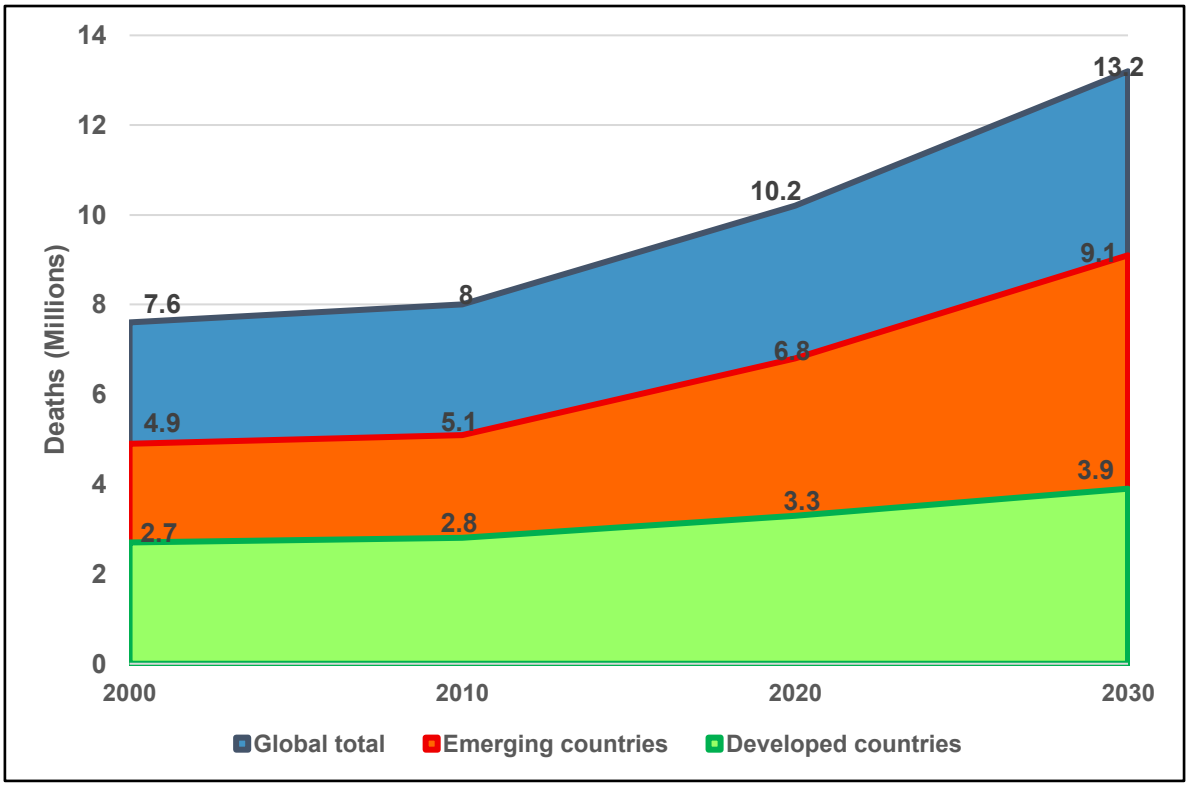


Figure 1.2: Global trends in cancer mortality [6]

According to World Health Organization (WHO) estimates, more than 40% of cancer deaths worldwide are attributable to tobacco use, unhealthy diets, alcohol

consumption, inactive lifestyles, and infection. This amounts to between 2.4 and 3.7 million avoidable deaths each year, 80% of which are in LMICs [5]. A substantial proportion of the worldwide burden of cancer could be prevented through the application of existing cancer control knowledge, and by implementing programmes for tobacco control, vaccination (for liver and cervical cancers) [11], and early detection and treatment, as well as public health campaigns promoting physical activity and a healthier dietary intake [2]. However, only 5% of global spending on cancer occurs in LMICs, despite these countries bearing a disproportionate burden of the disease, resulting in a marked spending inequity [12]. Just two cancers – breast and cervical – account for almost the same number of deaths among women of reproductive age in LMICs as maternal mortality [11,13].

1.3 THE CANCER EPIDEMIC IN SUB-SAHARAN AFRICA AND SOUTH AFRICA

Cancer is currently responsible for an estimated 533 000 deaths in sub-Saharan Africa annually, and the region already has among the highest mortality-to-incidence ratios globally [14]. South Africa has the largest human immunodeficiency virus (HIV) – and associated tuberculosis (TB) – epidemic in the world. As of 2020, 13.7% (8.2 million) of the population was living with HIV, more than 5 million of whom are on antiretroviral therapy (ART) [14]. Owing to the ongoing ART rollout, life expectancy is increasing, and the South African population is steadily ageing. With the transition to a Westernised lifestyle, cancer incidence is progressively rising [15]. In South Africa and other sub-Saharan African countries, cancer incidence is expected to double by 2050 [16].

In 2022, the South African National Cancer Registry reported a cumulative lifetime risk of being diagnosed with cancer before the age of 74 at 15.6% for males (compared to 23.6% reported by GLOBOCAN, the Global Cancer Observatory) and 12.0% for females (compared to 18.7% from GLOBOCAN) [16]. As shown in Table 1.1, the most prevalent cancers in South Africa were estimated to be breast, cervical, and colorectal cancers in females, while prostate, lung, and colorectal cancers were the most common in males [16].

Table 1.1: 2022 Age-standardised incidence of the most common adult cancers in South Africa [16]

Type of cancer for women	ASR	Type of cancer for men	ASR
Breast Cancer	34.02	Prostate	51.94
Cervical Cancer	23.02	Colorectal	11.03
Colorectal	6.84	Lung	10.85
Uterus	5.59	Non-Hodgkins lymphoma	5.07
Non-Hodgkins lymphoma	3.24	Melanoma	5.44
Melanoma	3.25	Bladder	4.43
Lung	3.19	Oesophagus	4.53
		Stomach	3.56
Total	43 860		

The quadruple burden of disease in South Africa has placed an enormous and increasing strain on the country's under-resourced three-tiered public health system [15]. The country's impressive successes in integrating HIV and TB care have not been extended to the management of other chronic diseases [17]. The South African public health system remains under-resourced and uncoordinated, unable to cope with the increasing burden of NCDs and cancer.

1.4 GLOBAL BURDEN OF CERVICAL CANCER

Cervical cancer remains a major public health concern, ranking as the fourth most common cause of cancer incidence and mortality in women worldwide. In 2020, new cases were estimated at 604 000 and deaths at 342 000 [18], approximately 90% of which occurred in LMICs. While cervical cancer can be cured if diagnosed at an early stage and treated promptly, LMICs have limited resources to respond to the overwhelming challenges that cancer brings to their national health systems.

In response, in 2020, WHO launched the global Cervical Cancer Elimination Initiative to accelerate the elimination of cervical cancer, aiming to reduce incidence below a threshold of 4 cases per 100 000 women in every country, and thus narrow international disparities associated with this disease [19]. The 90–70–90 target set by the initiative to be achieved by 2030 [20] is for 90% of girls to be fully vaccinated with the human papillomavirus (HPV) vaccine by the age of 15; 70% of women to be screened using a high-performance test by the age of 35, and again by the age of 45;

and 90% of women with pre-cancer to be treated, and 90% of women with invasive cancer managed [19].

1.5 BURDEN OF CERVICAL CANCER IN SUB-SAHARAN AFRICA

Although progress has been made in certain parts of the world, cervical cancer disproportionately affects women in low- and middle-income countries (LMICs), particularly in sub-Saharan Africa [21], which continues to carry the highest cervical cancer burden globally. In high income HICs, cervical cancer is gradually becoming rare, with age-standardised incidence rates (ASIRs) as low as 6–10 per 100 ,000 [6,22], largely due to well- organised, well-funded screening and HPV vaccination programmes, with the coverage rates exceeding 70%. whereas In contrast, coverage in SSA sub-Saharan Africa is often below 30%, and in some settings, below 10% [19,23–2625].

Even within HICs, women from racial and ethnic minority groups continue to experience disproportionately low screening uptake and treatment despite the availability of services. Barriers in these populations include socio-economic status, limited health literacy and awareness of cervical cancer, poor understanding of medical terminology, low perceived risk owing to absence of symptoms [26,27], stigma, discomfort with Pap smears, lack of social support, religious beliefs [28], and mistrust of healthcare systems [29]. In sub-Saharan Africa, cervical cancer is the leading cause of cancer-related deaths among Black women in the region [30–32]. Screening rates remain critically low – often below 30% – and in some areas, below 10% [19,23]. This high burden is closely linked to low screening uptake, late diagnosis, and limited access to timely treatment. Key contributing factors to low cervical cancer screening uptake include socio-economic status and limited awareness and understanding of cervical cancer, its risk factors, and the importance of early detection [33]. Other factors include fear of the screening procedure or associating it with stigma, misconceptions about cervical cancer, socio-cultural and religious beliefs, and negative attitudes of healthcare providers [34]. Cervical cancer screening is frequently under-prioritised within public health agendas, leading to insufficient investment in infrastructure, staff training, and outreach.

Healthcare providers in both HICs and sub-Saharan Africa recognise that multiple, intersecting barriers contribute to the persistently low uptake of cervical cancer screening among minority and underserved women. In both contexts, providers

identify limited knowledge about cervical cancer and its screening benefits, cultural and religious beliefs, stigma, and embarrassment related to cervical cancer screening procedures as the primary reasons [21]. Countries in sub-Saharan Africa cite health system limitations – including inadequate infrastructure, under-trained staff, and weak referral mechanisms – as major constraints [35]. They also highlight patients' preference for traditional, complementary, and alternative medicines [36]. Furthermore, weak referral and follow-up mechanisms mean that even when women are screened, those with abnormal results may not receive timely or appropriate treatment, resulting in missed opportunities for prevention [34,37].

1.6 BURDEN OF CERVICAL CANCER IN SOUTH AFRICA

As an HIV-endemic country, South Africa – home to only 0.73% of the global population of women over 15 years (20.2 million of 2.784 billion) – bears 2.3% of the global cervical cancer incidence burden, as reported in 2018 [38]. The ASIR at 23.02/100 000 makes cervical cancer the second most common cancer after breast cancer among women in South Africa (see Table 1.1). According to South African National Cancer Registry (2022) data, the ASIR (per 100 000 women) among different ethnic groups is: Asian (8.21), Black (26.86), Coloured (13.31), and White (16.28), which is significantly higher than in HICs [16].

Cervical cancer is currently the number one cancer-related cause of mortality among Black women in South Africa, despite the introduction in 2014 of HPV vaccination in schools and the National Department of Health's (NDoH) screening policies and guidelines [39]. The NDoH guidelines mandate screening HIV-positive women of any age, with follow-up screening every 36 months for those who screen negative, and six weeks postnatally for pregnant women. In South Africa, education, counselling, and screening for cervical cancer are provided in the primary healthcare system [39]. Women who screen positive for pre-cervical lesions are referred to district community health centres and tertiary hospitals for treatment with cryotherapy and large loop excision of the transformation zone. Women with cervical cancer are treated at tertiary hospitals [39].

Cervical cancer screening uptake in South Africa remains low, with national estimates around 20%, which is significantly below the 70% target set by the World Health Organization (WHO) for cervical cancer elimination [40]. This contrasts sharply with the higher screening rates typically observed in HICs, where well-

established programmes often achieve over 70% coverage [40,41]. Studies in South Africa show that screening uptake is influenced by several factors, including educational level, age, HIV status, contraceptive use, perceived susceptibility to cancer, and awareness of screening services [42,43]. Structural barriers such as staff shortages, long waiting times, and limited availability of HPV testing also constrain service delivery at the primary healthcare level [34,37,44], while social barriers are largely driven by community misconceptions [45].

Healthcare providers observe that many women lack basic knowledge about cervical cancer and its risk factors and often do not perceive themselves to be at risk in the absence of symptoms. Many fear pain or discomfort during screening procedures [46,47], stigma, and limited family or partner support [48]. Providers frequently cite systemic challenges including shortages of trained staff and long waiting times, all of which hinder effective screening implementation. Cultural norms, religious beliefs, and widespread reliance on traditional or alternative medicine often lead women to delay or avoid seeking screening at health facilities [37].

South Africa's current performance indicators for cervical cancer focus on reporting the number of women screened, but not on whether those who screened positive received appropriate treatment. This results in missed opportunities for precancerous lesion management and limits accountability. Although HPV testing is recommended in national policy and offers a more sensitive and scalable screening approach [39], it has not yet been widely implemented, largely due to cost and operational challenges. Together, these factors reflect persistent gaps in the cervical cancer prevention and control continuum in South Africa, reinforcing the need to strengthen early detection systems, improve referral pathways, and ensure timely access to treatment –particularly in primary care settings serving high-burden populations.

1.7 TREATMENT AND MANAGEMENT OF CERVICAL CANCER IN SOUTH AFRICA

South African clinical guidelines recommend a comprehensive approach to cervical cancer control that includes prevention through HPV vaccination, early detection of precancerous lesions via screening, and timely access to treatment for invasive disease [39].

Women who are found to have serious abnormal changes in the cells of the cervix (known as high-grade lesions or CIN 2/3) are offered timely treatment to prevent

progression to cervical cancer. This treatment can either destroy the abnormal cells by using heat (ablative treatment) or remove them by cutting out the affected tissue (excisional treatment). The primary treatment for locally advanced cervical cancer is chemoradiation therapy (CCRT), which combines chemotherapy and radiation and has better survival outcomes than radiation alone. For early-stage cancer, surgery is usually the first choice. In cases where the cancer is found very late, treatment often focuses on relieving symptoms rather than curing the disease [39].

A retrospective review at Tygerberg Hospital found a two-year overall survival rate of approximately 72% among women under 39 years who received primary CCRT [49]. Similarly, data from Groote Schuur Hospital indicated that women who received both chemotherapy and radiation had significantly better survival outcomes than those who received radiation alone [50].

1.8 STRUCTURE OF THE DISSERTATION

This dissertation comprises seven chapters structured to address the research question. Below is an outline with a brief description of each chapter:

Chapter 1 focuses on the context and background of the study and an outline of the dissertation.

Chapter 2 reviews the literature on cervical cancer, focusing on its epidemiology, causes, risk factors, prevention, diagnosis, and staging methods. It also examines South African guidelines for prevention and early detection, as well as barriers to early detection in sub-Saharan Africa. This is followed by the rationale for the study and the study aims and objectives.

Chapter 3 outlines the conceptual model and theoretical framework guiding the study's data collection and analysis. It provides a detailed overview of the Socio-Ecological Model and the Health Belief Model as the chosen frameworks.

Chapter 4 details the qualitative research design among providers and women attending primary healthcare clinics (PHCs), covering the aim and objectives, research design, sampling techniques, data collection methods, and data analysis approach.

Chapter 5 presents qualitative findings from interviews with healthcare providers' and facility managers. Framework data analysis was used to analyse in-depth interviews.

The healthcare providers' and facility managers results are conceptualised within the Socio-Ecological Model, with key themes and subthemes identified across all five domains (individual, interpersonal, organisational, community and public policy). Themes and subthemes are supported by quotations from the NVivo 12 Plus coding database, a software tool for qualitative data management and analysis.

Chapter 6 presents qualitative findings from perspectives of women patients attending HIV clinics, analysed using framework analysis of in-depth interviews. The results are conceptualised within the Socio-Ecological Model, with key themes and subthemes identified across four domains (individual, interpersonal and organisational, community). Additionally, the Health Belief Model was used to support the conceptualisation of women's risk perceptions and motivation for early cervical cancer diagnosis, with findings from levels within the Socio-Ecological Model constituting some of the modifiable variables. Themes and subthemes are supported by quotations from the NVivo 12 Plus coding database, a software tool for qualitative data management and analysis.

Chapter 7 provides an integrated discussion of the qualitative findings from the healthcare providers' and patients' perspectives. It summarizes the key results, presents concluding remarks, and addresses the study's limitations. The final section offers conclusions and recommendations for practice.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews the literature on cervical cancer, addressing causes, risk factors, prevention, diagnosis, and staging. It examines the global and sub-Saharan African burden of the disease, South African prevention and early detection guidelines, including screening and vaccination programmes, and beliefs and awareness levels.

2.2 CAUSE AND STRAINS OF CERVICAL CANCER

Cervical cancer is the human papillomavirus (HPV), which causes one in five cervical cancers [11,52]. HPV is a common and frequently asymptoatic sexually transmitted infection [52]. It is significantly more prevalent among women living with the human immunodeficiency virus (HIV) [55] than among those who are HIV-negative. The 14 most cancer-causing HPV strains are 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 66, and 68 [11]. The strains 16 and 18 are recognised as the most common types associated with the development of cervical cancer [11,53] yet in South Africa there is a high HPV-35 prevalence, especially among women with cervical intraepithelial neoplasm (CIN 3) [54].

Comprehensive cervical cancer control includes primary prevention (vaccination against HPV), secondary prevention (screening and treatment of pre-cancerous lesions), tertiary prevention (diagnosis and treatment of invasive cervical cancer), and palliative care. Recognising that HPV vaccination can prevent cervical cancer, the South African HPV school-based vaccination programme, targeting girls aged 9–13, was initiated in 2014 [55]. However, uptake of the vaccination programme in South Africa and other sub-Saharan African countries has been slow, particularly for follow-up vaccinations [55].

In 2002, the South African National Department of Health (NDoH) introduced a national cervical cancer screening programme in the primary healthcare setting for detecting and treating pre- and early cervical cancer lesions [56]. Despite these national interventions and the fact that cervical cancer is preventable and curable if detected early, cervical cancer diagnoses in South Africa have increased steadily from 6 181 in 2018 to 7 499 in 2022 [16]. The poor prognosis is associated with advanced-stage cervical cancer diagnoses among the socio-economically

disadvantaged, predominantly Black population, with an estimated half of all cervical cancer cases in this population resulting in death [46].

2.3 CERVICAL CANCER RISK FACTORS AND PREVENTION

Human papillomavirus (HPV) is one of the most common causes of sexually transmitted infections in both men and women worldwide [57]. A person's risk of contracting HPV increases with early sexual debut, having multiple sexual partners, a history of other sexually transmitted infections, and multiple childbirths [57–60]. Women living with HIV have a higher risk and persistence of multiple HPV infections, which are associated with an increased risk of progression to precancerous cervical lesions, compared to women not living with HIV [58].

2.4 DIAGNOSIS AND STAGING OF CERVICAL CANCER

To eliminate cervical cancer by 2030, the World Health Organization has set a target of 70% coverage of twice-in-a-lifetime screening. A multitude of screening methods are available, including cytology, HPV DNA testing, and visual inspection tests [60]. A practical approach to cancer management involves 4 steps: 1) establish the diagnosis; 2) define the extent of disease; 3) plan and implement treatment; and 4) follow the patient for evidence of recurrence or treatment-related complications [59]. The widely used staging system for cervical cancer is the International Federation of Gynaecology and Obstetrics (FIGO), based on clinical evaluation [61] and summarised in Table 2.1 below.

Table 2.1: 2018 FIGO staging classification for cervical cancer [61]

Stage			Description
I			The carcinoma is strictly confined to the cervix (extension to the uterine corpus should be disregarded
	IA		Invasive carcinoma that can be diagnosed only by microscopy, with maximum depth of invasion < 5 mm
		IA1	Measured stromal invasion < 3 mm in depth
		IA2	Measured stromal invasion ≥ 3 mm and < 5 mm in depth
	IB		Invasive carcinoma with measured deepest invasion ≥ 5 mm (greater than Stage IA), lesion limited to the cervix uteri
		IB1	Invasive carcinoma ≥ 5 mm depth of stromal invasion, and < 2 cm in greatest dimension
		IB2	Invasive carcinoma ≥ 2 cm and < 4 cm in greatest dimension
		IB3	Invasive carcinoma ≥ 4 cm in greatest dimension

Stage			Description
II			The carcinoma invades beyond the uterus, but has not extended onto the lower third of the vagina or to the pelvic wall
	IIA		Involvement limited to the upper two-thirds of the vagina without parametrial involvement
		IIA1	Invasive carcinoma $<$ 4 cm in greatest dimension
		IIA2	Invasive carcinoma $\geq$ 4 cm in greatest dimension
	IIB		With parametrial involvement but not up to the pelvic wall
III			The carcinoma involves the lower third of the vagina and/or extends to the pelvic wall and/or causes hydronephrosis or nonfunctioning kidney and/or involves pelvic and/or para-aortic lymph nodes
	IIIA		The carcinoma involves the lower third of the vagina, with no extension to the pelvic wall
	IIIB		Extension to the pelvic wall and/or hydronephrosis or nonfunctioning kidney (unless known to be due to another cause)
	IIIC		Involvement of pelvic and/or para-aortic lymph nodes, irrespective of tumour size and extent (with r and p notations)
		IIIC1	Pelvic lymph node metastasis only
		IIIC2	Para-aortic lymph node metastasis
IV			The carcinoma has extended beyond the true pelvis or has involved (biopsy proven) the mucosa of the bladder or rectum. (A bullous oedema, as such, does not permit a case to be allotted to Stage IV)
	IVA		Spread to adjacent pelvic organs
	IVB		Spread to distant organs

2.5 SOUTH AFRICAN GUIDELINES FOR PREVENTION AND EARLY DETECTION OF CERVICAL CANCER

The NDoH recommends the provision of cervical cancer screening using either a Pap smear or liquid-based cytology, at various intervals, depending on a woman's risk profile [39]. For low-risk women, three screening tests over a lifetime are recommended – every 10 years, starting at age 30 until age 50, as the onset of cervical cancer is rare before 30 in HIV-negative women. If abnormalities are detected, repeat screenings are recommended at three-yearly intervals until a negative screening result is achieved. For HIV-positive women, screening should be conducted every three years from the time of HIV diagnosis.

The World Health Organization recommends a 'screen-and-treat' approach that allows for treatment soon (if not immediately) after screening with high-risk HPV testing, followed by visual inspection of the cervix with acetic acid (VIA) [62]. If the HPV test is positive, VIA results are used to determine the extent of the lesions, the

immediacy of treatment, and the optimal therapy, such as cryosurgery or a loop electrosurgical excision procedure. However, VIA as a primary screening test should be phased out because of the inherent challenges of low specificity. In practice, South Africa does not use VIA but rather liquid-based cytology, as per NDoH guideline recommendations.

2.6 BARRIERS TO CERVICAL CANCER SCREENING AND PRE-CANCEROUS LESION TREATMENT IN SUB-SAHARAN AFRICA

Findings from a recent review article on perceived barriers to cervical cancer screening in Africa identified 28 screening barriers pertaining to women and 10 for service providers. Women mostly cited inaccessibility of screening services, lack of awareness and knowledge of cervical cancer and screening benefits, and financial and socio-cultural constraints. Service providers, on the other hand, perceived the lack of training necessary to conduct screening, lack of equipment and supplies, staff shortages, and the gender and age of the health practitioner as major barriers to providing screening services [34].

2.7 RATIONALE FOR THE STUDY

The incidence of cervical cancer in South Africa is disproportionately high. The mortality and morbidity rates are high for women in South Africa presenting with advanced stages of cervical cancer. Cervical cancer is highly preventable and can be easily treated if detected in the early stages. Early diagnosis of cervical cancer increases the likelihood of treatment being successful and improves the chances of survival. Screening for pre-invasive cervical abnormalities has the potential to save lives and limit the costs and burdens on South Africa's public health system [46]. Strengthening services for early detection and effective management of cervical cancer may increase patient survival rates and quality of life [60,63].

While early cervical cancer detection, screening, and diagnosis have been proven to boost patient survival rates and quality of life, implementing sustainable cervical cancer management guidelines in different primary healthcare settings is highly challenging in the South African Public Health Services [46]. Barriers to screening uptake and early cancer detection and treatment need to be identified and understood among the various stakeholders so that they can be addressed in future comprehensive community and health system interventions.

2.8 RESEARCH AIMS AND OBJECTIVES

This study aimed to explore provider and patient perspectives on barriers and enablers to cervical precancerous lesion detection and management in primary care clinic settings in Soweto, South Africa.

Objective 1: To explore experiences, barriers, and enablers of cervical cancer screening and precancerous lesion management among women attending clinics, as perceived by facility managers, nurses, and doctors from two community health centres and their feeder primary healthcare clinics in greater Soweto through in-depth interviews.

Objective 2: To explore among women routinely attending HIV clinics at community health centres in Soweto and Orange Farm, the perspectives and experiences of cervical cancer screening and the process of obtaining screening results in-depth interviews.

Objective 3: To triangulate the perspectives of healthcare providers and women in order to identify common and contrasting barriers and enablers to the detection of cervical precancerous lesions in primary care settings.

CHAPTER 3: CONCEPTUAL FRAMEWORK

3.1 INTRODUCTION

This chapter presents the conceptual models for this study: the Socio-Ecological Model (SEM) [64,65] for Objective 1 and the SEM integrated with the Health Belief Model (HBM) for Objective 2 [66]. The integration of these two models has been frequently used in the literature [68] to understand influences on health and wellbeing and associated behaviours over the lifespan [63]. For Objective 2, the integrated HBM and SEM were used to understand how SEM-level emerging themes may influence women's perceived susceptibility, perceived barriers, perceived benefits, and their self-efficacy, and how these factors influence the likelihood of them requesting or being willing to receive cervical cancer screening. This combined SEM and BHM model was employed for investigating the perceptions and experiences of cervical cancer and screening services within primary healthcare clinics in Soweto and Orange Farm.

Provider findings were integrated for interpretation using the Capability, Opportunity, Motivation-Behaviour (COM-B) framework. The COM-B framework offers a comprehensive understanding of the factors that drive or hinder health-related behaviour [67]. The components of the COM-B model – capability, opportunity, and motivation – align closely with key constructs commonly used in health behaviour research. Specifically, *capability* corresponds to knowledge and skills; *motivation* aligns with attitudes, perceptions, self-efficacy, perceived threats, and cues to action; and *opportunity* relates to barriers and facilitators within the environment. Drawing on these parallels, the findings from the two participant groups were analysed and compared, with similarities and differences discussed using a combined framework, as illustrated in Figure 3.1 below. These models informed the development of the interview guides and the systematic structuring of results.

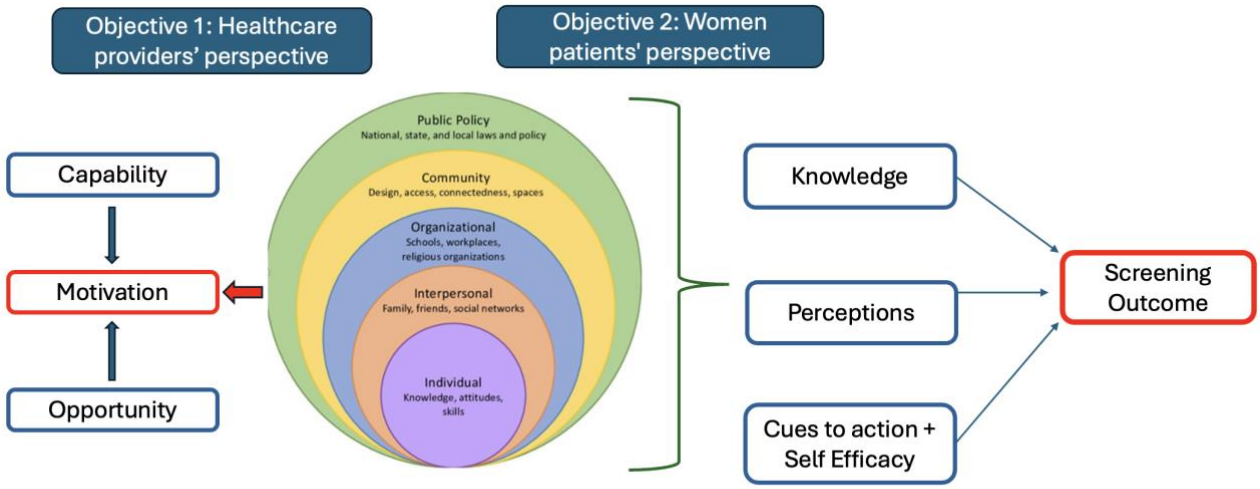


Figure 3.1: The Socio-Ecological and adapted Health Belief Model incorporated for determinants of screening uptake [65,66]

3.2 SOCIO-ECOLOGICAL MODEL

The Socio-Ecological Model (SEM) was developed out of the work of a number of notable researchers, including Bronfenbrenner's Ecological Systems Theory; McLeroy, Bibeau, Steckler et al.'s Ecological Model of Health Behaviours; and Daniel Stokols' Social Ecological Model of Health Promotion [65]. Bronfenbrenner hypothesised that to understand human development, the entire ecological system in which growth occurs needs to be considered. The SEM suggests that an individual's behaviour is integrated in a dynamic network of intrapersonal characteristics, interpersonal processes, institutional factors, community features and public policy. The SEM thus takes into consideration the *individual, interpersonal, organisational, community* and *policy factors* that may influence health behaviours and outcomes. The model assumes that interactions between individuals and their environment are reciprocal, implying that individuals are influenced by their environment and the environment is influenced by the individual. It also assumes that the environment is comprised of several overlapping levels [69]. Accordingly, barriers to accessing cervical cancer screening services and obtaining timely diagnosis and treatment can be classified into personal (individual), cultural, socio-economic, and institutional barriers [69].

Several studies in sub-Saharan Africa have used the SEM to examine cervical cancer screening uptake, offering insight into how individual, interpersonal,

community, organisational, and system level policy-level factors interact [34]. These studies highlight the importance of addressing multi-level barriers and often use mixed methods to combine depth and breadth. However, they tend to focus more on individual-level factors, with limited exploration of policy. A strength of the SEM is that it helps explain how individual, social, and environmental factors interact to influence behaviour, making it useful for designing community health interventions [71,71]. However, it has been criticised for its broad scope and for not consistently addressing specific needs. Eriksson et al. [72] note that different levels may sometimes conflict, and evidence remains limited on whether multi-level approaches are more effective than single-level ones.

3.3 HEALTH BELIEF MODEL

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict individual health behaviours by focusing on their attitudes and beliefs [73]. An individual's motivation to undertake a health-related behaviour such as cervical cancer screening can be divided into three categories: individual perceptions, modifying factors, and likelihood of action. *Individual perceptions* are factors that affect an individual's perception of illness, the level of importance of health, perceived susceptibility, and perceived severity. *Modifying factors* influencing behaviour include demographic, socio-psychological, and structural variables within the SEM that may affect individual behaviours.

Women's screening behaviours are governed their perceived susceptibility to developing cervical cancer, the degree of threat of the disease – its seriousness, perceived barriers, and enablers to accessing health services, and personal level of self-efficacy. These all serve as cues to action or inaction. The *likelihood of action* is the perceived benefits minus the perceived barriers to taking the recommended health action. The combination of these factors causes a response that often manifests as the likelihood of that behaviour occurring.

The HBM suggests that the perception of a personal health behaviour threat is influenced by three factors:

1. General health values, which include interest and concern for health
2. Specific health beliefs about vulnerability to a particular health threat
3. Beliefs about the consequences of the health problem

If a person perceives a threat to their health, is consecutively cued to action, and their perceived benefits outweigh the perceived barriers, then they are likely to undertake the recommended preventive health action. The key domains of the HBM are: 1) perceived severity (should the individual be afflicted with the disease); 2) perceived susceptibility (risk); 3) perceived benefits; 4) perceived barriers; 5) cues to action (events that motivate people to take action are crucial determinants of change); and 6) self-efficacy (the belief in being able to successfully execute the behavioural change).

Several studies in sub-Saharan Africa have employed the HBM to explore factors influencing cervical cancer screening uptake. Mabotja et al. [74] found that women's perceptions of susceptibility to cervical cancer, perceived severity of the disease, perceived benefits of screening, and perceived barriers, such as fear, stigma, and lack of knowledge, affect their willingness to undergo screening. Yirsaw et al. [75] applied the model in rural Ethiopia and found that awareness, education, confidence, and belief in the importance and benefits of screening strongly increased the chances of women undergoing screening for cervical cancer.

These studies underscore the usefulness of the HBM in identifying psychosocial and contextual drivers of screening behaviour across diverse settings. The HBM is widely used in health research due to its strong face validity, meaning that it aligns with common sense, and its predictive validity in explaining health-related behaviours across various contexts [76]. However, it has been criticised for focusing too narrowly on individual cognitive processes, often overlooking the broader emotional, social, and cultural influences that shape behaviour. Alyafei and Easton-Carr [77] argue that factors such as fear, stigma, cultural beliefs, and family dynamics are not adequately addressed within the HBM, limiting its ability to fully capture the complexity of real-world health decision-making, particularly in diverse or resource-limited settings.

3.4 THE CAPABILITY, OPPORTUNITY, MOTIVATION-BEHAVIOUR MODEL

The Capability, Opportunity, Motivation-Behaviour (COM-B) Model, developed by Michie et al. [67], offers a comprehensive framework for understanding the factors that drive or hinder health-related behaviour. According to the model, behaviour (B) is the result of an interaction between three essential components: capability (C), opportunity (O), and motivation (M) [67]. *Capability* is defined as the individual's psychological and physical capacity to engage in the activity concerned. This

includes having the necessary knowledge, skills, and confidence to take action. *Motivation* involves both conscious decision-making and automatic processes, such as emotions, habits, and internal drives that influence behaviour. *Opportunity* involves all the external factors that enable or trigger the behaviour, including the availability of healthcare services, clinic accessibility, supportive social norms, and health promotion messages. These three elements interact dynamically and must all be addressed to effectively support behaviour change.

The COM-B model provides a useful framework for understanding the factors that influence cervical cancer screening uptake. In the context of cervical cancer screening, capability refers to women's knowledge, awareness, and confidence to undergo screening. Opportunity includes external factors such as the availability and accessibility of services, supportive social environments, and cultural norms. Motivation involves both conscious decision-making and automatic responses such as fear, stigma, or habitual avoidance. By identifying these behavioural determinants, the COM-B model helps guide the development of targeted interventions that address specific barriers, ultimately supporting improved uptake of cervical cancer screening.

A key strength of the COM-B model is its practical orientation. It enables researchers and implementers to diagnose behaviour problems and link these diagnoses to appropriate intervention strategies [67]. Its use in intervention mapping has enhanced the design of more targeted and effective programmes [78]. However, some scholars have critiqued the framework for its broad and somewhat abstract categories, which may risk oversimplifying the complex psychosocial and structural factors influencing health behaviours [79]. Additionally, concerns have been raised regarding the need for clearer operational definitions and more consistent empirical measures for each component to enhance the framework's reproducibility, validity, and application in diverse contexts such as cervical cancer screening in low-resource settings [80].

CHAPTER 4: RESEARCH METHODOLOGY

4.1 INTRODUCTION

This chapter presents the study design, setting, sampling, data collection, analysis plan, ethical considerations, and reflections on the methodological approaches used.

4.2 RESEARCH DESIGN

This study used an interpretivist ontology and a constructivist epistemology and employed a phenomenological qualitative methodology [81]. Phenomenology, aligned with interpretivism, seeks to uncover the lived experiences, emotions, perceptions, and meaning-making that shape human understanding. This approach was appropriate for exploring how both women attending HIV clinics and healthcare providers perceive and experience the barriers and facilitators to early cervical cancer screening.

For Objective 1, **healthcare providers** (facility healthcare managers, doctors, and nurses) in Soweto and Orange Farm were interviewed. For Objective 2, **women routinely attending HIV clinics** were interviewed, 9 (60%) of whom had undergone cervical cancer screening procedures and 6 (40%) of whom had not.

In-depth interviews (IDIs) were conducted to explore women's decision-making around screening uptake, including factors such as knowledge, motivation, fear, and prior experiences. In-depth interviews with healthcare providers explored their understanding of cervical cancer screening guidelines, clinical management of screened patients, and system-level factors influencing early detection. The inclusion of provider perspectives also helped to triangulate patient-reported data, offering additional insights into the clinical and structural contexts shaping women’s experiences.

4.3 RESEARCH SETTING

The South African public health system is organised into a three-tiered structure that includes primary healthcare clinics, community healthcare centres (CHCs), and district hospitals (tier 1); regional secondary hospitals (tier 2); and tertiary hospitals (tier 3). Tertiary hospitals are often linked to universities and serve as teaching hospitals. Cancer patient pathways to care are arranged such that the first entry point is the primary healthcare system, with referrals to secondary tiers for diagnostic

services, and tertiary tiers for both diagnostic and treatment services [82]. Primary healthcare clinics (PHCs) provide basic services such as acute care, immunisations, family planning, and HIV testing, screening, and prevention. When care is unavailable at this level due to limited resources, patients are referred to CHCs or higher-level facilities for more specialised management [82,83]. With respect to cervical cancer management, screening is performed in primary healthcare facilities, while colposcopy and treatment of precancerous and cancerous lesions are provided in tertiary academic hospitals according to cervical cancer policy guidelines.

Data were collected from six primary healthcare clinics (PHCs): three located in Soweto (Orlando PHC, Diepkloof PHC, and Micheal Maponya PHC) and three in Orange Farm (Barney Molokoane PHC, Imbalenhle PHC, and Orange Farm Extension 7 PHC). Additionally, data from women were gathered from two CHCs: Lilian Ngoyi CHC in Soweto and Stretford Clinic in Orange Farm.

The three PHCs in Soweto serve an average annual patient volume of 98 067; Orlando PHC (31 200 patients), Micheal Maponya (123 000 patients), and Diepkloof PHC (140 000) patients. Similarly, the three PHCs in Orange Farm have an average annual patient volume of 38 080. Orange Farm Extension 7 serves 24 240 patients, Barney Molokoane handles approximately 50 000 patients, and Imbalenhle Clinic treats around 40 000 patients annually. All the PHCs, together with Lilian Ngoyi CHC and Stretford CHC, are within the referral network of the Chris Hani Baragwanath Academic Hospital (CHBAH) breast clinic and were selected as pilot sites for the study. The two CHCs serve the suburban communities of Soweto and Orange Farm, which are located within a 45 km radius of CHBAH. The hospital provides public tertiary care services to the more than two million greater Soweto, Johannesburg population.

Soweto is a peri-urban town within the south-western districts of Johannesburg [83]. Chris Hani Baragwanath Academic Hospital is a teaching hospital, within Soweto, affiliated to the University of the Witwatersrand (Wits), Faculty of Health Sciences. It is the referral hospital for cancer diagnostic and treatment services, including colposcopy and treatment services provided by the Gynaecology Department for women who screen positive for cervical precancerous and cancerous lesions and are referred from primary care feeder clinics.

4.3.1 Primary healthcare clinic

A primary healthcare clinic serves as the initial point of contact in the healthcare system, providing essential services such as immunisations, family planning, antenatal care, and the treatment of common illnesses. It also offers general practitioner care for managing conditions such as tuberculosis and HIV/AIDS, including counselling and support. Patients are referred to a CHC for further assessment and management [82] when the clinic cannot provide the necessary care or treatment, for example, imaging services.

4.3.2 Community healthcare centre

A community healthcare centre (CHC) plays a crucial role as the second tier of the healthcare delivery system, though it can also function as a point of first contact for patients in need of medical attention. It provides a broad range of services similar to those offered at a PHC but with several key additions. Notably, a CHC offers 24-hour maternity care, emergency medical services, and casualty care, ensuring immediate attention for urgent health conditions. It also offers basic imaging services such as chest X-rays and ultrasound services. In addition, it typically has a short-stay ward for patients requiring observation or brief treatment. While the CHC is well-equipped to manage a variety of health concerns, it also serves as a referral point, directing patients to higher-level care facilities, such as a district, secondary, or tertiary hospital, when specialised care is needed [82].

4.3.3 Soweto

Soweto is an urban settlement in South Africa, within the south-western regions of Johannesburg. It comprises approximately 87 townships spread across 200 km², with a population of approximately 1.9 people. As of 1 August, 2023, the population (permanent residents) included – besides infants and children – 225 615 young people between the ages of 18–29 years, 817 142 adults aged 30 to 60 years, 413 311 elderly people over 60 years old, and 26 543 people over 80 years. According to Statistics South Africa, 50% of Soweto's population are women [84]. Soweto was shaped by apartheid-era policies that forced Black South Africans to live in racially segregated areas, with its roots going back as far as 1905 [85]. Over time, this led to uneven development. Some areas are now well-established, while others remain informal settlements with limited access to basic services. The population is almost entirely Black African (98%), and unemployment remains a major challenge,

with estimates ranging from 45% to 65% [86]. Soweto has a substantial number of healthcare facilities at the primary and secondary/tertiary levels. These include 23 PHCs and 2 public hospitals – CHBAH (tertiary) and Bheki Mlangeni District Hospital. The PHCs in Soweto are strategically located to ensure that most households are within a reasonable proximity of 2 km or less, most of which are located within 20 km of CHBAH.

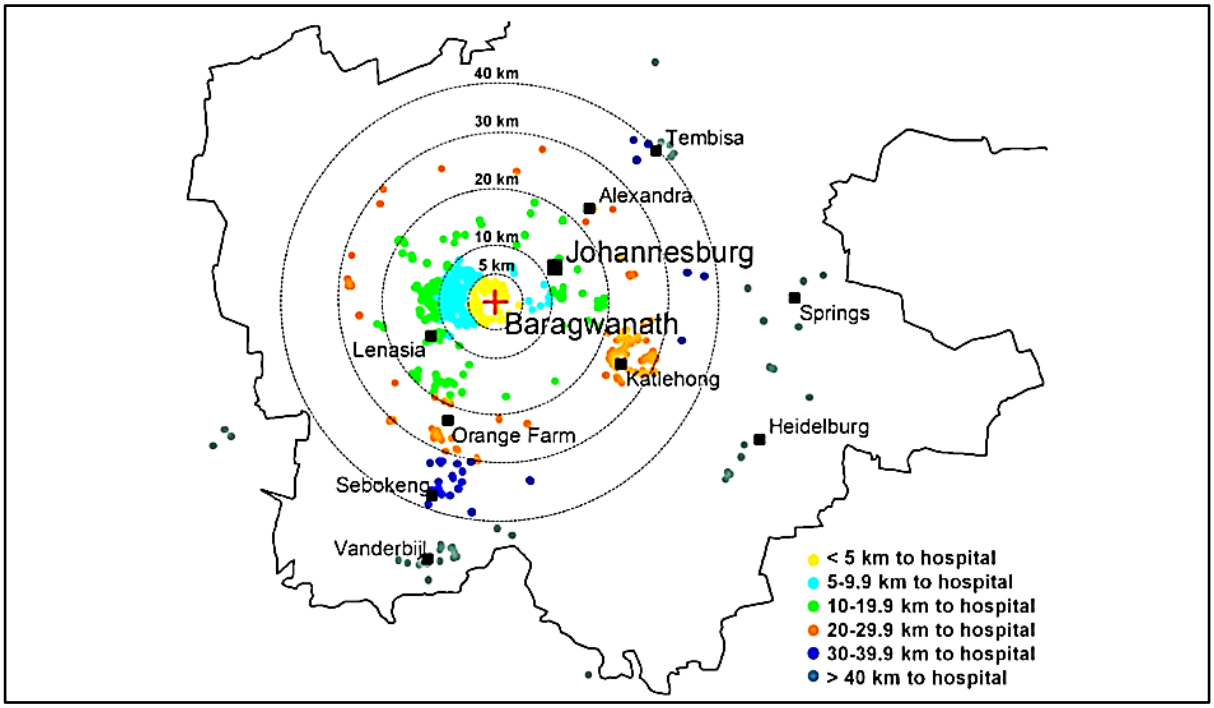


Figure 4.1: Location of community members referred from primary healthcare facilities to the tertiary Chris Hani Baragwanath Academic Hospital in Soweto and Orange Farm

4.3.4 Orange Farm

The Orange Farm community is a semi-rural, underdeveloped area, located approximately 40 km south of Johannesburg, towards the Vereeniging and Vanderbijlpark regions of Gauteng. Orange Farm is characterised by extreme levels of poverty and unemployment, with social challenges that include alcoholism, domestic violence, child abuse, substance abuse, HIV/AIDS, crime, and gangsterism [87]. It is one of the largest informal settlements in South Africa and is also one of Johannesburg's most geographically isolated communities. The majority of the houses are still galvanised iron shacks, built along some of the highest concentrations of gravel roads in the country. The population has grown to more than 380 000 families from an estimated 3 000 residents in the late 1980s, and 50.7% of the population is female [84]. The township has a large main clinic, Stretford Community Health Centre, also known as Stretford Clinic, and several minor clinics.

4.4 ETHICS STATEMENT

Study protocols were approved by the Wits Human Research Ethics Committee (Medical), South Africa (Ethics clearance numbers: M201145, dated 27 November 2020, and M220901, dated 2023/02/08) and the Research Committee of the Johannesburg Health District (NHRD Ref no: GP_202102_001, dated 28 November 2022). All participants provided voluntary written informed consent before the study commenced and were reimbursed for their time and transport (see Appendices A1, A2, B1, and B2).

This study involved sensitive topics, including cervical cancer and HIV, which are often associated with stigma, particularly linked to perceptions of promiscuity. Recognising the vulnerability of HIV-positive women, special care was taken to address ethical concerns related to privacy, confidentiality, and the potential for distress. To protect participants, all interviews were conducted in private settings within the healthcare facility to ensure confidentiality and create a safe environment where participants could speak freely without fear of judgement from interviewers or healthcare staff. For the single telephonic interview with a healthcare provider, the participant confirmed that they were in a private room to maintain confidentiality.

Anticipating the possibility of emotional distress, appropriate measures were planned to provide support; however, no participants experienced undue distress requiring counselling during or after the interviews. Throughout the study, efforts were made to build trust with participants by emphasising the voluntary nature of participation, ensuring confidentiality, and always respecting their dignity.

4.5 STUDY PARTICIPANTS AND SAMPLING

Study participants included women routinely attending HIV clinics and healthcare providers. This master's research was nested within a broader study that investigated screening opportunities for common adult cancers in South Africa, including breast and cervical cancer for women, and prostate and lung cancer. The dissertation, which specifically focuses on cervical cancer, was designed as a sub-study of the parent project. It received separate ethical approval to ensure that all study-specific considerations were appropriately addressed. Therefore, for this dissertation, both the healthcare provider and patient results have been analysed.

The information sheets and interviews for the full study were used for data collection. For the dissertation, I have focused specifically on the cervical cancer findings.

4.5.1 Healthcare providers (Objective 1)

The data collected between August and November 2021 focused on healthcare providers, including facility managers, doctors, and nurses. The data were drawn from a larger study in which I had previously been involved that investigated screening opportunities for common adult cancers in South Africa. A purposive sampling strategy was employed to recruit healthcare providers (medical officers and nurses) and facility managers from the eight primary healthcare facilities. Participants were eligible if they had a minimum of one year of service experience in managing non-communicable diseases, including cancer.

4.5.2 Women routinely attending HIV clinics (Objective 2)

A convenience and purposive sampling approach was used to recruit women, 30 years and older, from the two CHCs – Lillian Ngoyi and Stretford – for primary data collection conducted between March and August 2023. Sixty percent of the women participants had previously undergone screening for cervical cancer, while the remaining40% had not. I wanted to interview both groups to compare the levels of understanding of cervical cancer and screening procedures and obtaining screening results among them. I also wanted to explore the impact of clinic screening programmes on their cervical cancer awareness. Participants were eligible if they routinely attended six-monthly visits at the HIV clinics of the two CHCs. Enrolment was stopped after 15 interviews, at which point data saturation was attained. Data saturation is reached when no new data is collected with each subsequent interview [88]. Qualitative research suggests that data saturation can typically be reached with as few as 15 participants, while a maximum of 50 participants is usually enough to address the research questions [88,89].

4.6 DATA COLLECTION PROCEDURES

I approached facility managers at the clinics to introduce the study aims and was invited to conduct the in-depth interviews (IDIs). Healthcare providers **(Objective 1)** were recruited telephonically using a list with contact numbers of interested healthcare providers. For **Objective 2,** I applied a convenience sampling approach to actively approach women meeting inclusion criteria who were routinely attending HIV

clinics **(Objective 2)**. All interviews were scheduled at a date and time convenient for participants, and interviews were conducted in a private room at the healthcare facilities. Participants were informed about the duration of the study procedure when consenting and prior to study procedures on the day of the visit. Participants completed a brief socio-demographic questionnaire prior to taking part in the IDI (see Appendix C). All interviews were conducted in the participants' language of choice.

4.6.1 Transcription, coding, and assessment of data saturation

Transcription and coding were conducted concurrently with data collection to allow for iterative analysis. As interviews progressed, I met regularly with my supervisors to review and update the coding framework to incorporate emerging concepts. After each set of interviews, data were examined to identify whether new themes or significant insights were still emerging. This process included discussions with the supervisors to evaluate the richness and variation of responses.

Saturation was considered reached when consecutive interviews yielded no novel themes, codes, or perspectives relevant to the research questions. To ensure this was not premature, an additional interview was conducted at each study site beyond the point of perceived saturation. These follow-up interviews confirmed that no new information emerged, thereby validating that thematic saturation had been achieved. This approach ensured both depth and comprehensiveness in capturing participants' experiences and perspectives.

4.6.2 Interviewer training

My prior experience and training in qualitative research, particularly in conducting interviews, have been developed over 13 years in the field of HIV research. However, cancer research, specifically cervical cancer, was a new area for me. To prepare for this study, I received additional training and support from one of my supervisors. While my qualitative interviewing skills were well established, I acknowledge that my limited experience in the context of cervical cancer may have influenced the depth of my probing. With more familiarity in this specific field, some interviews might have benefited from deeper or more nuanced questioning.

4.7 MEASURES

4.7.1 Socio-demographic questionnaire

Following written informed consent, all participants were asked to complete a brief socio-demographic questionnaire prior to the interview (Appendix C). This collected details on age, gender, racial group, primary home language, and highest education level. For Objective 1 participants only, the questionnaire also captured the participant's role in healthcare.

4.7.2 Interview guide 1: facility managers and healthcare providers

A semi-structured interview guide for participants covered topics to identify attitudes and gather information on cancer-related factors regarding cancer awareness and knowledge (breast and cervical cancer for women, and lung and prostate cancer for men), early detection guidelines, and perceived barriers and facilitators to cancer screening and early detection. The guide also explored required support and motivation for implementing the South African National Department of Health's screening guidelines for cervical cancer. The interview guide explored healthcare provider and manager perceptions of patient-related barriers to early breast and cervical cancer screening (Appendix D1). The facility manager interview guide included their perceptions of the knowledge and ability of their healthcare providers to detect common cancers and conduct cervical cancer screening procedures (Appendix D2).

4.7.3 Interview guide 2: Women in HIV clinics

A semi-structured interview guide for participants (Appendix D3) covered topics to identify attitudes, awareness, and knowledge about cancers in general and cervical cancer in particular. The interview guide also elicited information about participants' health-seeking behaviour, their perceived susceptibility to cervical cancer, perceived benefits of early cervical cancer screening, and perceived barriers to cervical cancer screening. In addition, the role of culture and religion in health-seeking behaviour and decision-making was explored.

4.8 DATA MANAGEMENT

Signed informed consent documents and completed socio-demographic questionnaires were anonymised and kept in a locked cupboard at the Perinatal HIV

Research Unit of the University of the Witwatersrand located at CHBAH. Transcripts from the interviews were labelled with an anonymous code, with all identifiable information removed. Participants' names or any other identifying information were excluded from the transcripts. All audio files are stored on my laptop in an encrypted folder. Only I and my supervisors had access to study materials and findings.

4.9 DATA ANALYSIS

All IDIs were audio-recorded, transcribed verbatim, and translated into English. I led the data analysis, which was conducted iteratively using a framework analysis approach. Framework analysis has been used since 1980, and is a case and theme-based approach, using a matrix hierarchy of themes and subthemes. It reduces data through summarisation and synthesis [89]. I engaged in a process of data immersion by repeatedly reading two transcripts to gain a deeper familiarity with the data. Both transcripts were subjected to a line-by-line coding technique, in which individual codes were assigned to specific segments of text. These codes were subsequently organised into broader themes and subthemes. Following this, I developed a codebook initially based on an Excel spreadsheet, drawing from the two coded transcripts and the interview guides. The codebook was shared with my supervisors for review, input, conflict resolution, and final consensus. Thereafter, the codebook was entered into NVivo 12 Plus, after which all transcripts were uploaded and coded. Following the coding process, data were stratified by healthcare provider and facility managers (Objective 1) and by whether participants had been screened or not screened for cervical cancer (Objective 2). Barriers and facilitators were identified for early detection and management of cervical cancers. I then reviewed and an iteratively categorise all coded data.

4.10 REFLEXIVITY

I share similarities with the participants in terms of language, race, and ethnic background. Growing up in Soweto, a peri-urban area with limited resources, gave me a deeper understanding of participants' perspectives on healthcare and social norms.

During the interviews, I felt both excited and nervous, particularly when speaking with healthcare providers and facility managers, as I lacked a primary healthcare background. However, my experience as a social science researcher at the Perinatal HIV Research Unit since 2006 has equipped me with strong communication and

interpersonal skills, enabling me to engage with diverse groups. Some healthcare participants also expressed nervousness, viewing me as an expert assessing their work. Before each interview, I reassured them of my role as a student, emphasising that this was part of my learning journey about the healthcare system and cervical cancer, and confirmed their willingness to proceed. This perception may have influenced their responses, as they aimed to appear knowledgeable.

In addition, it is important to consider the potential for bias in the responses of facility managers. Given their leadership positions, some may have been reluctant to openly discuss the limitations or perceived shortcomings of their colleagues or staff. Social desirability bias may have influenced how they described the challenges within their facilities, possibly leading to more positive or guarded responses and limiting the depth of insight into operational barriers. At the end of the interview, most participants expressed how relaxed and free they felt during the interview and that this was a learning and self-reflection session for them, as the interviews had opened their eyes to how they had neglected crucial services, including cervical cancer screening.

Similarly, women patient participants felt uneasy, particularly with the word “interview”. To ease their discomfort, I referred to the sessions as “discussions”. Some may have hesitated to critique their healthcare facilities, especially since interviews took place within those settings. To address their concerns, I reassured them of my role as a student, emphasising that this was part of my learning journey about the healthcare system and cervical cancer. I also emphasised that that I was not affiliated with the Department of Health and provided my supervisors’ contact details for verification.

4.11 PERSONAL POSITIONALITY

As a trained social worker with extensive experience working with women living with HIV, my professional background has shaped my understanding of health-seeking behaviours, and the systemic challenges women face within the healthcare system. My early impressions, informed by interviews with HIV-positive women, revealed a concerning pattern of poor health literacy regarding HIV. This experience led me to anticipate similar, if not greater, challenges in the context of cervical cancer screening, particularly among women who are already medically vulnerable.

Consequently, I remained mindful of my own preconceived biases throughout the research process.

Entering the field of cancer research as a newcomer, I became increasingly aware of these preconceived notions and biases, especially around the assumed transferability of HIV-related health literacy to other health conditions such as cervical cancer. During the interviews, I was struck by how often women described healthcare experiences as cold, uncaring, or lacking empathy. This made me reflect on how healthcare systems and provider attitudes may silence or overlook patients' voices.

I critically examined my role as a researcher and student, recognising that I might have unintentionally adopted some patients' viewpoints. This motivated me to better capture the women's true experiences. I discussed my findings with colleagues and supervisors to ensure my analysis was fair, honest, and truly reflected what the women shared, rather than my own interpretations.

4.12 TRUSTWORTHINESS OF THE RESEARCH

To ensure trustworthiness in this qualitative study, I applied the four key criteria of credibility, transferability, dependability, and confirmability, as outlined by Ahmed. [90]. Although interviews with healthcare providers and HIV-positive women were once-off sessions, I built rapport before and during each session by ensuring that they felt comfortable. I introduced the study to them and explained the reason for conducting the research during the consenting process and as a preamble to the interviews. I practised reflexivity by noting any personal assumptions or potential biases that could influence how I collected or interpreted the data [91] and discussed these notes with my supervisors. Interviewing the healthcare providers and women patients separately allowed for triangulation of findings, helping to compare and validate similarities and differences between provider and patient perspectives [92]. I also provided detailed descriptions of the study context and sampling to support transferability within the Soweto context [93]; I recognised that the findings might not be transferable to other low- or middle-income country contexts. To strengthen confirmability, I engaged supervisors not directly involved in data collection to review my coding and interpretation, and maintained a reflexive journal throughout the process.

CHAPTER 5: FINDINGS – PERSPECTIVES FROM HEALTHCARE PROVIDERS

5.1 INTRODUCTION

Chapter 5 presents the study findings of provider perspectives, organised according to the Socio-Ecological Model (SEM). The model comprises five levels, described below.

The *individual level* is concerned with an individual's knowledge and skills. At this level, the aim was to explore healthcare providers' and patients' knowledge and perceived barriers to cervical cancer screening. It also examined healthcare providers' perception of skills and proficiency to perform the cervical cancer screening procedure and the support required by healthcare providers from National Department of Health (NDoH) policymakers.

The *interpersonal level* relates to an individual's relationship with other people and includes influences on the patient and healthcare provider attitudes. Patients' perceptions of attitudes towards cervical cancer were also considered.

The *organisational level* addresses elements that would contribute to or hinder the uptake of cervical cancer screening.

The *community level* examines the different institutions within the community and the influence that they have towards health-seeking behaviours. In this study, the focus was on community perceptions about cervical cancer and its influence on screening leading to early detection.

The *policy level* of the SEM addresses the NDoH's provision of training and support to healthcare providers, which will enable them to perform their job more effectively and with much more ease, as they are trained to conduct cervical cancer screening procedures.

5.2 PARTICIPANTS' CHARACTERISTICS

As presented in Table 5.1, 22 participants were interviewed: 9 facility managers, 10 nursing sisters, and 3 medical officers. Only one participant (4.6%) was male, 95.5% were female. The median age of the participants was 47 years, with a range of 39–58 years. All participants had completed their tertiary education.

Table 5.1: Healthcare providers' characteristics

	Responses	Number N (%)
Participants' role	Clinic manager	9 (40.9)
	Clinic nursing sister/Nurse	10 (45.5)
	Medical officer	3 (13.6)
Gender	Females	21 (95.5)
	Males	1 (4.6)
Median age (QR)		47 [39–58]
Education	Tertiary level	22 (100)

5.3 INDIVIDUAL LEVEL

At the individual level, one key theme with four subthemes emerged on the perceived barriers to early detection of cervical cancer.

5.3.1 Perceived barriers to early detection of cervical cancer

The four sub-themes that emerged are: 1) limited knowledge of cancer and early detection guidelines, 2) proficiency in carrying out cervical screening procedures, 3) staff attitudes towards learning about common cancers and performing cervical cancer procedures, and 4) cancer is often overlooked by healthcare providers cancer.

5.3.1.1 Limited knowledge of cancer and early detection guidelines

Healthcare providers were aware of but had limited detailed knowledge of the NDoH's cervical cancer screening and early detection guidelines, as illustrated in the following extract from an in-depth interview (IDI):

> *I: Are you aware of the South African National Department of Health screening guidelines for common cancers, including those for cervical cancer? R: Yeah. I: Okay, how were you made aware of these guidelines? R: We're usually given an induction training or workshop.* (IDI 004 – Facility manager)

> *I: Okay, and then what do you know about the South African guidelines about screening for common cancers? R: I'm not knowledgeable about them. The one that I know the most about is the one about cervical cancer… It's the one*

that's being preached the most. I: Do you know what it says? R: Not really, but it includes Pap smear, the guidelines, and its prevention.
(IDI 010 – Healthcare provider)

Some facility managers indicated that they were last trained on cancer detection and management during their nursing diploma training and had not received any refresher training or support from the NDoH since then:

I: From your experience or knowledge, what kind of training or when was the last time you were trained on cancer? R: During my training? I: Yes, your training. R: It was back in the 1990s (IDI 001 – Facility manager)

Facility managers were asked about their impressions of the level of knowledge about cancer of their clinic nurses and doctors. Most perceived their clinic nurses and doctors as having sufficient knowledge about cancer detection and management:

Because they know when to refer, and they know what to look for, I think, and they know how to read the results as well, given the PSA and the cervical screening. They know how to interpret the results so I would say average.
(IDI 013 – Facility manager)

5.3.1.2 Proficiency in carrying out cervical screening procedures

Facility managers and healthcare providers expressed that they were not sufficiently skilled to perform the cervical cancer screening procedures due to insufficient training and exposure to the screening procedure:

I also think us [healthcare providers], we are not equipped. We don't have information… we are not well trained … The training is needed.
(IDI 011 – Facility manager)

R: The last time we did that procedure [cervical screening] *was when we did the assessments* [final year exam for nursing diploma]*. I: Hmm. R: From there, if you do not practise inserting the speculum, the skill wears off.*
(IDI 001 – Facility manager)

However, a few healthcare providers perceived themselves to be competent and efficient in carrying out the cervical screening procedure:

R: You have to be gentle, and you must have the skill because, remember, the speculum has the screw that you have to adjust when you have inserted it into

the vagina, and it does not need to hurt the patient. You have to see your cervical mouth, and that's where you make sure that speculum is in correctly. You then tighten the speculum, and then you take your smear. I: So, in terms of taking this smear, is there a specific rule of thumb that states how you should take the smear? R: With the brush, so there is a brush, and then there's this protruding one. So, what you do is that you go [insert] *and rotate anticlockwise, and you will have this smear. You will also have a bottle with a solution in it. You dip the brush. I have forgotten how many times you have to dip it, but you don't just do it once because that's me and needs to remain inside the solution.* (IDI 015 – Healthcare provider)

5.3.1.3 Staff attitudes towards learning about common cancers and performing cervical cancer procedures

A few facility managers perceived that some healthcare providers were hesitant to learn new skills and change and were uncooperative in skills development:

R: And again, sometimes, the very same service provider is not comfortable in doing that [cervical screening] *or not competent… Not competent and not comfortable. And again there are those procedures that we all say. "I don't want to do this, I hate this part".* (IDI 001 – Facility manager)

Only one facility manager believed that there were no real barriers preventing healthcare providers from providing cancer screening services:

I don't see anything that would prevent us from doing the early detection. I don't see anything that would prevent us from screening for any cancer. We must just do our work. (IDI 005 – Facility manager)

5.3.1.4 Cancer is often overlooked by healthcare providers.

Some healthcare providers and facility managers recognised that cervical and other cancer symptoms are often overlooked by healthcare providers because their training emphasises communicable diseases and sexually transmitted infection treatment algorithms. They tend to treat the immediate symptoms first, following set protocols, without initially considering cancer:

I: How would you deal with a patient with cervical cancer symptoms, for example, a smelly discharge? R: With a smelly discharge, we think STI first – you know, in the setting, you treat even if maybe it's related to cervical cancer.

But anyway, it's not harmful to treat as though it's an STI. (IDI 016 – Healthcare provider)

… Our guidelines, even our PACs [Post-acute care books], *they will tell you that this is what you start with then you do this. They would even go to the extent of informing you that even in management, this is how you provide education. They would guide you in non-clinical/non-medical ways then once you exhausted non-medical or non-clinical, then comes cancer.* (IDI 018 – Facility manager)

One facility manager explained that cancer, including cervical cancer, is often not associated with Black people and is perceived to be prevalent in White people:

… When I work at Sandton or White people spaces [affluent communities]*, it is something I would first dive into. I don't know why, but when I work at the townships, I wouldn't. I don't know why; maybe we think that it* [cancer] *exists much amongst White people or maybe because they are more open and free and too observant of the bodies. Then you come this side and ask our people, "So you know what cancer is?" and they would ask, "What is that? What does it do? Is it painful?".* (IDI 018 – Facility manager)

5.3.2 Provider perceptions of patient barriers to cervical cancer screening

Six sub-themes emerged within the theme of healthcare provider perceptions about patient barriers to cervical cancer screening: 1) patients' limited awareness of cancer signs and symptoms, 2) patients' misconceptions about the cervical cancer screening procedure, 3) patients' fear of a cervical cancer diagnosis, 4) patients' use of alternative, traditional, and home remedies, 5) late patient presentation for consultation at primary healthcare, and 6) patients' view of the healthcare system as curative and not preventive.

5.3.2.1 Patients' limited awareness of cancer signs and symptoms

Most healthcare providers reported that patients did not recognise cervical cancer signs and symptoms:

It's the knowledge because most people don't know what cervical cancer is, and when you tell them about the Pap smear and that it helps to detect for cancer, they assume that you are telling them that they have cancer. (IDI 014 – Healthcare provider

A few healthcare providers further shared that patients were not educated about the purpose of cervical cancer screening:

> *And some women didn't even understand why we are doing a Pap smear and what is there to be picked up* [detected]*.* (IDI 019 – Healthcare provider)

5.3.2.2 Patients' misconceptions about the cervical cancer screening procedure

Some healthcare providers reported that patients perceived the cervical cancer screening procedure as painful:

> *From my experience, I think there's a perception that Pap smears are painful This is whether from an experience from a friend hearing from a friend or it's just a myth that is just out there.* (IDI 019 – Healthcare provider)

5.3.2.3 Patients' fear of a cervical cancer diagnosis

A few healthcare providers speculated that some patients' fear of screening for cancer was associated with the fear of a cancer diagnosis:

> *Some already have fears because some of these cancers are genetic; you'll find that they've met someone before who had this cancer, and they died…* (IDI 019 – Healthcare provider)

5.3.2.4 Patients' use of alternative, traditional and home remedies

Most healthcare providers and a few facility managers indicated that patients used over-the-counter medicines or home remedies to treat the symptoms first, thereby delaying access to primary care clinics:

> *Our patients not reporting early as well to the clinic, you know, they will stay at home and use muti's* [traditional herbs] *… so they try all these things before they come to the clinic, and by the time they come it's late.* (IDI 013 – Facility manager)

> *In the sense that they procrastinate, or they go and seek help elsewhere, or they treat themselves at home with whatever – apply spirit, whatever they think will work. They use Zambuk or Vicks* [over-the-counter topical medications]*.* (IDI 019 – Healthcare provider)

5.3.2.5 Late patient presentation for consultation at primary healthcare clinics

Most healthcare providers observed that patients sought medical help only when their symptoms became severe and painful:

> *I think others also, they come when they feel like increasing severity of symptoms, like now the pain is worse, then they feel like, okay, now I need to come. But they can sit for a month thinking it will be a bit better. But once it starts getting worse.* (IDI 016 – Healthcare providers)

5.3.2.6 Patients' view of the healthcare system as curative and not preventive

A few healthcare providers explained that patients used the healthcare facility only when they were sick, possibly unaware that they could attend the facility for preventive services:

> *Actually, the patients only come when they have a problem. They don't just come willingly and say that they want to do a Pap smear.*
> (IDI 014 – Healthcare provider)

5.4 INTERPERSONAL LEVEL

Two major sub-themes emerged when examining provider perspectives on their interpersonal skills and patient interaction: 1) healthcare providers' poor interpersonal skills and 2) healthcare providers' perceptions of negative patient attitudes.

5.4.1.1 Healthcare providers' poor interpersonal skills

Some healthcare providers and a facility manager acknowledged that poor interpersonal skills among healthcare providers, reflected in negative attitudes towards patients, discouraged patients from visiting the healthcare facility:

> *Some people see us as people who have attitude, so you cannot build rapport with them because they already have the impression that the nurses are rude.*
> (IDI 014 – Healthcare provider)

> *Patients are lazy to come to the clinic because of the bad attitude that the nurses have towards them. We don't treat them well. Yes, it's the bad attitude we have towards them.* (IDI 017 – Facility manager)

Another facility manager reported how nurses used aggressive and confrontational questioning when engaging with patients during screening visits, negatively affecting the patient-provider interaction:

> *And before that, again with us, we would be asking why patients want to do Pap smears with nurses. That's another thing that prevents patients – they don't get to be free, to say this is what I want because they will be asked questions and all that based on our attitude.* (IDI 003 – Facility manager)

5.4.1.2 Healthcare providers' perceptions of negative patient attitudes

Healthcare providers perceived some patients as having a negative attitude towards the healthcare facility and staff:

> *R: I'm not really sure, but what I've observed is that sometimes our patients are very impatient… They know exactly what they are here for, and that's what they want to do. They want to consult and go home, but immediately you start preaching and giving education to them, they get annoyed.*
> (IDI 015 – Healthcare provider)

5.5 ORGANISATIONAL LEVEL

From a provider perspective, themes emerged regarding both healthcare provider and patient barriers concerning healthcare facility issues.

5.5.1 Healthcare providers barriers

Four sub-themes emerged: 1) prioritisation of cervical cancer screening for women living with HIV, 2) healthcare workforce shortages, 3) high patient volumes, and 4) inadequate cervical cancer screening equipment supply chain management.

5.5.1.1 Prioritisation of cervical cancer screening for women living with HIV

A few facility managers and healthcare providers revealed that cervical cancer screening was encouraged primarily for women living with HIV:

> *We do a cervical Pap smear for cervical cancer on women of 30 years and above, and mostly, it's with patients that are HIV-positive.*
> (IDI 002 – Healthcare provider)

One healthcare provider further indicated that the facility had a dedicated room for cervical screening for women living with HIV:

For patients who are on HIV treatment, there is a nurse who works at a room that you call room 100. If they want to do a Pap smear, they do it in that room. (IDI 007 – Healthcare provider)

5.5.1.2 Healthcare workforce shortages

Most healthcare providers indicated that they were unable to routinely perform cervical and other cancer screening for all women patients because they were short-staffed:

Here in our clinic with the nurse clinicians, six people [nurse clinicians] *have left and have never been replaced. And after those people left, the department introduced the clinics like the youth clinic and Mina clinic* [Mens Health clinic]. *All those clinics and the PrEP* [pre-exposure prophylaxis] *clinic need to come out of this pool of clinicians. I: From the staff that's left? R: Yes. I: Okay. R: Shortage number one.* (IDI 002 – Healthcare provider)

A few healthcare providers also expressed their concerns about the limited number of healthcare providers sufficiently skilled to perform cervical screening procedures:

I can also say shortage of skilled people because if everyone is skilled, then we don't have to refer people to other places… If we're all skilled, then we will all be able to perform the procedures. I don't even have to refer the patient; I would just get all the equipment and do the procedure on the spot. (IDI 015 – Healthcare provider)

5.5.1.3 High patient volumes

Most healthcare providers indicated that because of the high patient volumes at the healthcare facilities, they were unable to offer routine cervical cancer screening services to all women who presented at the healthcare facilities:

R: It's the ratio of the patients that we see. We are very few and we see a lot of patients. At times you find that you end up seeing 50 patients in a day, which is impossible to see those patients if you still must do cervical examinations on all those patients. (IDI 007 – Healthcare provider)

5.5.1.4 Inadequate cervical cancer screening equipment supply chain management

Most healthcare providers and facility managers reported that the main barrier to providing cervical screening in healthcare facilities was the limited availability of screening equipment (speculums, beds, autoclaving machines, and screens):

> *A shortage of equipment, like, I can say that people are here at the clinic, but we don't have equipment like your speculums. Speculums are not sterilised, and we don't have disposable speculums.* (IDI 015 – Healthcare provider)

> *Let's say, now I'm seeing ****, and I have to do a Pap smear on you. Now there's no speculum. There's no autoclave machine in this clinic; we don't have a disposable vaginal speculum which was going to be the best. I: So, it's the steel ones? R: The steel ones need to be sterilised, and there are no autoclaving machines.* (IDI 001 – Facility manager)

A few healthcare providers also noted that because of limited screening tools, they were often required to schedule return appointments for patients. However, some patients did not return, which providers attributed to their inability to find time in their schedules to attend the clinic:

> *I want to do the procedure, but there is no speculum. You will also see that the nurse has tried to look in about three rooms and there is no speculum. I: Hmm. R: "Come back next week." Sometimes the patient is working and cannot be absent again twice in a month.* (IDI 009 – Healthcare provider)

In addition to the limited screening equipment, a few facility managers and healthcare providers indicated that the screening rooms were not conducive to carrying out cervical screening procedures.

> *R: The other things – it's things like screens in the rooms. We don't have screens in our rooms. I: And why are these screens so important? I'm just trying to get the full picture and understanding. R: It's for patients' privacy because if I'm going to ask patients to take off their clothes and lie down, without this screen or a curtain then that patient is going to feel like they're not respected.* (ID 005 – Facility manager)

> *And another thing, if the hospital is full, the space, as you can see, we don't even have beds in our room where we are.* (IDI 011 – Healthcare provider)

One facility manager and a healthcare provider stated that having a conducive and dedicated cancer screening room would make women comfortable:

> *I am thinking that we will need a cancer check room and staff members that are well trained and willing, and let's see if we open a room because sometimes women are also scared. So at least if we have a room that just test cancers…* (IDI 018 – Facility manager)

> *Maybe if we can have mobile rooms, because when you look at the structure of our clinic, I don't see how they can build something, but if we can have mobile consulting…* (IDI 009 – Healthcare provider)

One healthcare provider, however, maintained that space was not a barrier, explaining that the clinic had many consulting rooms and that patients could sit outside a consulting room until called to be screened.

> *The space is not an issue; the patient can be outside* [the consultation room]. *We have 30 consulting rooms; at least if one sister could be doing two patients* [cervical cancer screenings] *a day, how many could we do a day?* (IDI 017 – Facility manager)

Another healthcare provider suggested that cervical cancer screening should be made available in all consulting rooms by all healthcare providers and not be designated to a specific room or provider.

> *I feel that a Pap smear shouldn't be something that is done to a specific group of people. If I'm in the dressing room and a patient needs* [to do a pap smear]*, I should know and go get the speculum patients, the Pap smear should be done if there is a need. The patients must… "Go that side, go that side".* (IDI 002 – Healthcare provider)

5.6 COMMUNITY LEVEL

5.6.1 Healthcare provider perceptions of community barriers to cervical cancer screening demand

Three major sub-themes emerged: 1) community perceptions of the cervical screening procedure, 2) community perceptions of cancer as a White man's disease, and 3) influences from cultural beliefs.

5.6.1.1 Community perceptions of the cervical screening procedure

Most healthcare providers observed a general perception among the community that the Pap smear procedure is painful and, as a result, women do not attend for cervical cancer screening:

> *From my experience, I think there's a perception that Pap smears are painful. This is whether from an experience from a friend, hearing from a friend, or it's just a myth that is just out there.* (IDI 019 – Healthcare provider)

> *Well, it's the fear of the unknown and many of them say that it* [a Pap smear] *is painful because they have heard from someone that it is painful, and it's just uncomfortable, but not painful. (*IDI 014 – Healthcare provider)

5.6.1.2 Community perceptions of cancer as a White man's disease

A few healthcare providers and a facility manager stated the community perceived cancer as a "White man's disease":

> *Lack of knowledge – they have no knowledge about this, and we grew up with the concept that cancer is a disease for White people.* (IDI 009 – Healthcare provider)

5.6.1.3 Influence from cultural beliefs

According to most healthcare providers and a few facility managers, communities perceived that their illness could be the result of being bewitched, leading them to consult with traditional healers first, and only visit the healthcare facility when symptoms persisted:

> *I: Why do you think that is, that a person will start with Mr Sithole* [traditional healer] *before they come to the clinic? R: Sometimes, it's because of their religions and beliefs; they will say it's witchcraft… So, they see it as something else that someone has done to them. So, our belief system sometimes also affects the treatment.* (IDI 013 – Facility manager)

> *Yes, it's the self-medication and also the myth that maybe someone is bewitching you. You know most of our patients when they come here, they can link their sickness to something that was happening in their life, for example, they will say, I started developing 1234 after I used this thing or after*

I bought a certain item, and that is when you have to give education.
(IDI 015 – Healthcare provider)

5.7 POLICY LEVEL

5.7.1 Policy barriers to adequate provision of cervical cancer screening services

Only one sub-theme emerged: inadequate training support to providers by the NDoH.

Inadequate training support to providers. In-service training is an essential component of healthcare profession, ensuring that healthcare providers remain competent, adaptable, and capable of service delivery, however, some facility managers and healthcare providers expressed concern about not being adequately supported with cancer training by the NDoH:

> *We don't get in-service training about that. We only get that we want targets, we want 50 Pap smears, and 30 prostates but is the information being made relevant, current and consistent? My knowledge is limited, and I would just refer because it is treated somewhere else.* (IDI 018 – Facility manager)

> *I don't know if you have the new guidelines. The problem is one of the challenges with Dr* [Name withheld to protect privacy] *was the doctor who was training PAC to the nurse clinicians. Every Wednesday, in this clinic, there used to be an in-service for all the nurse clinicians in the Gauteng region. They would come, and we'd be updated on everything – new policies, EDL, whatever. Everything was here since Dr* [Name withheld] *left and went on pension; there has never been even one* [in-service training].
> (IDI 002 – Healthcare provider)

5.8 PROVIDER SUGGESTIONS FOR ENABLERS TO EARLY DETECTION OF PRECANCEROUS AND CANCEROUS CERVICAL LESIONS

Five suggestions were made: 1) in-service training for healthcare providers on identifying cancer signs and symptoms, and on cancer-related policies; 2) increased staffing capacity; 3) provision of facility resources and supplies to support cervical cancer diagnostic screening; 4) in-clinic patient education on the importance of cervical cancer screening; and 5) community education on early signs and symptoms of cervical cancer.

5.8.1.1 In-service training for healthcare providers on identifying cancer signs and symptoms, and on cancer-related policies

Most facility managers and healthcare providers motivated for in-service training on cancer screening methods and guidelines:

> *The first one I would say is that if these people* [healthcare providers] *can be given in-service training regularly to do the* [cervical cancer] *screenings"* (IDI 005 – Facility manager)

> *We could go for in service training and with regards to implementing them* [screening guidelines]*, we can, as a team, give each other topics. We can perhaps allocate people to give each other health talks about the guidelines.* (IDI 007 – Healthcare provider)

One facility manager also suggested that the in-service training should not only be for healthcare providers, but also for all clinic staff who interact with patients:

> *For me, I can say in-service training is also important. I don't think it should only be to nurses; it can also be clerks and cleaners… because when a patient comes, they don't know who they are talking to; they just know that this person works at the clinic. So, even if they meet a cleaner, then the cleaner can also have some knowledge or information about where to send the patient and that can also help.* (IDI 003 – Facility manager)

5.8.1.2 Increased staffing capacity.

Most facility managers and healthcare providers requested that the NDoH increase staffing capacity to ensure adequate provision of cervical cancer screening services:

> *If they* [government] *can give us more staffing* [human resource]*, replace those who are going on pension, and increase total clinic physicians to work at the clinic.* (IDI 001 – Facility manager)

> *I think there is a lot of work that the nurses are doing and there's a shortage of staff. And that makes it impossible for everyone* [patients] *to get everything that they should be getting from the clinic.* (IDI 008 – Healthcare provider)

5.8.1.3 Provision of facility resources and supplies to support cervical cancer diagnostic screening

Most facility managers and healthcare providers requested that the NDoH adequately equip its facilities to ensure they are conducive environments:

> *… Also provide us with resources such as your speculums, make sure that windows have curtains, and KY gel* [for cervical cancer screening].
> (IDI 001 – Facility manager)

> *R: We don't even have beds in our room where we are at. We run out of the speculums; you find that they are finished.* (IDI 011 – Healthcare provider)

5.8.1.4 In clinic patient education on the importance of cervical screening

One facility manager and healthcare provider suggested that a healthcare provider should be available in the healthcare facility, who regularly provides patients with information about the importance of cancer screening to motivate them to undergo cervical cancer screening:

> *Maybe for us a shortage is a person that can be dedicated to be doing that [*cervical screening] *and encouraging people who are 30 years and older that they should go for a Pap smear to be done, and so that they can explain why they are being encouraged to do a Pap smear.* (IDI 003 – Facility manager)

> *If we do health education in the morning at the admin area where everyone is gathered, explain what a Pap smear is… why we are doing these screening procedures? I think that would be the first part of motivating the patients… We also need to have pamphlets and distribute pamphlets within the clinic as well.*
> (IDI 015 – Healthcare provider)

5.8.1.5 Community education on early signs and symptoms of cervical cancer

Almost all facility managers and healthcare providers emphasised the importance of educating the community on cancer signs and symptoms so that they could seek help promptly and enable early detection. One suggested strategy was to empower ward-based community health workers with knowledge of cancer symptom detection; when visiting households, they could also educate community members:

> *I think it's health education, especially because we have* warbots [ward-based community workers] *who do outreach in the community. Empower the*

warbots, and then they can educate the community about the signs and symptoms to enable early detection so that they can educate the community on what to do when they notice signs and symptoms. (IDI 007 – Healthcare provider)

Another suggestion by some healthcare providers was mass education, including events such as campaigns, to educate the community on cancer and the importance of screening:

We can also do campaigns where we go out and educate, for instance, when it's Cancer Week, we can go out to the malls and educate the people and tell them why it's important to screen for cancer, because that is where people are gathered. (IDI 015 – Healthcare provider)

CHAPTER 6: FINDINGS – WOMEN ATTENDING HIV CLINICS

6.1 INTRODUCTION

Chapter 6 presents the study findings from women participants, structured according to the same Socio-Ecological Model (SEM) used for healthcare providers, with the addition of components from the Health Belief Model (HBM). Given the modifiable influences within the SEM, the HBM is introduced to explore how key variables – such as perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action – affect women's cues to action, resulting in them ultimately demanding or not demanding cervical cancer screening services.

6.2 PARTICIPANTS' CHARACTERISTICS

As presented in Table 6.1, a total of 15 female patients attending HIV clinics at Lilian Ngoyi and Stretford Community Health Centres were interviewed, comprising 9 who had previously undergone cervical cancer screening and 6 who had not. The participants exhibited similar sociodemographic characteristics, with a median age of 40 years (range: 30–64 years). All participants identified as Black, 87% had attained at least some high school or tertiary education, and 47% were employed. The homogeneity in sociodemographic attributes among participants indicates that the sampling strategy was appropriate for obtaining meaningful insights into cervical cancer screening uptake within this population.

Table 6.1: Sociodemographic characteristics of participants screened and not screened for cervical cancer

	Responses	Number N (%)	Screened N (%)	Not screened N (%)
Gender	Female	15 (100)	9 (60)	6 (40)
Age average [range]		40 [30–64]	42 [30–62]	40 [32–55]
Racial group	Black	15 (100)	9 (100)	6 (100)
Home language	Sesotho	5 (33)	2 (22)	3 (50)
	Xitsonga	4 (27)	3 (33)	1 (17)
	isiZulu	4 (27)	3 (33)	1 (17)
	isiXhosa	2 (13)	1 (12)	1 (16)

	Responses	Number N (%)	Screened N (%)	Not screened N (%)
Highest level of education	Informal/some primary school only	2 (13)	1 (11)	1 (16)
	Completed some high school education but not matric	8 (53)	5 (55)	3 (50)
	Completed and passed matric and/or some tertiary education	5 (33)	3 (33)	2 (30)
Employment status	Employed-full time and piece work	7 (47)	4 (44)	3 (50)
	Unemployed/pensioner	8 (53)	5 (56)	3 (50)

6.3 OVERVIEW OF RESULTS

Women participants across both groups shared similar views on key themes, including knowledge of cancer and cervical cancer, perceptions of cancer as a deadly disease, fear associated with cancer, and the belief that screening is painful. While all participants recognised the benefits of early detection, most did not understand the preventive aspect of cervical cancer screening. Notably, only screened women perceived themselves to be at risk. Health-seeking behaviour, the role of religion in healthcare decisions, barriers to disclosing symptoms, and challenges in the continuity of care were consistent across both groups, as were the motivators and facilitators for cervical cancer screening. No other material differences were noted between the two groups of women, other than that the screening made them more aware of the process.

6.4 INDIVIDUAL LEVEL

6.4.1 Socio-Ecological Model

Six major sub-themes emerged to reflect patients' level of understanding of cervical cancer and diagnostic methods: 1) general knowledge and awareness of cancer; 2) cervical cancer knowledge; 3) cervical cancer signs and symptoms; 4) knowledge of cervical cancer diagnostic method; 5) knowledge of cervical cancer treatment; and 6) sources of cervical cancer information.

6.4.1.1 General knowledge and awareness of cancer

Both screened and unscreened patients demonstrated some understanding of the causes of cancer. For example, during the in-depth interviews (IDIs), some participants expressed the belief that cancer could be hereditary, while others reported that lifestyle factors were influential in the development of cancer:

> *According to what I have heard is that it is genetic, if somebody had cancer at home, it's possible for some of you to also get it; it's generational.*
> (IDI 005 – Screened)

> *I think somewhere, somehow, I can say cigarette smoking can allow you to have cancer, especially lung cancer, right? I think we have lung cancer if I'm not mistaken. Yes, I forgot about lung cancer; I think it is caused by tobacco.*
> (IDI 006 – Not screened)

A few screened and unscreened women patients derived their knowledge and awareness from personal experiences with others affected by cancer, often referring to experiences of a relative with breast cancer:

> *P: There was my aunt who had breast cancer. She had both her breasts, but when cancer attacked her, the left breast was gone. I: So, when you say the left breast was gone, do you mean they cut it off? P: I don't think they cut it off; it looks like it was being eaten away* [shrinking]*. I just saw her breast shrinking, and she ended up dying.* (IDI 009 – Not screened)

> *I knew about it when I was growing up – maybe I was 13, because my mom died due to cancer, and her sister too. My aunt died of cancer, so I know a lot about cancer.* (IDI 008 – Screened)

6.4.1.2 Cervical cancer knowledge-

Most patients had some level of awareness or understanding of cervical cancer. A common term they used to describe cervical cancer was "cancer of the womb":

> *I: What is cervical cancer? Let's start there. P: Cervical cancer is cancer of the womb, yes.* (IDI 009 – Not screened)

Although most women participants, screened and unscreened, were knowledgeable about cervical cancer, a few across both groups did not know about cervical cancer:

P: I don't know. I just hear womb cancer, but I don't have any information. (IDI 014 – Not screened)

I don't know anything. I just see people when they are sick; they just perish [die]*. I don't know what is happening, but I just feel their pain that if this person has cancer, it must be painful.* (IDI 003 – Screened)

6.4.1.3 Cervical cancer signs and symptoms

Understanding of the signs and symptoms that could be indicative of cervical cancer varied considerably: screened patients demonstrated in-depth understanding, while unscreened participants showed little to no understanding:

They say you bleed, and your bleeding is heavy and find that a person will be having their periods for more than seven days. Then there is also pain that you feel in your vagina so it might be. (IDI 005 – Screened)

Others say dirty blood comes out that is smelly a lot. You start coming out sores that don't stop down there in the vagina, you have a smell even if you have taken a bath. (IDI 003 – Screened)

I: Do you know the signs or symptoms of cervical cancer? P: No. (IDI 002 – Not screened)

6.4.1.4 Knowledge of cervical cancer diagnostic method

Most patients across both groups were aware that a Pap smear is the procedure used to screen for cervical cancer. They also demonstrated knowledge about the instrument used to collect the cervical specimen and understood how the specimen is collected for testing:

They just use a small metal that opens your womb and then take a brush to get something inside your womb, and they send it for a test; that's it. (IDI 002 – Not screened)

I have heard that they go to the clinic, and they put something like a spatula [speculum] *or whatever and they check by taking a sample to go and check at the laboratory. And then the results will come back and tell you if you have cancer or not. (IDI* 004 *– Not screened)*

However, a few patients across both groups were unfamiliar with the screening procedure for cervical cancer:

> *I: Ok, and then cervical cancer – do you know how they check for it and how it's detected? P: I don't know how it's checked.* (IDI 008 – Screened)

> *I: Which ways do you know that are used to diagnose cervical cancer? P: No, I don't know what I can say on how it is screened.* (IDI 004 – Not screened)

6.4.1.5 Knowledge of cervical cancer treatment.

Most patients across both groups had no awareness or knowledge about the treatment used for cervical cancer:

> *I: Ok, alright so how is cervical cancer treated or managed? P: I don't have a clue as to how it is managed.* (IDI 010 – Screened)

> *I: How is cervical cancer treated or managed? P: I don't know.* (IDI 002 – Not screened)

A few screened patients had some understanding that cervical cancer is a disease that is treated by a specialist and that one must know the staging before commencing treatment. No non-screened patients demonstrated this understanding:

> *I think after you are diagnosed with cervical cancer, it's whereby you have to go to a specialist. I don't think they have specialists at the clinics. Then they will check which stage you are on so that they can prescribe the kind of medication that they will use.* (IDI 005 – Screened)

6.4.1.6 Sources of cervical cancer information

Within both groups, information was received from a variety of sources. Some received information from the healthcare facility and some from the media:

> *I: Where do you get your information about cervical cancer? P: I got it from the clinic. The last time I came for checkups, some ladies came from Bara to teach us; they taught us about five different cancers. They also told us that it's important for women to check.* (IDI 010 – Screened)

> *They* [healthcare providers] *encourage us whenever we come to the clinic. Like when you come for family planning, they ask you if you have done a Pap smear. They will then explain to you how the procedure works. If you want to,*

you can book [schedule an appointment]*, and then they will give you a date, and you can come back and do it.* (IDI 001 – Screened)

A few patients learned about cervical cancer through traditional media outlets such as television, radio, or newspapers, as well as through family.

I: Where and how did you get information about cervical cancer: P: In most cases, I like listening to the radio. So I like listening to health talks, so I usually get information from there if I have time to listen; that's where I get it from. (IDI 012 – Screened)

I: How did you learn about self-examination? P: In pamphlets and on the TV; I heard them talking about breast cancer. (IDI 013 – Not screened)

6.4.2 Patients' perceptions (Attitudes)

Two sub-themes reflected patients' perceptions: 1) perceptions of cancer, including cervical cancer, as a deadly disease and 2) patients' self-perceived risk.

6.4.2.1 Perceptions of cancer, including cervical, as a deadly disease

Fear of cancer was prevalent among most patients in both groups. Many mentioned that simply hearing the word "cancer" triggered feelings of fear. For many, the association between cancer and death was deeply ingrained:

Cancer is dangerous disease. If you don't look after your diet, you'll have problems but if they check it in time, you can be safe. Yes, so, cancer is not a game; it's dangerous. (IDI 005 – Screened)

I just think that cancer is a sickness that kills, and it's different. There is breast cancer and womb cancer; they are just different, but I think if you have it, it is scary. (IDI 014 – Not screened)

6.4.2.2 Patients' self-perceived risk

Most screened and unscreened patients considered themselves at risk of cervical cancer and attributed this risk to factors such as living with HIV, which they believed increased their susceptibility to illnesses, and the perception that cervical cancer runs in families:

I think I am at high risk; cancer is very scary because my aunt had breast cancer. (IDI 015 – Screened)

I think so because I heard that with HIV you are prone to getting a lot of diseases. (IDI 009 – Not screened)

A few screened and unscreened women patients attributed their low risk to minimal sexual activity, while others could not explain their perception of being at low risk:

I'm not sure for now because I think the risk of cervical cancer for me is minimal. I think it's likely to happen if you live with a partner but for me, since I am single, I don't think that's much of a risk for me. (IDI 005 – Screened)

I: How at risk are you or how at risk do you think you are of getting cervical cancer? P: The chances are very extremely low, my darling. (IDI 006 – Not screened)

One screened participant believed that God would not allow her to have cancer:

I: How at risk are of getting cervical cancer? P: I don't think I would get it.
I: You don't think so – why? P: The God that I pray to won't allow it.
(IDI 010 – Screened)

6.4.3 Cues to action

Three sub-themes emerged that reflected on the women participants cues to action: 1) Patients' negative cues to action with respect to undergoing the cervical cancer screening procedure; 2) Probing cues to action impacts of the provision of cervical cancer community screening service (as opposed to only provided in the clinics); and 3) Positive cues to action with respect to general health-seeking behaviour

6.4.3.1 Patients' negative cues to action with respect to undergoing the cervical cancer screening procedure

The HBM domain of perceived barriers revealed pain as a significant concern regarding cervical cancer screening. Some screened patients indicated that the procedure was painful, while some unscreened women had heard from other community members that it was painful but had not experienced it themselves

They do that cotton down there, it's painful but, what more can you do? Nothing. (IDI 015 – Screened)

I hear that it is painful and they use a steel instrument. I have never done a Pap smear; I will experience it when I go and do it. (IDI 009 – Not screened)

The first time I heard that they use an instrument, and this instrument opens you up, so I am a very scared person. So, when I heard about instruments, I just said no ways am I going there. I won't agree to open my legs and having an instrument going inside of me. I'm very sorry. (IDI 012 – Screened)

A few patients reported no pain during the procedure, with some indicating only slight discomfort:

The sister who was going to examine me told me not to stress, it's not painful and it won't take more than 30 minutes. And I said, "Okay" and then I did it. It wasn't painful; I didn't feel anything. I was just amazed when they said I must clean myself up – I'm done. (IDI 001 – Screened)

Despite encouragement by healthcare providers to be screened, one participant indicated that her fear of undergoing the cervical cancer screening procedure was based on the explanation given of how the procedure is conducted:

I was scared. Even now I'm going but I am scared. I: What are you scared of? P: They will be telling you that they will insert a steel instrument inside of you and when I think of it, I just feel scared. Today I have the guts to go, I will go it's my first time and when I think of the steel instrument, I just feel scared. They have explained it to me the way it is. (IDI 014 - Not screened)

6.4.3.2 Probing cues to action impacts of the provision of cervical cancer community screening service (as opposed to only provided in the clinics)

Most screened and unscreened participants were open to the idea of community-based screening as an alternative to clinic-only services. They were willing to be screened in the community but emphasised that confidentiality would have to be ensured:

Not in public – I won't be comfortable answering some of those questions in front of people. If a person comes to the location and they want to screen me, like the HIV tents come with, in there you can be free and talk to the person. (IDI 001 – Screened)

I: How would you feel about having something like that being done in the community, that will help determine if you are at risk of getting cervical cancer

or not? P: I would be happy about that so that we can have knowledge – us that are in the dark who know nothing. (IDI 004 – Not screened)

6.4.3.3 Positive cues to action with respect to general health-seeking behaviour

Women's general health-seeking behaviours were probed, specifically where they first sought medical assistance when unwell. The majority of woman participants across both groups reported that healthcare facilities are their primary point of care:

When I am sick generally, I go to the local clinic. (IDI 003 – Screened)

I: So, when you are sick where do you usually go? P: I come to the clinic only. (IDI 006 – Not screened)

Although most identified healthcare facilities as their primary point of care, some screened participants noted that they sometimes had to purchase over-the-counter medication from local pharmacies for flu symptoms because healthcare facilities frequently lacked such medications:

Oh, I do. I use mostly Dis-chem I have a Dis-chem card, like flu medication for the baby and if my mom is sick and if I am also sick with flu or something. Sometimes I don't get a chance to go to the clinic because I am working and you know when you get to the clinic, they just give you Panado and that time you have flu, not a headache. (IDI 015 – Screened)

The same participant indicated that her first point of care was with a private doctor, citing the long waiting times at the healthcare facility; however, she consulted at the clinic when she could not afford private healthcare:

P: It's the private doctor. I only go to the clinic when I don't have money, but if I have money, I go to a private doctor. (IDI 005 – Screened)

6.4.4 Negative cues to action regarding disclosure of possible cervical cancer symptoms and accessing screening services

Three sub-themes emerged that reflected the women participants cues to action regarding disclosure of possible cancer symptoms: 1) feeling uncomfortable /embarrassed to talk about sysmptoms; 2) fear of being judged; and 3) fear of cervical cancer diagnosis.

6.4.4.1 Feeling uncomfortable/embarrassed to talk about symptoms

A few women patients across both groups expressed concerns about feeling uncomfortable or ashamed when talking about the symptoms of cervical cancer:

> *I think she gets embarrassed about the discharge. If it's the smelly one, I think she might think that they will say she smells. I'm sure it's being ashamed, just like me – I would be ashamed.* (IDI 006 – Not screened)

> *I think she gets embarrassed about the discharge, if it's the smelly one think she might think that they will say she smells.* (IDI 010 – Screened)

> *P: There is also this thing that the people that consult us tell people our things; that is the problem. I: Confidentiality. P: So, you see if I'm going to tell you my things and tomorrow, I hear them from my next door, I'm never going to be honest.* (IDI 003 – Screened)

6.4.4.2 Fear of being judged

A few patients perceived that some women may hesitate to seek care from healthcare providers for fear of being judged for their symptoms, while others may experience internalised stigma:

> *I would say people are afraid of being judged. If I can come to you as a doctor and say, "My discharge smells", I will think that he will judge me, why is it smelling, whatsoever.* (IDI 007 – Screened)

> *I don't know; maybe the nurses have an attitude, or maybe you find her being angry.* (IDI 014 – Not screened)

> *Judgemental, that the nurse will judge me that I have this because I am busy and sexually active, things like that.* (IDI 005 – Screened)

One unscreened patient indicated that some women might be afraid to seek medical care or disclose their symptoms to healthcare providers because they might then be required to inform their partners and risk being labelled as unfaithful by abusive partners:

> *P: Other people are in a relationship with men that are troublesome, that are abusive. So, if they are going to come here to the clinic and say that they have a discharge, the bleeding, and the pain, maybe the doctor will say, "Come with*

your partner", and the sister will come with her partner. The partner will say, "You are cheating on me, why is it like this? That means if I'm at work you must be doing one, two, three". (IDI 013 – Not screened)

6.4.4.3 Fear of cervical cancer diagnosis

Barriers to women being screened for cervical cancer were explored with the patients and most of the women across both groups shared that most women are afraid of the actual cancer diagnosis:

> *Other people are scared because once you find out that you have cancer, it is a must to take action. If you come late, it will be you who is delaying, and you will die.* (IDI 003 – Screened)

I: So, others are scared that they will find out they have cancer? P: I think for others is just being scared, fear of the unknown. Thinking, what if I go and they tell me it's cancer? It's best not to know; it's best I stay like this, not knowing what is happening. (IDI 013 – Not screened)

6.4.5 Traditional health practitioner use

The findings did not indicate that consultations with traditional health practitioners were a barrier to accessing primary healthcare. Two participants identified themselves as traditional healers. One patient reported that although she was a traditional healer, she did not consult with traditional healers. However, her parents had taken her to consult with a traditional healer because she was ill. The other participant said she only consulted a traditional healer when she felt her life was stagnant or noticed certain signs:

> *I don't want them* [sangomas] *in my whole life. I went there because of my parents; I was sick.* (IDI 003 – Screened)

> *I go there to consult. I'm sure in life there are things that you come across with and you know how we Black people are. The way this one is looking at me, it's like they are bewitching me. If I see rats in my house, I would say it looks like these are not here to do good and sometimes you try this and it doesn't work and try here and it still doesn't work. I would go out and check to see where the blockage in my future is?* (IDI 013 – Not screened)

A few patients across both groups reported having consulted with traditional health practitioners for the sole purpose of spiritual or psychological healing because they felt as if their lives had become stagnant. These consultations included “Ukuhlola” (spiritual reading/consultation) and cleansing rituals.

> *It’s that I can’t bathe with water only, and I always purge and steam those are the things I live by.* (IDI 009 – Not screened)

> *P: My things were not going well for me; my life was a mess by then I just saw It’s like in closed in* [stagnant]*, nothing was working out. I didn’t see what was happening with my life it was like I’m stuck in one place. So, my friend said there is someone that I know who’s knows such things maybe we can go and consult and see maybe he can help us.* (IDI 001 – Screened)

One unscreened patient indicated that she believed in traditional health practitioners and their ability to treat some conditions that cannot be treated by Western doctors:

> *Like with sangomas, there are illnesses that you can have, and the clinics can never heal it and the sangomas can help you. Just like this illness called shingles… when it starts people will say its HIV, and they will tell you that you now have HIV. This thing appears on people with HIV. And that’s not true In other cases, it’s because you are being bewitched. They are able to heal it faster or you may die if they say go to the clinic.* (IDI 014 – Not screened)

Some patients across both groups indicated that they did not believe in traditional health practitioners and therefore did not consult with them:

> *I don’t believe in that, even though my granny was a traditional healer, but I don’t believe in that.* (IDI 005 – Screened)

> *I: And then what are your thoughts about consulting traditional healers; what are your thoughts? P: I don't play around that side. I've never tried, and I don't believe in that; I believe in God.”* (IDI 006 – Not screened)

A few patients from both groups shared that although they believed in traditional health practitioners, they usually sought out medical care at the clinic when ill. They only consulted the traditional health practitioners when they did not recover after seeking help from the Western doctors:

I: Does it happen that you start this side then you go to the other side? P: No, it doesn't happen. In most cases, you need to look at something through doctors. In most cases, I start at the clinic, and then if they can't see anything… I decide to go to a traditional healer. (IDI 013 – Not screened)

Before I got sick, I went to the clinic, and when I went to the clinic, I couldn't get help, and I was getting worse. So, I went to another prophet, and then he told me that this is what is happening, and I told him that I come from the clinic, and I don't have pain anywhere. I don't feel any pain, but I can feel that I am sick. I ended up dreaming of white beads that I had to put on.
(IDI 012 – Screened)

6.5 FAMILY LEVEL INFLUENCES ON SCREENING BEHAVIOUR

6.5.1 Positive cues to action

6.5.1.1 Encouragement by family

Two patients mentioned being influenced by family members to undergo screening for cervical cancer – one directly and the other indirectly. The first patient was directly encouraged by her aunt, who had been diagnosed with cervical cancer:

My aunt before, when she found out that she has it, encouraged all the girls to go and do it. She said, "Please go and do Pap smears for your own health's sake so that you don't find yourself like me and find out late. Please make sure that every chance that you get go to the clinic and do the Pap smear."
(IDI 001 – Screened)

6.5.1.2 Cervical cancer in the family

One screened patient who was concerned about an unusually long menstrual cycle recalled that her aunt had experienced similar symptoms, which ultimately led to a cancer diagnosis. This prompted her to undergo a Pap smear:

I: What was your reason for doing the Pap smear? P: Because I was scared – I had my periods non-stop. They never stopped; I got scared cause I know my aunty and her child had the same bleeding problem then found it was cancer, so I was scared then decided to do a Pap smear. (IDI 008 – Screened)

6.5.2 Self-efficacy

6.5.2.1 Patients' perceptions about the benefits of early detection of cervical cancer – perceived benefits and barriers

Most patients across both groups recognised that early intervention could significantly reduce the spread of the disease and improve health outcomes. A few screened participants appreciated the preventive aspects of cervical cancer screening, understanding that if detected and treated in its pre-cancerous stage, a woman would not develop cervical cancer:

> *So that you can find out early if you have cancer so that you can get treatment done early. It's better to get it done than to find out late.* (IDI 005 – Screened)

> *It's good so that you can get help sooner because we do not know, or let me just say, I don't know what damages it causes in my body. I always hear that the disease spreads in the body. So, if they find it early, they can heal it quicker and if it can be reduced in the body, they can do that.* (IDI 013 – Not screened)

6.5.2.2 Patients' self-efficacy perspectives with respect to preventive medicine.

Within the HBM motivation (self-efficacy) domain, patients were probed on their perceptions and behaviours associated with preventive health practices. It was clear that preventive health practices and services were foreign concepts for patients who were not able to make any connection between cervical cancer screening and prevention of the disease. Some did, however, appreciate that preventive medicine in general prevented one from developing a certain illness or condition, but they made no connection between screening and cervical cancer prevention.

Perceptions varied regarding the benefits, efficacy, and adverse effects of preventive medicines:

> *I: How did you feel about receiving medication to protect you from getting something? P: Some help, some don't. They killing you, telling you go, you understand, but then there are certain pills they give us they do help. Just like the vaccine* [COVID-19] *they gave us – it killed some people but it helped other people. It goes both ways.* (IDI 002 – Not screened)

I: What are your thoughts about using preventive medicines, so using medicines to prevent you from getting something? P: To have medication to prevent something is like it reminds you that there are such illnesses, but at the same time, it's easy that it helps you to be alright. So, it's two ways, like it's just fear; you just have that fear that if I miss this medication, I might get sick. (IDI 005 – Screened)

P: You get given something and they say it will prevent this, and next it doesn't. For example, you go and take an injection for family planning, and they tell you it's 99.9% effective and that 1% or that 0.1%, where does it go to? So, it means there is a possibility that you might get this thing. So, even with that medication that I would be taking, I will know that there will be a possibility that you can get cancer, or I might not get it. I: Would you take preventive medicines or would you Not? P: I would; I would rather be safe than sorry. (IDI 013 – Not screened)

6.6 ORGANISATIONAL LEVEL PERSPECTIVES ON THE HEALTH SYSTEM: PERCEIVED BARRIERS TO SCREENING ACCESS

6.6.1 Negative cues to action

6.6.1.1 Withholding of screening services

A few unscreened patients indicated that they had not undergone cervical cancer screening because they did not meet the screening criteria at the time they wanted to do a Pap smear. One woman stated that she was never offered a Pap smear or encouraged to have one at the healthcare facility:

I: So, you mentioned earlier that you've never done a cervical cancer [Pap smear] *but you want to do cervical cancer* [Pap smear]*. Why haven't you done a Pap smear before? P: It's just that I wasn't in that certain age – I wasn't 32 yet back then; I was still young.* (IDI 006 – Not screened)

They have never. I have never had the luck to find someone talking about it when I'm there. (IDI 004 – Not screened)

6.6.1.2 Long waiting times

Most patients across both groups expressed their unhappiness with the slow service received and the long waiting periods at the healthcare facilities:

My clinic is alright but sometimes the service is very slow. You know how the clinic is – you can come at 6 am and wait at the gate and then they open at 7 am. You have to wait for them to first have breakfast and they start at 9 am. But now we are used to it; we know that this clinic is like this. (IDI 014 – Not screened)

You can wake up early and the service is slow. Then you come in the afternoon thinking it will be better, but still their service is still a bit slow. (IDI 001 – Screened)

6.6.2 Staff attitude

Most patients across both groups reported that they had no complaints or concerns regarding the service received at the healthcare facilities. One participant even highlighted how the matron at one of the facilities was actively involved and treated patients with kindness and respect:

They treat me well so far, besides the one that happened about the baby – let's forget about that one; it's in the past. Even the matron is a very good person. She treats us well if something is not going well. Maybe the lines are stuck – she comes and talks to us nicely in a human way. (IDI 009 – Not screened)

It [service received] *is beautiful; I don't have a problem with it. I don't have a complaint.* (IDI 010 – Screened)

A few patients across both groups expressed satisfaction with most healthcare providers. However, one department and two healthcare providers were identified as occasionally treating patients poorly, making some patients uncomfortable about returning to the healthcare facility:

You know what, my clinic is fine; it's just that you get those ones that would make you feel like you must just stay at home and not go to the clinic. They don't treat us well sometimes. (IDI 013 – Not screened)

Alright, doctors and nurses are fine, I won't lie, there is just one doctor whose head is not fine – she is rude. (IDI 015 – Screened)

One screened patient who expressed dissatisfaction about the attitude of the community health workers:

People with attitude are the caregivers, the ones that think they are nurses, and they just caregivers. They act as if they are nurses. (IDI 015 – Screened)

6.6.3 Barriers to continuity of healthcare: Clinic hopping

6.6.3.1 Concerns about privacy

Participants across both groups expressed concerns about privacy, citing it as a reason why some women sought care at multiple clinics:

*If like you, are positive and you find out at ********* Clinic, and when you come to ********* Clinic to fetch your medication for the first time, you see someone from your location* [neighbourhood]*. You change and you go to ***** and there they tell you that the clinic you are supposed to go to is at ******* and then you keep changing.* (IDI 014 – Not screened)

Ok, it is stigma; to say I don't want people to see that I am sick. They will talk about me, and they will start treating me funny, you see. (IDI 005 – Screened)

6.6.3.2 Missed scheduled appointments

A few screened patients cited missing appointments as a reason for clinic hopping. They suggested that these patients might avoid returning to the same clinic for fear of being reprimanded or scolded by healthcare providers for missing their appointments:

So, you find that you have defaulted, so when I come to this site, I tell lies and say it's my first time… That is how people's information gets lost.
(IDI 003 – Screened)

6.6.3.3 Staff and patient attitude

Participants across both groups described how disrespectful behaviour either from patients or healthcare providers created tension and discouraged continuity of care:

*Attitude of the one that is hopping – they come here to *********, and they insult the nursing sisters, and they go to one and they insult the nursing sisters, and then they go to ****** (IDI 009 – Not screened)

I think it's because of the service and the bad attitudes they have in all these clinics because some people have short tempers. You find that this person has a short temper just because he is sick. You find that he has a toothache or

something. And then you come along as the sister telling him your own things and he just gets upset. (IDI 007 – Screened)

6.7 COMMUNITY LEVEL

6.7.1 Cues to action

6.7.1.1 Perceived community perceptions of cervical cancer

Patients' views of what their communities thought about cervical cancer were examined by asking them: "What beliefs do people have about cervical cancer?" Most women participants across both groups reported that the community viewed cancer as a deadly disease:

They believe that cancer kills; that is what they believe. Cancer kills, and it can't be cured. It's incurable if you have it you have it, you will die.
(IDI 015 – Screened)

People believe that cancer kills. (IDI 004 – Not screened)

In addition to perceptions of cancer as deadly, one patient mentioned that in some cases, people believed cancer to be a punishment from their ancestors:

It's because, in many cases, they believe it's the ancestors. Like the cancer thing – they would say they are not sick, but they are punishing her, things like that. (IDI 004 – Not screened)

Another noted that cancer was perceived as a White man's disease:

In our society, they think it's a White thing [White man's disease].
(IDI 002 – Not screened)

6.7.1.2 Community perceptions of the cervical cancer screening procedure

Patients were also questioned about their community's views on cervical cancer screening. Most patients across both groups stated that community members who had undergone the screening found it painful and were often concerned about the speculum used during the procedure:

They say there is an instrument that they insert into you, and it opens you up. I asked them if it's painful. (IDI 013 – Not screened)

They say that we are scared to do Pap smear because it's painful. (IDI 003 – Screened)

6.7.1.3 Community perceptions of the role of traditional health practitioners

Traditional healers were generally perceived as having a positive impact on managing illness:

> *Yes, they do go to sangomas; each person has their own thing that they like. They have a belief that if they go to a traditional healer, they will get help. If they go to the clinic, they can never get help.* (IDI 014 – Not screened)

While some patients noted that some community members who believed in witchcraft attributed their illness to a supernatural force:

> *It's this thing of having many beliefs; people believe that they are being bewitched, things like that. And I think, what pushes them there is to find out what is the course of their illness. We never think it just normal sickness; we always think of witchcraft.* (IDI 010 – Screened)

> *I: In the community where you come from, from your observations, where do you think the belief is at? P: People love sangomas. I: Why do they love sangomas? P: I don't know; you know people always think they are being bewitched, that is how they are.* (IDI 009 – Not screened)

6.7.2 Community knowledge of cancer

One patient mentioned that in some instances, the community perceives that some illnesses, such as cancer, are a form of punishment from the ancestors:

> *It's because, in many cases, they believe it's the ancestors. Like the cancer thing – they would say they are not sick, but they are punishing her.* (IDI 005 – Screened)

6.7.3 Role of religion in health-seeking behaviour – community religious resources as a cue to action

Most patients across both groups indicated that while they had strong religious beliefs, religion did not directly influence how they sought medical care. Many reported sharing their health issues with their congregations, where they were encouraged to seek medical treatment and also receive prayer for spiritual support:

They encourage us because I moved from Christianity to a spiritual home now where they motivate you. If you not feeling well, there's nothing much you can do but go to the clinic. If they give you pills, drink them. It's your life. Yes, God will help you but help yourself first so he can help you. (IDI 001 – Screened)

I: How much of a role does your religion play in terms of you going to the clinic? Does it influence whether you go to the clinic when you are sick or not? P: No, for me, if I'm sick, I go to the clinic. (IDI 012 – Not screened)

6.8 MOTIVATORS/ENABLERS FOR CERVICAL CANCER SCREENING IN THE HEALTHCARE SYSTEM

6.8.1 Health system positive cues to action

6.8.1.1 Encouraged by healthcare providers to undergo Pap smear screening

Most screened patients had been encouraged to undergo screening by healthcare providers due to an underlying health condition. All but one actively sought cervical cancer screening:

I: What made you to do it this year? P: It is because the doctor told me long time to go and do Pap smear. (IDI 012 – Screened)

6.9 FACILITATORS TO CERVICAL CANCER EDUCATION

Strategies to educate and encourage women to identify the signs and symptoms of cervical cancer and undergo cervical cancer screening were explored with the patients. From these discussions, two primary themes emerged: 1) in-clinic education and 2) community education.

6.9.1 Community education

Most women patients across both groups suggested using community outreach campaigns to educate people about cervical cancer. They recommended holding these campaigns in busy places such as malls and taxi ranks, as well as at churches, with experts sharing information about the disease, especially targeting women:

I think we need campaigns at the locations and be taught about what is cervical cancer because a lot of people still don't understand what cervical cancer is. So, if we can get people to do campaigns and teach us that this is

cervical cancer, you get it like this, and this is how you treat it, and if you get it, this is how you treat it. (IDI 001 – Screened)

"I think through radios, TVs and pamphlets messages like that and awareness's sometimes they do door to door. And talk to people and leave pamphlets, others they call them at the malls and at the stadiums."
(IDI 013 – Not screened)

6.9.2 In-clinic education

Some patients across both groups mentioned that many patients did not know the symptoms of cervical cancer. They suggested that the clinic could educate people about the disease while they wait. This could be done through morning talks in the waiting area, and by displaying posters and distributing pamphlets with information on the causes and symptoms of cervical cancer:

It's for us to go to the clinics and while we sit there, someone should come and address us about this thing [cervical cancer] *because some of us are still in the dark. We don't know; we only go to the clinic if there is pain. If there is no pain, we don't think of going to the clinic.* (IDI 004 – Not screened)

I think if they can be called in the halls. Number two: put up posters at the clinics – the causes of cancer – so that we can read. Just like you said, it's good to know early and how you can get it and then tell us the room.
(IDI 010 – Screened)

6.9.3 Media

In addition to in-clinic and community campaigns, a few patients across both groups suggested sharing information through traditional media such as TV and radio, as well as social media platforms like Facebook, TikTok, and Instagram:

I will use HIV as an example for everything. Do you see how HIV is announced. We know that we are HIV-positive today because it's been announced and advertised. Growing up, there were mobile clinics for people to go and test. It's always been announced on radios – they will be telling on how you need to condomise to prevent HIV, things like that. Even this cervical cancer – it needs to be announced so that it's heard of and that it is alive and real. That is when people will wake up, do you understand?
(IDI 007 – Screened)

I think through radios, TVs and pamphlets messages like that and awareness's sometimes they do door to door. And talk to people and leave pamphlets, others they call them at the malls and at the stadiums.
(IDI 013 – Not screened)

CHAPTER 7: DISCUSSION

7.1 INTRODUCTION

This chapter first integrates the findings for each objective (Objective 1: healthcare providers) and (Objective 2: primary care women patients). Thereafter, the findings from the two objectives are triangulated, highlighting similarities and differences. It also draws conclusive insights and acknowledges the study's strengths and limitations.

7.1.1 Objective 1: Healthcare providers perspectives

As depicted in Figure 7.1a, healthcare providers in this study reported several challenges that negatively affected the delivery of cervical cancer screening services. These included limited knowledge of cervical cancer and related policies, inadequate clinical skills in performing screening procedures, and insufficient resources such as staff, infrastructure, and supplies. Staff were resistant to acquiring new knowledge and were perceived as unsupportive, compounded by staff rotations, which hindered knowledge and skills acquisition. Inadequate screening facilities, supplies, and access to screening laboratory results posed significant barriers to cervical cancer screening provision. Collectively, these factors contributed to reduced screening service supply and compromised service quality. Providers also expressed frustration at the perceived lack of leadership and prioritisation from the National Department of Health (NDoH), whose lack of provision of adequate cervical cancer screening facilities and supply chain management made healthcare providers feel unsupported.

In addition to structural and provider-level barriers, healthcare providers noted that patients were often misinformed about cancer risks and symptoms. Many women were perceived to delay seeking medical help until severely ill, opting for self-medication or consulting traditional healers. They viewed primary care clinics as offering curative rather than preventive services. Perceived pain associated with the Pap smear procedure and low perceived risk of cervical cancer, especially among women who were not sexually active or who associated cancer with family history, hindered motivation for seeking cervical cancer screening services.

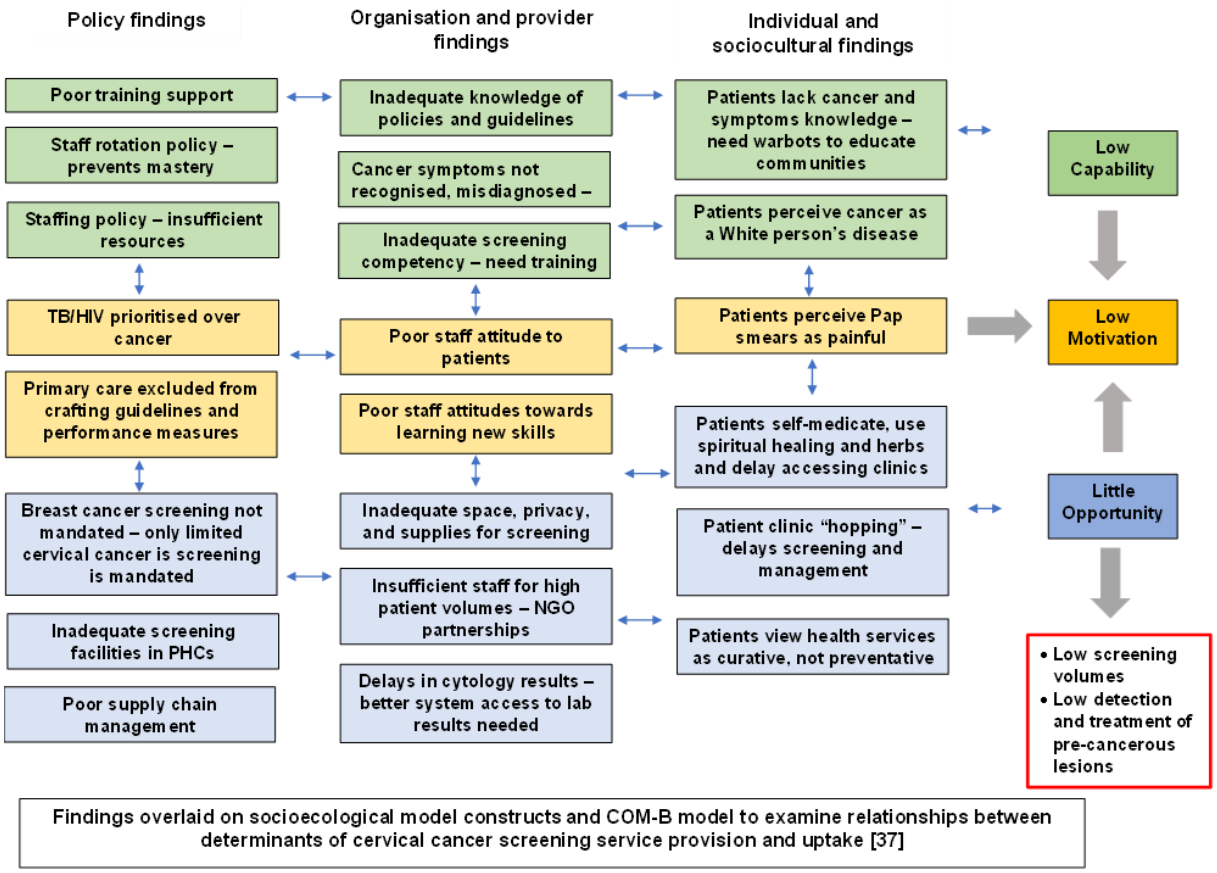


Figure 7.1a: Healthcare providers' perspectives and their complex interaction [37]

To address these gaps, healthcare providers suggested a combination of ongoing in-service training, clear screening guidelines, improved access to test results, and enhanced collaboration with cancer-focused non-governmental organisations. They also recommended increased community outreach using ward-based teams to improve public knowledge, and the inclusion of frontline providers in policy development to ensure more practical and supportive interventions.

The study's findings are aligned with recent sub-Saharan Africa review articles by McFarland et al. [94] and Pierz et al. [46], who also revealed that women feared cervical cancer, and did not understand that it is preventable nor that screening is a preventive measure. Such findings were echoed by other researchers in Durban, SA [94,95] and in Western Kenya [95], who reported that although women had heard of cervical cancer, their knowledge of the risks, signs, and symptoms of these cancers was poor, with limited awareness of the need for cancer screening. The very real perception that women undergoing the Pap smear procedures find them painful is a serious, commonly reported barrier to cervical cancer screening. Patients' cultural

and religious barriers were also mentioned, with provider barriers, including failure to inform or encourage women to screen, cited as key barriers to screening uptake.

Pierz et al. [46] highlighted patient perceptions of cancer risk and opinion of influential community members, trust in the health services, political will, and support and encouragement of the patient by providers as facilitators to screening uptake. Poor primary care provider cancer knowledge was also confirmed by Marlow et al. in Saudi Arabia [27] and by Bateman et al. [97] in Tanzania. In a recent study in the Western Cape of SA, Moodley et al. [98] noted the difficulty primary care providers experienced in distinguishing symptoms of infectious diseases from those of cervical cancer in settings of high infectious disease prevalence. They pointed to a need to support primary care healthcare providers in assessing symptomatic patients [98]. Inadequate resources for primary care cancer screening services were also reported by Bateman et al. [97] and by Diala et al. in Western Kenya [96], with clinicians revealing massive challenges in navigating large patient volumes in crowded clinics, faulty equipment, and unreliable power supplies.

To better understand how these factors interact, I applied the Socio-Ecological Model (SEM) and the COM-B (Capability, Opportunity, Motivation-Behaviour) framework [30,31]. These frameworks helped map the multilevel influences on both service provision and demand for cervical cancer screening. At the capability level**,** providers were often untrained or underprepared for screening duties due to a lack of support and frequent rotations. Patients, meanwhile, lacked basic cancer knowledge and held beliefs that reduced their perceived vulnerability, particularly among Black South African communities.

From an opportunity perspective, screening services were constrained by a shortage of personnel, inadequate facilities and equipment, and logistical issues such as delays in receiving laboratory results. The absence of a national mandate for cervical cancer screening, and limitations in screening availability, further narrowed access. Patients, perceiving clinics as spaces for curative rather than preventive care, often sought alternatives such as self-treatment or traditional medicine, or moved between clinics – actions that disrupted care continuity.

Motivation to provide or seek screening services was also lacking. Providers reported feeling excluded from decision-making processes and performance evaluations related to cancer screening, leading to diminished interest in learning or promoting

screening. Patients, in turn, reported negative experiences, feared painful procedures, and often encountered unwelcoming staff factors that discouraged them from returning.

In sum, these multilevel dynamics, rooted in limited capability, constrained opportunity, and weak motivation, contribute to the ongoing under-utilisation and suboptimal delivery of cervical cancer screening in primary healthcare settings. These findings highlight the urgent need for systemic improvements, including training, infrastructure support, community engagement, and policy alignment, to enable and sustain effective cervical cancer screening provision and community uptake.

7.1.2 Objective 2: Women patients' perspectives

The findings from the women patients' perspectives demonstrate the complex interplay of individual, interpersonal, and health system factors that influence women's screening behaviour. As shown in Figure 7.1b, these interplays involve knowledge and attitudes which, in turn, influence cues to action and self-efficacy in seeking cervical cancer screening services. From a knowledge perspective, I found that most women participants had a limited understanding of cancer in general. Although some demonstrated partial knowledge about cervical cancer, such as recognising its association with sexual activity, they lacked awareness that cervical cancer is both preventable and can be cured. Moreover, they demonstrated little understanding of the importance and benefits of preventive health. These knowledge gaps were echoed at the community level, where various misconceptions about the causes of cervical cancer were evident. Health messages received by patients at the primary healthcare facilities often failed to emphasise that cervical cancer can be prevented and cured, representing a critical missed opportunity for health education and promotion.

Cervical cancer was commonly perceived by both women and the broader community as a deadly disease, often linked to spiritual beliefs, with many viewing it as a punishment from ancestors. Risk perceptions among women varied: some considered themselves at high risk due to their HIV-positive status, while others believed their risk was low because they had few sexual partners. Among women who had not undergone screening, the procedure was perceived as painful, and those who had been screened often described it as a painful experience. Poor

provider skills may have contributed to women experiencing pain during the screening procedure. Cervical cancer was also perceived as a “White person’s disease”, contributing to a low sense of personal risk among community members. These perceptions served as significant barriers to cervical cancer screening uptake.

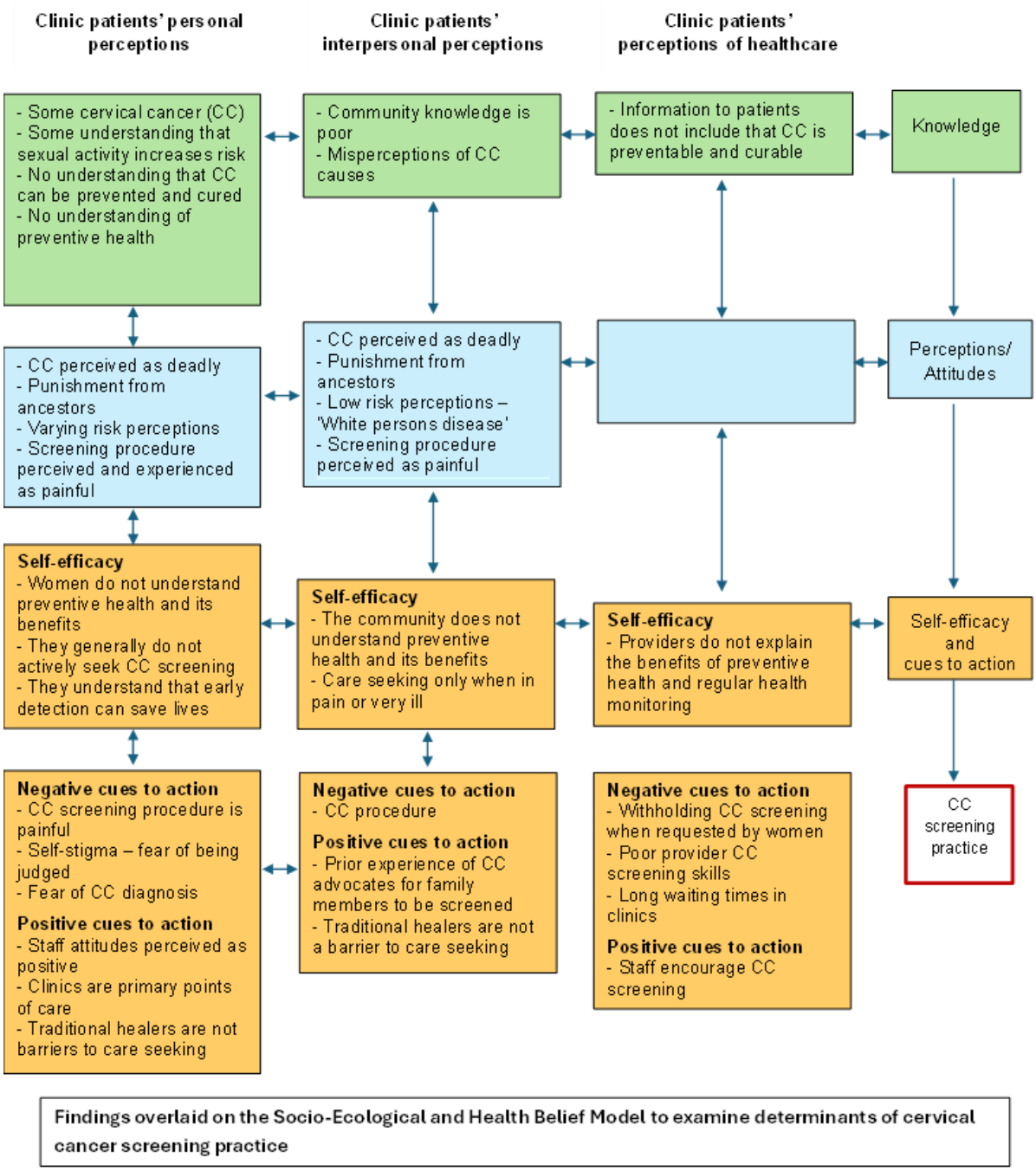


Figure 7.1b: Women patients’ perspectives and their complex interaction[37]

Self-efficacy indicates whether an individual feels confident in their ability to take action such as seeking cervical cancer screening or adopting preventive health behaviours. The findings indicate that most women participants lacked an understanding of preventive health and its benefits and generally did not actively

seek cervical cancer screening, despite some awareness that early detection can save lives. Similarly, within the broader community, understanding of the value of preventive health was limited, with most individuals only presenting at primary healthcare facilities when already ill. This behaviour was further influenced by gaps in communication within the healthcare setting, where the importance of prevention and the benefits of routine health monitoring were not clearly conveyed. Consequently, opportunities to promote proactive health-seeking behaviours may have been missed.

Cues to action are factors that determine health seeking behaviour, such as women actively requesting cervical cancer screening by women. In this study, both negative and positive cues to action were found to influence women's willingness to undergo cervical cancer screening. The perception that cervical cancer screening is painful further discouraged women at the community level. From the health system perspective, additional negative cues included some withholding of screening services from women who actively requested them. Poor provider skills may result in causing pain to patients, and the long waiting times at clinics were also negative cues to action. However, important positive cues to action also emerged. At the interpersonal level, women appreciated the positive attitudes of some healthcare providers, acknowledged that clinics were often their first point of care, and noted that traditional healers were not perceived as barriers to accessing services. At the community level, prior experiences of cervical cancer among family members motivated cervical cancer screening. Healthcare providers actively encouraged women patients to screen.

Knowledge gaps among both women and healthcare providers emerged as major barriers to cervical cancer screening, findings echoed in other sub-Saharan African studies [99]. Similarly, providers reported limited knowledge of screening guidelines, inadequate training, and few opportunities for skills development, issues consistent with reports from other low-resource settings [94,100]. Health messages at clinics frequently failed to correct these misconceptions, reflecting missed health promotion opportunities. Women expressed low self-efficacy due to limited understanding of preventive care and poor communication from providers, aligning with studies showing low confidence to seek services in similar contexts [99,101]. Negative cues such as fear, stigma, and distrust of the health system discouraged screening, compounded by structural issues such as long waits and understaffing [102,103].

Nonetheless, positive motivators such as personal or family cancer experiences and respectful provider interactions could enable uptake when present. Cultural beliefs, such as viewing cervical cancer as spiritual punishment or a condition affecting other groups, also played a role [100]. These barriers disproportionately discouraged women from seeking care, while providers highlighted systemic challenges in delivering it, pointing to the need for integrated interventions that enhance both demand and service quality.

In sum, these interconnected findings reveal that limited knowledge of cervical cancer as a preventable and highly curable disease is coupled with perceptions of cervical cancer as deadly and of the screening procedure as painful. This, combined with limited understanding of the benefits of preventive health behaviour, does not encourage self-efficacy and cues to actively request cervical cancer screening. These barriers are compounded by inadequately trained providers in both cervical cancer and the screening procedure. Better training of screening nurses is needed, as are consistent, easy-to-understand cervical cancer educational messages for both women attending clinics and the community at large. The findings also highlight the urgent need for better infrastructure, electronic tracking tools, and better supply chain management to support cervical cancer screening and treatment services. Furthermore, policy revision must include pre-cancerous lesion along with screening volumes reporting. Addressing these multi-level barriers is critical to improving screening uptake and pre-cancerous lesion treatment.

7.2 TRIANGULATION OF HEALTHCARE PROVIDER AND CLINIC WOMEN FINDINGS

Triangulation is a research approach that strengthens the validity of findings by using different methods, sources, theories, or researchers to study the same topic. It captures similarities and differences in the findings that can be used to influence policymakers to develop interventions. This approach improves the credibility and depth of findings by capturing diverse experiences and viewpoints [92,104]. In this study, triangulation compares the findings from the perspectives of two different stakeholders (primary healthcare providers and women patients), presented below are common and divergent findings of the two stakeholder groups.

7.2.1 Common findings

7.2.1.1 Knowledge and Capacity

Providers and patients have insufficient knowledge and awareness of cervical cancer and the guidelines, with providers lacking proficiency in performing cervical cancer screening procedures, exacerbated by staff rotations. Healthcare messages are inconsistent and inadequate to address patient misperceptions, giving rise to myths, misconceptions, and negative experiences among both stakeholder groups.

7.2.1.2 Motivation, cues to action, and self-efficacy

Low self-efficacy and active screening demand emerged as a common theme. Primary care facilities place insufficient emphasis on preventive health service messages and failed to educate patients about the benefits of preventive health behaviour. Consequently, patients sought health care for curative rather than preventive reasons. Women therefore lacked understanding of the benefits of preventive health behaviour.

In terms of cues to action, negative factors such as fear of pain, stigma, and fear of diagnosis were common among women and the community. These factors were reinforced by provider reports of patients' hesitancy and, in some cases, denial of screening even when requested, highlighting provider gatekeeping and systemic failures. Structural barriers such as long waiting times due to understaffing further discouraged screening uptake. However, positive cues to action were also present. Women appreciated respectful interactions with providers and were motivated by personal or family cancer experiences. Clinics remained the primary point of care, and providers generally encouraged and facilitated screening uptake.

Motivation emerged as a challenge for both groups. Women were discouraged by past negative experiences and unfriendly clinic environments and staff, was an issue acknowledged by providers who experienced burnout.

7.2.1.3 Opportunity and attitude

Structural challenges such as staff shortages, inadequate infrastructure, inadequate cervical screening supply chain management, and delayed lab results limited service availability. While both groups faced these barriers, women were primarily deterred from seeking care, whereas providers reported systemic constraints in delivering services.

7.2.2 Unique findings

Risk perceptions varied: some HIV-positive women acknowledged heightened vulnerability, while others believed they were at low risk due to having few sexual partners. Providers perceived that patients did not consider themselves to be at risk for cervical cancer, as they believed cancer in general was a “White person’s disease”, which further discouraged screening. The fear and experience of pain among patients and community women alike may not be unfounded but may, in fact, be caused by providers’ inadequate technical skills and lack of anatomical knowledge of the location of the cervix.

7.3 IMPLICATIONS FOR POLICY INTERVENTION

The common findings represent a unified voice from both provider groups, highlighting a widespread need that requires immediate policy action. I suggest the following urgent policy interventions:

- Providers require regular clinical and practical training on cervical cancer, including guidelines, updates, and screening skills. Patients, in turn, need education that communicates consistent, unambiguous messages. These messages must clearly articulate the risk factors for cervical cancer, who should undergo regular screening, and that the disease is both preventable and curable if identified early. Such messages must also be shared at community level, using existing resources such as churches, community health workers, traditional health practitioners, and community leaders. Campaigns should be aired regularly on community radio stations and crafted to reduce fear of and stigma associated with cervical cancer.
- Primary healthcare facilities should begin providing preventive health messages to patients and community members, highlighting the benefits of preventive health behaviours. Simple messages that are easily understood by patients should be delivered verbally and displayed on posters in clinics. These interventions are essential for shifting patients’ focus from curative to preventive health-seeking behaviours. Communities should be encouraged to access clinics’ preventive health services and not just when they are ill. Furthermore, they should be encouraged to demand cervical cancer screening services. Such interventions should be assessed for their capacity to increase clinic uptake of preventive health services.

- Supply chain management for cervical cancer screening procedures requires improvement to reduce delays in cervical cancer screening provision. Such interventions are expected to increase motivation of providers and patients alike.
- The NDoH must invest in improved facilities for screening and address delays and barriers in accessing laboratory results. This, too, is expected to improve provider and patient motivation.
- The unique findings reveal blind spots in provider perceptions. Inclusive stakeholder engagement involving patients, community members, primary care providers, and policymakers is essential.
- Providers must understand that community women experience real pain during cervical cancer screening procedures, often due to inadequate provider skills. Staff rotations should be limited, and specialist cervical cancer screening providers should be allocated to these services. A shared understanding of cervical cancer risk must be established. Conversations around perceived risk and prevalent myths are vital to determine how best to respond.

7.4 STUDY STRENGTHS AND LIMITATIONS

By incorporating the perspectives of both women and healthcare providers, the study findings offer a comprehensive understanding of the interplay of factors influencing cervical cancer screening provision in clinics and uptake by women. The Health Belief Model, the Socio-Ecological Model, and COM-B provided a framework to understand the interrelated factors influencing screening provision and uptake. They also enabled the identification of policy intervention needs. As with all qualitative study designs, the findings provided depth rather than generalisability. Future quantitative study designs are required across many settings in South Africa to assess the generalisability of findings within the South African context.

Selection bias may have occurred, as women participants routinely attended the HIV clinic, suggesting that the results may not represent the broader population, including those women living with HIV who do not seek healthcare regularly. The limited geographic context, confined to two community health centres and six primary healthcare facilities within greater Soweto, may not reflect the experiences and

barriers in other regions or healthcare settings. Additionally, reliance on self-reported perceptions and experiences introduces the potential for social desirability bias.

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APPENDICES

APPENDIX A1: INFORMATION LEAFLET AND INFORMED CONSENT FORM FOR INDIVIDUAL IN-DEPTH INTERVIEWS FOR MANAGERS/HEALTHCARE PROVIDERS

Exploring Interventions aimed at CANcer prevention and early DetectiOn using South African Cancer Management Guidelines

VERSION: Protocol Version 1.0 dated 4 November 2020
PRINCIPAL INVESTIGATOR: Dr Maureen Joffe
QUALITATIVE RESEARCH INVESTIGATOR: Dr Janan Dietrich
TELEPHONE: 0829240000 (Joffe), 0119899890 (Dietrich)
SPONSORS: Bristol Myers Squibb Foundation-Secure the Future and
BMSF – Multi-Sector Coalition in Implementation Research in Global Oncology (CIRGO)

INTRODUCTION

Good day, my name and surname is_____.
I am a _____ (designation) at the Soweto Comprehensive Cancer Centre at the Chris Hani Baragwanath Academic Hospital (Bara) in Soweto. I would like to invite you to take part in a research study to understand how we can best implement the South African National Department of Health guidelines for early detection, management of pre- and cancerous lesions and referral of symptomatic patients for diagnosis and treatment. We also want to learn what potential changes we have to make to implement the guidelines in a routine clinic setting. This study is currently funded by Bristol Myers Squibb Foundation-Secure the Future and BMSF-Multi-Sector Coalition in Implementation Research in Global Oncology (CIRGO)

Before agreeing to participate, it is important that you read and understand the purpose of the study, the study procedures, benefits, risks, discomforts, and precautions as well as the alternative procedures that are available to you. You have the right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to participate. Please ensure that understand what is involved before you agree to take part in this study. Feel free to ask the research staff any questions you may have.

Once you understand the study and you decide to take part, we will ask for your written consent to participate. We will also ask your written consent to record the interviews. You will receive a copy of these consent forms for your records. This process is called informed consent.

WHY IS THIS STUDY BEING DONE?

We are conducting these interviews to learn the following:

- To understand contextual (clinic setting specific) enablers and barriers to sustainable implementation of the South African guidelines for breast, cervical, lung and prostate cancer.
- To develop an interventional package to implement the early detection, referral, and cervical pre-cancerous lesion management guidelines.

WHERE WILL THE STUDY BE DONE?

We will invite 10 clinic managers and 10 healthcare providers (nurses and doctors) from selected and nearby clinics in Soweto.

HOW LONG IS STUDY PARTICIPATION AND HOW MANY PEOPLE WILL PARTICIPATE?

Healthcare managers and healthcare providers will take part in an interview that will take 45 to 60 minutes. We would like to conduct 20 Interviews, 10 with managers and 10 with healthcare providers. We will select managers, doctors and nurses with experience and reputation in providing services to patients with non-communicable diseases at the designated primary care clinics.

WHAT DO I HAVE TO DO IF I AM IN THIS STUDY?

After signing informed consent process, you will be asked to complete a short demographics questionnaire. You will then take part in the In-depth interview. You will be asked questions about key enablers and barriers to implementation of the South African National Department of Health guidelines for early detection, management of pre- and cancerous lesions and referral of symptomatic common cancers in adult patients. We would like to be able to understand training needs and other gaps that have to be addressed for successful implementation of these guidelines.

The interviews will be audio-recorded and the reason for this is that we want to be able to capture accurately what you were asked and what you said during the

interview. We will not be able to write down everything that you say during the interviews. We will use the recording for the purposes of this study only. The recording will be typed out and if necessary, translated into English. The translation will be entered into a computer program for analysis. Only the study staff will have access to the audio recording and the transcripts, your information will be kept

Only you as the participant or research assistant will be present during the In-depth interview. We ask that you use first names only (or fake names), not your real names to make sure that the information you provide will be private.

WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?

There are no direct benefits to the participant for taking part in the study. However, we will be able to use the information that participants will provide to make necessary contextual changes to implement the South African guidelines for common cancers in routine clinic settings.

WHAT ARE THE RISKS OF BEING IN THIS STUDY?

There are no direct risks for taking part in this study.

RIGHTS AS A PARTICIPANT IN THE STUDY

Your participation in this study is entirely voluntary and you can decline to participate, or stop at any time, without stating any reason. Refusal to participate, or withdrawal from the study will not affect your employment within the public sector. There will be no negative consequences if you want to stop taking part.

WITHDRAWAL FROM THE STUDY

If you wish to stop participation, please tell the research staff. You do not have to give a reason why you want to leave the study, but any information you provide to study staff will be helpful. The investigator may also withdraw you from the study if it is considered to be in your best interest.

WHAT ABOUT CONFIDENTIALITY?

We will make an effort to keep your personal information confidential. All the information we collect for this research study will be stored in locked file cabinets and kept in secure computer files. Your name or any other identifying information about you will not be included in the transcripts. If a publication results from this study, transcripts and audio files will be kept for two years. If the findings of this study are

not published, the transcripts and audio files will be kept for 6 years. No individual identities will be used in any reports or publications that may result from this study.

REIMBURSEMENT FOR PARTICIPATION

There is no cost for you to be in this study. Participants will be reimbursed R200 as an appreciation of their time.

WHAT DO I DO IF I HAVE QUESTIONS OR PROBLEMS?

If you have questions about this study or any problems that you think may be related to this study, contact the principal investigator, **Dr Maureen Joffe at Tel: 0829240000 or Dr Janan Dietrich at Tel: 0119899890.**

ETHICS APPROVAL

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (Wits HREC – Medical) and written approval has been granted by that Committee. The study has been structured in accordance with the Declaration of Helsinki (last updated: October 2013) which deals with the recommendations guiding doctors in biomedical research involving human participants. A copy may be obtained from me should you wish to review it.

If you have any additional questions about your rights as a research participant, you should contact the University of the Witwatersrand Human Research Ethics Committee (Wits HREC - Medical) who are overseeing the conduct of this study at this clinical research centre. An Ethics Committee is an independent committee established to help protect the rights of research subjects.

If you have questions about your rights as a research participant, or problems or concerns about how you are being treated in this study, please contact:
Prof Clement Penny, Chairperson
The University of the Witwatersrand
Human Research Ethics Committee
Johannesburg
Telephone number: +27 11 717 2301

SIGNATURE PAGE

AUDIO RECORDING

Please indicate below using your initials, whether you agree to allow audio recording of your interview:

YES	**NO**
YES, I agree to allow audio recording of my interview.	NO, I do not agree to allow audio recording of my interview.
INITIALS**:**	*INITIALS:*

STATEMENT OF CONSENT

Before you sign this consent form, make sure of the following:

- You have read this informed consent form, or someone has read it to you.
- This study has been explained to you, and you had your questions answered.
- You understand you can ask more questions at any time.
- You have understood everything that has been explained to you, and you consent to participate in an interview for this research study.
- You understand that you can without prejudice withdraw your consent at any time.

Participant's Name and Surname (Print)	**Participant's Signature / Thumbprint**	**Date**	**Time**
Staff conducting consent discussion Name and Surname (Print)	**Staff Signature**	**Date (dd/mmm/yyyy)**	**Time**

APPENDIX A2: INFORMATION LEAFLET FOR INDIVIDUAL IN-DEPTH INTERVIEWS FOR PATIENTS

PROTOCOL: To explore Primary care provider and patient perspectives on barriers and enablers to cervical precancerous lesion detection in primary care clinic settings in Soweto.

VERSION: Protocol Version 1.0 dated 22 March 2022

SUPERVISORS: Prof Janan Dieterich; Dr Maureen Joffe

QUALITATIVE RESEARCH - **MASTERS STUDENT**: Ms Gugulethu Tshabalala

SPONSORS: Bristol Myers Squibb Foundation-Secure the Future and

BMSF- Multi-Sector Coalition in Implementation Research in Global Oncology (CIRGO)

INTRODUCTION

Good day, my name and surname is Gugulethu Tshabalala. I am a MSc student at the University of the Witwatersrand. I would like to invite you to take part in a research study to understand the reason why patient screen or do not screen for cervical cancer in primary care clinics. This study is currently funded by Bristol Myers Squibb Foundation-Secure the Future and BMSF-Multi-Sector Coalition in Implementation Research in Global Oncology (CIRGO). Before agreeing to take part, it is important that you read and understand the purpose of the study, the study procedures, benefits, risks, discomforts, and precautions as well as the alternative procedures that are available to you. You have the right to withdraw from the study at any time. This information leaflet is to help you to decide if you would like to participate. Please ensure that understand what is involved before you agree to take part in this study. Feel free to ask the research staff any questions you may have.

Once you understand the study and should you decide to take part, we will ask for your written consent to participate. We will also ask your written consent to record the interviews. You will receive a copy of the consent form for your records. This process is called informed consent.

WHY IS THIS STUDY BEING DONE?

We are conducting these interviews to learn the following:

- To understand the things that might help or make it difficult to pick up cervical cancer in a woman attending the primary care clinics.
- To understand how you would feel about learning about common cancers in general and how to look for signs and symptoms of common cancers in yourself with the help of a trained fieldworker

We have not invited you to be part of the interview because we think that you may have cancer however, we are eager to hear from you today to get a sense of your views and experiences in screening for cervical cancer.

WHERE WILL THE STUDY BE DONE?

We will invite patients attending local primary clinics in Soweto and Orange Farm.

HOW LONG IS STUDY PARTICIPATION AND HOW MANY PEOPLE WILL PARTICIPATE?

Participants will take part in an interview that will take 45 to 60 minutes. We would like to conduct up to 20 interviews with women (30 years and older) who routinely attend six monthly visits at the selected clinics will be invited to participate in the in-depth interviews.

WHAT DO I HAVE TO DO IF I AM IN THIS STUDY?

After signing informed consent form, you will be asked to complete a short demographics questionnaire. You will then take part in an in-depth interview. You will be asked questions about common cancers affecting women as well as what would work and would not work to encourage women to test (screen) for cervical cancer.

The interviews will be audio-recorded and the reason for this is that we want to be able to capture accurately what you were asked and what you said during the interview. We will not be able to write down everything that you say during the interviews. We will use the recording for the purposes of this study only. The recording will be typed out and if necessary, translated into English. The translation will be entered into a computer program for analysis. Only the study staff will have access to the audio recording and the transcripts, your information will be kept.

Only you as the participant and myself (the student) will be present during the interview. I will ask that you use your first name only (or fake name), not your full name and surname, to make sure that the information you provide will be private.

WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?

There are no direct benefits to the participant for taking part in the study. However, we will be able to use the information that participants will provide to make necessary contextual changes to implement the South African guidelines for common cancers in routine clinic settings.

WHAT ARE THE RISKS OF BEING IN THIS STUDY?

There are no direct risks for taking part in this study.

RIGHTS AS A PARTICIPANT IN THE STUDY

Your participation in this study is entirely voluntary and you can choose not to participate, or stop at any time, without stating any reason. Refusal to participate, or withdrawal from the study will not affect the services that you receive at the clinic in anyway. There will be no negative consequences if you decide not to take part, or if you take part and you decide at a later date you want to stop taking part.

WITHDRAWAL FROM THE STUDY

If you wish to stop participating, please tell the student. You do not have to give a reason why you want to leave the study, but any information you provide to study staff will be helpful. The investigator may also withdraw you from the study if it is considered to be in your best interest.

WHAT ABOUT CONFIDENTIALITY?

We will make an effort to keep your personal information confidential. All the information we collect for this research study will be stored in locked file cabinets and kept in secure computer files. Your name or any other identifying information about you will not be included in the transcripts. If a publication results from this study, transcripts and audio files will be kept for two years. If the findings of this study are not published, the transcripts and audio files will be kept for 6 years. No individual identities will be used in any reports or publications that may result from this study.

REIMBURSEMENT FOR PARTICIPATION

There is no cost for you to be in this study. Participants will be reimbursed with R200 to cover for your time and participation.

WHAT DO I DO IF I HAVE QUESTIONS OR PROBLEMS?

If you have questions about this study or any problems that you think may be related to this study, contact **my supervisor, Prof Janan Dietrich at Tel: 011 989 9890 or myself (Gugulethu Tshabalala on 066 266 3826)**

ETHICS APPROVAL

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (Wits HREC – Medical) and written approval has been granted by that Committee. The study has been structured in accordance with the Declaration of Helsinki (last updated: October 2013) which deals with the recommendations guiding doctors in biomedical research involving human participants. A copy may be obtained from me should you wish to review it.

If you have any additional questions about your rights as a research participant, you should contact the University of the Witwatersrand Human Research Ethics Committee (Wits HREC - Medical) who are overseeing the conduct of this study at this clinical research centre. An Ethics Committee is an independent committee established to help protect the rights of research subjects.

If you have questions about your rights as a research participant, or problems or concerns about how you are being treated in this study, please contact:
Prof Clement Penny, Chairperson
The University of the Witwatersrand
Human Research Ethics Committee
Johannesburg
Telephone number: +27 11 717 2301

APPENDIX B1: INFORMED CONSENT FORM SIGNATURE PAGE

STATEMENT OF CONSENT

Before you sign this consent form, make sure of the following:

- You have read this informed consent form, or someone has read it to you.
- This study has been explained to you, and you had your questions answered.
- You understand you can ask more questions at any time.
- You have understood everything that has been explained to you, and you consent to participate in an interview for this research study.
- You understand that you can without prejudice withdraw your consent at any time.

Participant's Name and Surname (Print)	Participant's Signature / Thumbprint	Date	Time
Staff conducting consent discussion Name and Surname (Print)	Staff Signature	Date (dd/mmm/yyyy)	Time

**For participants who are unable to read, also complete the signature block below:*

*Witness' Name and Surname (Print)	Witness' Signature	Date (dd/mmm/yyyy)	Time

**Witness is impartial and was present for the entire consent process.*

APPENDIX B2: INFORMED CONSENT FORM SIGNATURE PAGE

STATEMENT OF CONSENT

Before giving consent/agreeing to take part in the study, make sure of the following:

I agree that my participation will remain anonymous YES NO

I agree that the interview may be audio recorded YES NO

Participant's Name and Surname (Print)	**Participant's Signature**	**Date (dd/mmm/yyyy)**	**Time**
Name and Surname (Print) of Study Staff conducting consent	**Study Staff Signature**	**Date(dd/mmm/yyy)**	**Time**

**For participants who are unable to read or write, also complete the signature block below*

*** FOR ANY IMPARTIAL WITNESS** (*Please make a mark (**X**) in the box*.)

o I have received and read this Consent Form, and any other written information provided to the participant.

o I have attended all verbal discussions between the investigator/study coordinator or designee and participant about the study.

o By signing, I attest that the information provided was accurately explained to, and apparently understood by the participant and that informed consent was freely given.

# Witness' Name and Surname (Print)	Witness' Signature	Date	Time

 # Witness is impartial and was present for the consent process.

Retain original Informed Consent Form on file. Offer participant a copy. Place a copy in medical records if applicable.

***For participants who are unable to read, also complete the signature block below:**

*Witness' Name and Surname (Print)	Witness' Signature	Date (dd/mmm/yyyy)	Time

**Witness is impartial and was present for the entire consent process.*

APPENDIX C: PARTICIPANT SOCIODEMOGRAPHIC DATA COLLECTION FORM

Interview date: _____

Study ID number: Quali

Current Age: _____

Gender: Male ____ Female ____

Racial group: Black___ Asian___ Coloured ___White ___

Primary Healthcare clinic recruited from: _____

Home language: _____

Highest level of education achieved:

Informal education / some primary school only

Completed some high school education but not matric

Completed and passed matric

Completed some college or university education but do not have a diploma or degree

Have a college diploma (e.g. Nursing diploma, marketing diploma, management diploma)

Completed university education and have a basic degree (e.g. BSc, Nursing degree, MBBCh)

Completed postgraduate education (e.g. Master's degree or PhD degree)

Participant role:

Patient*

Clinic Manager

Clinic nursing sister/ nurse

Medical Officer

***For clinic patient participants only**

Your employment status

Unemployed

Piece work or temporary work

Self-employed

Fully employed (permanent job)

Was employed before but now retired

APPENDIX D1: IN-DEPTH INTERVIEW GUIDE FOR HEALTHCARE PROVIDERS

Important to note

This is a semi-structured interview guide. We may make changes in the phrasing and order of questions as interviews are conducted. New questions may also be added based on emerging interview data and to ensure that we achieve data saturation.

Introduction

Hello. My name is _____ and my colleague's name is_____. Thank you for agreeing to be part of this interview today.

In the next **45 to 60** minutes, I would like to talk with you about screening for common cancers within the South African public healthcare sector. Your complete honesty is very important as we would like to hear different perspectives. Please remember that there are no wrong answers. Your time and experiences are valuable and I want you to feel respected and comfortable. Now I'm going to turn on the audio recorder, is that OK?" Wait to hear a verbal yes

Attitudes, awareness and knowledge about COMMON cancers and early detection guidelines

Keep reassuring at each section we are genuinely getting info with no value judgement for answers provided

1. What comes to mind when you think of common cancers and their management in primary care settings?
   Tell me about your experience in dealing with common cancers in primary care settings
2. What do you know about the South African guidelines about screening for common cancers? What do they say with respect to early detection?
3. What is/are major role(s) of primary care in managing common cancers?
   How do you rate your own knowledge and training about common cancers?
4. Please share the current practice in your clinic for managing patients that come for
   - Breast symptoms e.g. lump, blood – from admin until they leave (how do they flow through your clinic) to being seen by nurse or doctor to eventual referral to tertiary.
   - Cervical symptoms (symptomatic) e.g. smelly discharge or risks (e.g. HIV+ women sexually active) to being seen by nurse or doctor to eventual referral to tertiary.

- lung symptoms e.g. persistent cough or blood in sputum to being seen by nurse or doctor to eventual referral to tertiary.
- prostate symptoms e.g. weak stream, frequent urination, pain during sex to being seen by nurse or doctor to eventual referral to tertiary.

This section we will focus on breast and prostate cancer

Breast cancer

1. What activities do you have in place to look out for early signs for breast cancer in clinic women? (Probe- If no activities: Why not? If there are activities: What is helping and what is the problems identified?)
2. Do you carry out routine screening for breast cancer symptoms? (yes: explain step by step what they do and if no: please share why screening is not done)
3. Please share the standard of practice for breast cancer symptoms screening (Probe: Do you do any screening? What does guidelines say? What is done, what is expected to be done as per guidelines)
4. What screening procedures are recommended for breast cancer screening?
5. What in your opinion makes it difficult or challenging for women to come with early breast symptoms to your clinic?
6. What are the challenges or barriers you and your colleagues experience in providing routine clinical breast examination in your clinic? (Probe: *Probe:* healthcare setting problems, patient behaviour, perceptions, resources)
7. What in your experience or opinion are the enablers to early detection of breast cancer?

Prostate cancer early screening, identification and management

1. What activities do you have in place to look out for early signs for prostate cancer among men attending your clinic? *(Probe -yes: explain step by step what they do and if no: please share why screening is not done)*
2. Do you carry out routine prostate cancer symptom screening (yes: explain step by step what they do and if no: please share why screening is not done)
3. Please share the standard of practice for prostate cancer symptom screening (Probe: What is done, what is expected to be done as per guidelines)
4. What in your opinion makes it difficult or challenging for men to come into the clinic with prostate symptoms to get a PSA test done?
5. What are the challenges or barriers you and your colleagues experience in screening men for prostate symptoms and performing PSA testing in your clinic?
6. What fears might men have in revealing their prostate symptoms to clinic nurses or doctors?
7. What in your experience /opinion are the barriers to early detection of prostate cancer?
8. What in your experience/opinion are the enablers to early detection of prostate cancer?

This section will focus on cervical and lung cancer

Lung Cancer

1. What activities do you have in place at your clinic to look out for persistent respiratory symptoms in adults? *(Probe –if there are activities: explain step by step what they do and if no activities: please share why screening is not done)*
2. Please share the standard of practice for early cancer screening for lung cancer (Probe: What is done)
3. Please share how you handle patients that have TB whose symptoms do get better on treatment or do not have TB but have a persistent cough that does not resolve?
2. What are the challenges or barriers that you or your colleagues may face in identifying patients in your clinic with symptoms that may indicate lung cancer?
3. How do you pick up/identify patients who don't get better on TB treatment or those who test negative after TB test?
4. What are the barrier to identifying patients not getting better on TB treatment and those whose who test negative for TB but have persistent cough?
5. What are the enablers to identifying patients not getting better on TB treatment and those whose who test negative for TB but have persistent cough?
6. What are the challenges or barriers that you and your colleagues identify when you realise that the symptoms might be cancer (*Probe: What process would come into place and patient flow)?*
7. What would enable you to identify that you could be dealing with a patient with a chronic respiratory disease e.g. lung cancer
8. What do you believe are the barriers to identifying early-stage lung cancer among TB negative patients and TB positive patients whose symptoms do not resolve after 2 months TB treatment?
9. What in your experience are the barriers to early detection of Lung cancer?
10. What in your experience are the enablers to early detection of Lung cancer?
11. What prevents patients with persistent cough from coming into the clinic?
12. What enables patients to come into the clinic with a persistent cough?

Cervical cancer

We now focus on cervical cancer with respect to screening and early detection- we are not talking about vaccination in schools, so ignore HPV vaccinations please

1. What activities do you have in place to look out for early signs of cervical cancer in women attending your clinic?
2. Do you carry out routine screening for cervical cancer (yes: explain step by step what they do and if no: please share why screening is not done)
3. Please share the standard of practice for early cancer screening for cervical cancer (Probe: What is done, what is expected to be done as per guidelines)
4. What screening procedures are recommended for cervical cancer screening?
5. What in your opinion makes it difficult or challenging for women to attend cervical screening in primary care clinics?
6. What are the challenges or barriers you and your colleagues experience in providing routine cervical screening in your clinic? (Probe: *Probe:* healthcare setting problems, patient behaviour, perceptions, resources)

7. What in your experience are the barriers to early detection of Cervical cancer?
8. What in your experience are the enablers to early detection of Cervical cancer?

Perception of programme, interest in learning more

1. What in your opinion is the best way to make healthcare providers aware of the guidelines for early detection of common adult cancers?
2. What is needed to implement the guidelines routinely in primary care? *(Probe: What training, support and other interventions are required to help you implement the guidelines?)*
3. What do you think about fieldworkers assisting with awareness education, symptom probing and navigation of patients for screening and referral to your clinic providers?
4. How do you think fieldworkers could add more value for cancer management in your clinic?
5. What do you think about having trained fieldworkers helping to follow up on outstanding blood and cytology results?
6. What do you think about having trained fieldworkers checking up on patients who had TB tests to see if the symptoms are getting better or not?
7. What is your referral process for TB patients not getting better?
8. What do you think about an easy-to-use electronic database to track patients and test results for screening programs?

References used for developing the guides

Lyttle NL, Stadelman K. Assessing awareness and knowledge of breast and cervical cancer among Appalachian women. Prev Chronic Dis. 2006 Oct;3(4):A125. Epub 2006 Sep 15. PMID: 16978500; PMCID: PMC1779289.

Kaninjing E, Lopez I, Nguyen J, Odedina F, Young ME. Prostate Cancer Screening Perception, Beliefs, and Practices Among Men in Bamenda, Cameroon. *Am J Mens Health*. 2018;12(5):1463-1472. doi:10.1177/1557988318768596

Grimes C, Dankovchik J, Cahn M, Warren-Mears V. American Indian and Alaska Native Cancer Patients' Perceptions of a Culturally Specific Patient Navigator Program. *J Prim Prev*. 2017;38(1-2):121-135. doi:10.1007/s10935-016-0458-z

Roth JA, Carter-Harris L, Brandzel S, Buist DSM, Wernli KJ. A qualitative study exploring patient motivations for screening for lung cancer. *PLoS One*. 2018;13(7):e0196758. Published 2018 Jul 5. doi:10.1371/journal.pone.0196758

APPENDIX D2: IN-DEPTH INTERVIEW GUIDE FOR HEALTHCARE FACILITY MANAGERS

Introduction

Hello. My name is _____ and my colleague's name is_____. Thank you for agreeing to be part of this interview today. In the next **45 to 60** minutes, I would like to talk with you screening for and management of common cancers within the South African public healthcare sector. Your complete honesty is very important as we would like to hear different perspectives. Please remember that there are no wrong answers. Your time and experiences are valuable, and I want you to feel respected and comfortable. Now I'm going to turn on the audio recorder, is that OK?" Wait to hear a verbal yes

Attitudes, awareness and knowledge about COMMON cancers and early detection guidelines in your clinic

1. How in general are common cancers detected and managed in your clinic?
2. Where does your clinic refer patients with symptoms that may be cancer?
3. Are you aware of the SA National Department of Health's screening guidelines for common cancers?
4. What are your thoughts and feelings about these guidelines?
5. What are your opinions about routine screening for early cancer symptoms in primary care clinics?

Benefits of and barriers to cancer screening in your clinic

6. What is your general impression of the level of knowledge about cancer of your clinic nurses and doctors?
7. What is your general impression of the ability of your c nurses and doctors to detect cancer symptoms in adult patients?
8. Does your clinic have the required resources (space, infrastructure and staff) to implement the cancer early detection and referral guidelines?
   If yes or no, please elaborate
9. In your opinion what are the barriers that you and your clinical staff experience in implementing these early detection guidelines?
10. In your opinion what would enable the routine implementation of these guidelines
11. What would be required to be put in place to enable routine annual screening of women aged 30 and older for cervical diagnostic testing
12. What would need to be put in place to enable routine clinical breast examination for women 40 years and older
13. What would need to be put in place to probe men 45 years and older for prostate symptoms in your clinic?
14. How do you manage TB+ patients on treatment or TB- patients *whose respiratory symptoms don't get better*?

15. How are clinical staff delegated to manage cancer and non-communicable diseases?
16. How do staff rotations help or hinder cancer management?

Motivational factors for clinic managers

1. What support from district and National DOH structures and managers would be required to implement the early detection and referral guidelines in primary acre?
2. What would be required to motivate and get buy-in from your clinical staff to routinely use the guidelines?

Perception of program, interest in learning more

1. What is the best way to make primary healthcare facility managers aware of the South African cancer early detection guidelines?
2. What is the best way to make primary healthcare providers aware of the South African cancer early detection guidelines?
3. What would motivate you to be a champion for these guidelines?
4. What do you think about assigning trained fieldworkers to your clinics to help in cancer screening activities?
5. What do you think about using an electronic database to track the patients and diagnostic tests for the screening programs?
6. What additional support would you need to implement the guidelines?

We have come to end of interview is there anything else you may wish to add

References used for developing the guides

Lyttle NL, Stadelman K. Assessing awareness and knowledge of breast and cervical cancer among Appalachian women. Prev Chronic Dis. 2006 Oct;3(4):A125. Epub 2006 Sep 15. PMID: 16978500; PMCID: PMC1779289.

Kaninjing E, Lopez I, Nguyen J, Odedina F, Young ME. Prostate Cancer Screening Perception, Beliefs, and Practices Among Men in Bamenda, Cameroon. *Am J Mens Health*. 2018;12(5):1463-1472. doi:10.1177/1557988318768596

Grimes C, Dankovchik J, Cahn M, Warren-Mears V. American Indian and Alaska Native Cancer Patients' Perceptions of a Culturally Specific Patient Navigator Program. *J Prim Prev*. 2017;38(1-2):121-135. doi:10.1007/s10935-016-0458-z

Roth JA, Carter-Harris L, Brandzel S, Buist DSM, Wernli KJ. A qualitative study exploring patient motivations for screening for lung cancer. *PLoS One*. 2018;13(7):e0196758. Published 2018 Jul 5. doi:10.1371/journal.pone.0196758

APPENDIX D3: WOMEN PATIENT INTERVIEW GUIDE

Introduction

Hello. My name is _____, I am a student at the University of the Wits and doing my Master of Science. Thank you for agreeing to be part of this interview today. In the next 45 to 60 minutes, I would like to talk with you about common cancers within the South African public healthcare sector. We would like to hear different perspectives. Please remember that there are no wrong answers. Your time and experiences are valuable, and I want you to feel respected and comfortable. Now I'm going to turn on the audio recorder, is that OK?" Wait to hear a verbal yes

Individual level

Attitudes, awareness and knowledge about cancer

- What is the first thing that you think when you hear the word *cancer*? *Probe*: what cancers have you heard of? (breast, cervix, lung and prostate cancers)
- What do you think causes cancer (Probe: God's will, witchcraft, bad luck, diet, lifestyle)
- What types of regular check-ups do you know to detect cancer?
- Now I would like to know a bit about cervical cancer. What do you know about cervical cancer (womb cancer)? (Probe: signs or symptoms)
- How is cervical cancer diagnosed?
- What do you know about a pap smear? *Probe:* frequency of exam, prevention measures
- How do you feel about being examined for womb cancer
- How is cervical cancer treated and/or managed? Probe: where do people go? Clinic/traditional healer/spiritual healer
- Have you been screened for cervical cancer?

Health seeking habits

- What is your general feelings and thoughts about preventive medicine?
- What are your thoughts and habits for consulting with traditional healers [e.g. prompts for cleansing, maintaining health, seeking help for health problems]?
- What are the social and cultural norms around consulting with traditional healers
- • How and when do you use community pharmacies?
- How and when do you use community GPs
- Do you feel your health is in your hands

Perceived susceptibility

- How at risk you are you of having cervical cancer? Probe: Why, If no: why not?
- What do you understand about early detection of cervical cancer? Probe: benefits of early detection
- What do you know about the link between viruses and cervical cancer
- Have you heard about HPV (human papillomavirus)?
- What do you know about the link between HIV and HPV?

- How often do you think you should be screened for cervical cancer?
- Have you been screened for cervical cancer before?
- What was the reason for screening for cervical cancer? (Probe: medical/personal reason)
- Can you share your experience of being screened for cervical cancer.
- How important is it for women to get a pap smear done?

Perceived benefits

- What do you think are benefits of early screening? (Pap smear)

Perceived barriers

- What are your difficulties that prevent you from going for cervical cancer screening?
- What are other woman's difficulties that prevent you from going for cervical cancer screening?
- What would help you and other women in your community to notice early signs of cervical cancer?
- If you knew and notice a symptom of cervical cancer on your body, what would you do?
- What would prevent you from going for a cervical screening (pap smear)?
- How would you feel about being screened in the community for cervical cancer signs? (Being asked sensitive questions about sexual practise and medical history)
- If they found a worrying sign, how would you feel about being referred to a clinic?

Interpersonal level

Cultural and religious beliefs

- Does your culture/religion hold any beliefs about cancer? Probe: what are they? (Probe: what is cancer known as, how is it diagnosed, what causes it, how is it treated, is there a cure for it?)
- What role does culture/religion play in your health seeking behaviour?
- How does culture impact you when making decisions about your health or treatment

Stigma

- What beliefs do people have about cancer
- What would your reaction be if you learned that a close friend/relative was diagnosed with cervical cancer?

Organisational

- Where do you usually go to seek healthcare
- What would make you decide to go to the clinic (Prompt: when you feel sick, pain or general check-up)
- Do you go to the same clinic, or do you go to different places? If different places, why?
- Can you tell me a bit about your local clinic (Probe: what is it like going there?)
- How do they feel about community clinics [quality of service and attitudes of nurses and doctors]
- What challenges do you personally experience with accessing healthcare services? (Transport, family, children, time off, relationship)
- How do healthcare providers (nurses and doctors) treat you?
- How does the treatment towards you make you feel?
- What in your opinion make women go from one clinic to the next?

Community

- Does your culture/religion hold any beliefs about cancer? Probe: what are they? (Probe: what is cancer known as, how is it diagnosed, what causes it, how is it treated, is there a cure for it?)
- What role does culture/religion play in your health seeking behaviour? (where
- How does culture impact you when making decisions about your health or treatment

Motivational factors for patients to seek help

- What are the difficulties in women talking to doctors or nurses in the clinics about symptoms that you think might be cervical cancer?
- What are the things that help in talking to doctors or nurses in the clinics?
- What do you think about being taught about harmful lifestyle habits that might cause common cancers? (Probes: do you know of any harmful lifestyle habits that might cause common cancer? Should these be taught? By whom? Would you be interested?)
- How would you feel about a nurse or doctor referring you to Bara Hospital for further cancer tests?
- What would motivate women to talk to their doctor or physician about getting a cervical cancer screening exam?

In conclusion

- What is the best way to make patients aware of the common cancers like cervical cancer that we spoke about today?
- Understanding that early-stage cervical cancer can be successfully treated, what can be done to help patients to go for screening to detect cervical cancer early?

APPENDIX E: FACULTY APPROVAL

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

15 August 2022
Person No: 1354725
PAG

Miss G Tshabalala
21222
grapefruit street
Protea Glen Ext 29
1819
South Africa

Dear Miss Gugulethu Tshabalala

Master of Science in Medicine: Approval of Title

We have pleasure in advising that your proposal entitled *Exploring primary care providers' and patients' perspectives on barriers and enablers to cervical precancerous lesion detection in primary care clinic settings in Soweto* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX F: ETHICS CLEARANCE

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO:	Ms G Tshabalala School of Clinical Medicine Department of Medicine Division of Internal Medicine Medical School University E-mail: 1354725@students.wits.ac.za
CC:	Supervisor: Professor J Dietrich and Dr M Joffe <dietrichj@phru.co.za> and <HREC-Medical Research Office@wits.ac.za>
FROM:	Mr Iain Burns Human Research Ethics Committee (Medical) Tel: 011 717 1252 E-mail: Iain.Burns@wits.ac.za
DATE:	2023/02/08
REF:	R14/49
PROTOCOL NO:	**M220901** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)
PROJECT TITLE:	*Exploring primary care providers' and patients' perspectives on barriers and enablers to cervical precancerous lesion detection in primary care clinic settings in Soweto*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

APPENDIX G: RESEARCH COMMITTEE OF JOHANNESBURG HEALTH DISTRICT APPROVAL

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Joburg
a world class African city

Research Committee of Johannesburg Health District

Enquiries: Prof S. Moosa | 0824466825 (WhatsApp) | shabir@profmoosa.com

DATE: 28th November 2022

ATT: Dr Maureen Joffe

EMAIL: mjoffe@witshealth.co.za

Dear Sir/Madam

STUDY TITLE: IICANDO: Implementing primary care interventions aimed at CANcer prevention and early DetectiOn using South African Cancer Management Guidelines

NHRD REF. NO.: GP_202102_001

OFFICIAL APPROVAL

The District Research Committee has reviewed your application. This letter serves as a final approval letter for this study.

The following conditions must be observed:

- The facilities in which the research will be conducted are listed below
- These facilities will be visited from: 2022/11/28 to 2026/03/30
- Participants' rights and confidentiality will be maintained all the time.
- Neither the District nor the facility will incur any additional cost for this study.
- No resources (Financial, material and human resources) from the above facilities will be used for the study.
- The study will comply with Publicly Financed Research and Development Act, 2008 (Act 51 of 2008) and its related Regulations.
- You will submit a copy (electronic and hard copy) of your final report. In addition, you will submit an annual progress report to the District Research Committee.
- If this is academic research then your supervisor and the University will ensure that these reports are being submitted timeously to the District Research Committee.
- The District must be acknowledged in all the reports/publications generated from the research and a copy of these reports/publications must be submitted to the District Research Committee.
- You will liaise with the manager/s listed below as relevant before initiating the study.