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Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

By

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i

"The only thing necessary for the triumph of evil (cervical cancer) is for good men to do nothing".

Edmund Burke [Emphasized]

"Whatever the mind of man can conceive and believe, it can achieve".

Napoleon Hill

"With God all things are possible"

Matthew 19:26

DECLARATION

I declare that this thesis, which I hereby submit for the degree Doctor of Philosophy in Health Systems at the University of Pretoria, School of Health Systems and Public Health, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.

Oscar Tapera

DEDICATION

I dedicate this work to my late mother, Sarah Chavhi, who was my source of inspiration and encouragement and to all women who live with cervical cancer.

ACKNOWLEDGEMENTS

ABSTRACT

Background

Cervical cancer is one the fastest growing public health challenges in low to middle income countries. About 85% of new diagnoses worldwide are reported in low-income countries and cervical cancer is the fourth cause of mortality in the same contexts. In Zimbabwe in 2018, 3186 new cases of cervical cancer were dignosed accounting for 18.2% of all new cases of cancer reported in that year. However; despite the growing burden of the disease, health systems in countries in the less developing world are too fragile to provide comprehensive treatment and care required by women who need them. This study was aimed at understanding access and utilization of cervical cancer treatment and palliative care and their associated determinants among women with the disease in Harare, Zimbabwe.

Methods

This study utilized a sequential explanatory mixed methods design, with quantitative study in the form of analytical cross sectional surveys being the major designs. Three surveys were designed and used namely; community, patient and health worker surveys. Qualitative study was used to understand deeper and explain unexpected and surprising results from the surveys. The qualitative data collection methods used in this study comprised of in-depth interviews, focus group discussions and key informant interviews. Data collection tools for the qualitative study were finalized after the analysis of results from surveys to guide the issues that needed exploration using qualitative techniques. The first step of this study was the design and validation of structured questionnaires for the three surveys. The validation process involved factor and principal component analyses to identify meaningful constructs relevant to the research questions. After obtaining the meaningful constructs, Cronbach's internal consistency coefficient analysis was conducted and constructs with coefficients ≥0.70 were retained in the questionnaires. Data collection of the surveys was conducted in communities selected through a multistage random sampling approach and treatment health facilities in Harare.

Findings

This research revealed that the designed structured questionnaires for community, patient and health worker surveys to investigate access and utilization of cervical cancer treatment and palliative care services were valid and reliable for use in surveys. This study showed that socio-demographic factors played a minor role in explaining disparities in access and uptake of cervical cancer screening treatment and palliative care in Zimbabwe. Societal and health system determinants played a major role in entrenching inequities to access and utilization of cervical cancer treatment and palliative care. Health system barriers played a key role in influencing access and usage of treatment and care among women with cervical cancer. This research further revealed that while general awareness, knowledge of risk factors, prevention and treatment of cervical cancer were relatively high, knowledge of causes remained relatively low. Utilization of cervical cancer screening and access to regular doctors were relatively high among women with cervical cancer. Some of the major barriers to access and usage of cervical cancer services identified in this study were : limited resources, limited health worker knowledge about cervical cancer, centralized services, limited physical infrastructure, limited human resources especially specialists, limited donor support and competing priorities on the part of the government. This study also revealed a myriad of model strategies that could be considered to improve access and usage of cervical cancer treatment and palliative care services.

Conclusions

This study revealed a plethora of evidence relevant to cervical cancer programme and policy development in low-income settings affected by the growing burden of cervical cancer. The consideration and implementation of the model strategies reported in this study might go a long way in addressing the majority of the impediments to access and utilization of cervical cancer treatment and care in Zimbabwe and other similar contexts. However, the success of future cervical cancer programmes is hinged on the strengthening of the National Cancer Control Programme and key strategies in the Ministry of Health and Child Care. It is proposed that this lead institution take ownership

and stewardship of policies and interventions including coordinating different partners. Furthermore, wider dissemination of relevant research, wider stakeholder engagements and collaborations and strong political will of the government is required to invest and mobilize resources to strengthen non-communicable disease interventions

Key words: Cervical cancer, Zimbabwe, equity, access, utilization, sequential explanatory mixed design, determinants, treatment, palliative care.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
CT	Computerized tomography
DHIS	District Health Information System
DNA	Deoxyribonucleic acid
FGD	Focus group discussion
FIGO	International Federation of Gynaecology and Obstetrics
GoZ	Government of Zimbabwe
HCHEC	Harare Central Hospital Ethics Committee
HIV	Human immunodeficiency virus
HPV	Human papilloma virus
JREC	Joint University of Zimbabwe and Parirenyatwa Hospital
MoHCC	Ministry of Health and Child Care
MRCZ	Medical Research Council of Zimbabwe
NCCP	National Cancer Control Programme
NGO	Non-governmental organization
NGO	Non-governmental organization
PSI	Population Services International
REC	Research Ethics Committee
SD	Standard Deviation
SSA	Sub-Saharan Africa
TB	Tuberculosis
UN	United Nations

VIAC   Visual inspection with acetic acid cervicography

WHO   World Health Organization

ZDHS   Zimbabwe Demographic and Health Survey

DEFINITION OF KEY TERMS

Cervical cancer treatment: medication or procedures performed to cure, to prolong useful life and improve the quality of life of cervical cancer patients[2].

Palliative care: Also known as **supportive, hospice or terminal care** are defined by WHO as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual[2, 55].

Equity in health refers to the absence of systematic disparities in health (or major social determinants of health) between groups with different levels of underlying social advantage/disadvantage-that is, wealth, power or prestige[45].

Inequity can be described as those inequalities that are unfair and it systematically puts groups of people who are already socially disadvantaged (for example, by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic or religious group) at further disadvantage with respect to health.[45]

Focus group discussion is defined as a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment. [89]

Key informant interview involve interviewing a select group of individuals who are likely to provide needed information, ideas, and inshights on a particular subject.[83]

In-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation.[90]

Face-to-face interview or one-on-one interview is a data collection method when the interviewer directly communicates with the respondent in accordance with the prepared questionnaire.[91]

CHAPTER ONE

1.0 GENERAL INTRODUCTION

1.1 Introduction

Cervical cancer is a major public health problem because it is a cause of high morbidity and mortality amongst women in Zimbabwe. It is the most common type of cancer among black women and accounts for 18.2% of all cancers. Recent statistics estimate the cumulative risk among black women to be about 6.73%, age-adjusted incidence to be about 43.1% and mortility to be about 20%.[1] The majority of cases of cancer (87%) present clinically at advanced stages (3 and 4) and these are associated with low survival rates and high mortality rates due to limited access to early detection and treatment.[2]

Zimbabwe is recovering from one of the most devastating politico-social and macroeconomic crises which peaked in 2008 and which resulted in weakened health services delivery countrywide due to limited financial resources and mass exodus of health professionals to other countries.[3] This situation impacted negatively on distribution of health services and human resources especially specialist doctors particularly in public sector health facilities at a time when cervical cancer has become a serious public health challenge. The Government of Zimbabwe (GoZ) adopted the multicurrency regime (MCR) in February of 2009 to usher in a new economic dispensation meant to address a massive economic crisis. The multicurrency regime addressed hyperinflation and stabilized the economy thereby allowing both the public and private sector the opportunity of engaging in medium to long term planning.[4] The MCR addressed deterioration of social services such as healthcare by stabilizing medical costs and health insurance financing.[4] Mass exodus of health professionals from the country, high medical costs and poor performance of health insurance financing prior to 2009 were barriers to access and utilization of health services. In addition it also created health inequities in the country.[5] It is not clear how the

macroeconomic environment has influenced access and uptake of treatment and palliative care by cervical cancer patients.

Prevention of cervical cancer

Cervical cancer prevention, screening and treatment of pre-cancerous lesions have been evaluated in many countries with good results. These secondary interventions were faced with several challenges some of which have remained unresolved and failing to increase service coverage particularly in developed countries. However, there have been serious commitments to address some of the barriers to access and uptake of cervical cancer preventive services [8, 9-12].

Chidyaonga-Maseko et al[9] in their Malawi study noted individual, societal and health system barriers to access of health promotion, awareness and screening services. The use of Pap smear for screening women for cervical pre-cancer has been practiced since 1940s; however, due to relative low sensitivity and requirements for infrastructure and technical staff it may not be available in developing countries.[9] Recent studies have demonstrated the usefulness of visual inspection with acetic acid cervicography (VIAC) and human papilloma virus (HPV) DNA tests for screening women at risk of cervical cancer in developing countries.[10,11]. Ebuet al[27] in their Ghana study reported institutional and personal factors as barriers which needs addressing to improve access to cervical cancer screening. In a Rwandan study by Binagwahoet al[28] it was reported that integration of cervical services with women health services was crucial. They also reported that political will, cross-sectoral collaborations, adequate planning, innovative partnerships and robust monitoring and evaluation systems were imperative to achieve high nationwide coverage of HPV vaccination and screening for cervical cancer within a short space of time.[28] The integration of cervical cancer screening within HIV/AIDS and family planning programmes is a fairly recent development in Zimbabwe and it has led to some improvements in service provision.[8] These organized screening programmes have been reported as having a greater potential for participation and improving equity in access to services.[12] However, there remains a huge gap of engaging diagnosed cervical cancer patients into treatment and care programmes in Zimbabwe mostly due to centralized services.

The World Health Organisation (WHO) recommended target group for HPV vaccination are 9 – 13 year old girls who have not yet become sexually active[6]. In 2014 – 2015, Zimbabwe piloted the HPV vaccine in 3 districts with great success. This national scale up is targeting girls aged 10 – 14 and will subsequently be vaccinating girls in Grade 5 in or out of school from May, 2019. Vaccinations will take place at schools, hospitals and clinics countrywide. Girls, who will have missed the vaccination during the campaign, can get vaccinated at clinics. About 888,826 girls were targeted by the end of May 2018. The HPV vaccine is a safe and effective vaccine that presents exciting opportunities for public health in the longer term. High HPV vaccine coverage will reduce the economic and human costs of cervical cancer in the long term. The benefits of the vaccine are realized years after the young girls have been vaccinated.[92] However; the organization of these preventive interventions for these young females at school going level in Zimbabwe could be further strengthened to achieve universal coverage for optimal health outcomes.

1.1.1 Access and utilization of cervical cancer treatment and palliation services

Global overview

Over the years, surgery, radiotherapy and chemotherapy have been used either singly or in combination to treat cervical cancer and the resultant survival and patterns of failure have led to the development of safer and effective protocols.[16] In a Canadian systematic review by van Lonkhuijzen & Thomas[17] it was noted that the choice of curative versus palliative radiotherapy for advanced cervical cancer in resource-limited settings was influenced by factors such as patient co-morbidities, availability of and distance from a treatment centre and local resources. In an US study researchers found that utilization of adjunct chemotherapy for high risk cervical cancer was associated with patient's age, race and pathologic risk factors.[18] In yet another US study, it was found that in resource poor contexts, lack of skilled medical staff, radiation equipment, lodging facilities and lack of access to care limit the use of curative radiation treatment.[19] Dreyer[20] noted that clinical, histological and radiological assessments of cervical cancer using international guidelines such as International Federation of Gynaecology and Obstetrics (FIGO) were crucial to determine the treatment option of each patient. Advanced stage presentation and gaps in prevention, screening and treatment

capacities contribute to high mortality of cervical cancer in sub-Saharan Africa.[21] Limited human resources and infrastructure have also been noted as barriers to comprehensive cervical cancer care in poor countries. However, the use of cost effective interventions can help reduce the morbidity and mortality associated with cervical cancer in these settings.[21]

Overview of Africa

The incidence of cervical cancer has been reported to vary by region, with Eastern and Southern parts of Africa carrying the largest burden.[31] Despite the fact that cervical cancer is preventable through early detection and treatment, most sub-Saharan countries' health systems are weak such that most cases are presented in late stages (FIGO stage III and IV) which are often untreatable and only suitable for palliative care.[16] The pursuit of equity in health and healthcare services is a key feature of health policy in developing countries but cervical cancer treatment service equity in access is still largely unknown. Cervical cancer is a complex condition which requires continuum of care and comprehensive programmes to improve health outcomes, which are also dependent on the stage of the cancer. The presentation of late stage cancer is influenced by access and utilization patterns of preventive or screening services in health facilities.[2, 14] Moreover, strategies for introducing and strengthening cervical cancer prevention and control programs must focus on appropriate and cost effective services which are available to women who need and use them. Without ensuring these goals are achieved, the universal coverage required to reduce the overall disease burden may not be realised.[32, 33]

According to the health behaviour model by Andersen and Newman,[34, 35] societal, health system and individual factors influence utilization of health services. These factors include need factors, predisposing factors or also referred to as social differentials (e.g education, gender, ethnicity, age) and enabling factors (e.g health insurance, income, health personnel). All these factors that influence access and utilization of cervical cancer treatment and palliation services cannot be ignored and identifying critical barriers and strengthening systems to improve access and utilization is paramount in developing countries.[27, 33]

Overview of Zimbabwe

Cervical cancer treatment and care which entail services such as surgery, radio-and chemotherapy as well as palliative care are still largely underdeveloped in Zimbabwe.[2,14]These services are largely centralized, which presents access and utilization challenges for the patients. In the centralized public sector institutions treatment costs are exorbitant and the referral systems are too weak to afford women with locally advanced cervical cancer access to high level of care.[2] Limited and centralized treatment and care services for cervical cancer patients has promoted medical tourism to countries such as South Africa, India, China and Europe by the affluent members of society. This has a negative impact on perceptions, acceptance and utilization of health services in the country which in turn entrenches inequities.[15] However, high level of quality research is lacking to evaluate treatment outcomes hence optimal treatment remains unknown.[29]

In 2000, Chirenje and colleagues[7] reported that 77% of women diagnosed with cervical cancer (1995-1997) were engaged into treatment using radiotherapy. No recent data exists on the proportions of women with confirmed cervical cancer who engage into treatment and care. While knowledge about the disease, its risk factors and screening programmes has improved over the past few years a huge information gap exists about treatment and palliative care interventions in the country. Fallala & Mash[8] in their Bulawayo, Zimbabwe study noted that of the 10.8% women who tested positive to VIAC, 61.1% received immediate treatment while 38.9% were either delayed or referred to a gynaecologist. There is no evidence of a system to follow-up on these 38.9% to ensure that they received treatment and care. Lack of a system to follow-up patients predisposes women to high risk of late stage disease presentation which is associated with increased morbidity and mortality in developing countries like Zimbabwe.[2] The provision of treatment and palliative care services is still very limited in the country. Several factors were noted by Pomerai and colleagues[6] to influence knowledge about cervical cancer. These include lack of prioritization of the disease by health workers and Ministry of Health and Child Care (MoHCC), lack of a clear case definition of the disease as well as limited funding from global donors. This doctoral research study is

envisaged to cover the gap by answering some key questions and setting a foundation for further research in cervical cancer treatment and palliative care in Zimbabwe.

Palliation services

Palliative care has been defined by the World Health Organization (WHO) as an approach meant to improve the quality of life of patients and their families from the effects of life threatening illnesses through the prevention and relief of pain and other problems which are psychosocial, physical and spiritual. This approach of care is required from the early stages of the disease and is usually provided in conjunction with other therapies such as chemo and radiotherapy and those investigations aimed at understanding the distressing clinical complications.[22] Palliative care has been shown to improve patient outcomes including mortality when integrated with disease-modifying therapy.[23]

In a US pilot study by Nevadunsky and colleagues[24] the researchers in their findings argued that palliative care also known as end-of-life care for patients with gynaecological cancers included futile, aggressive treatments and invasive procedures whose impact on longevity and quality of life were unknown. In the US the cost of palliative care have been rising significantly and as a matter of fact it has become a national policy priority with studies showing that integrating palliative care within the oncology services would be cost effective, has a positive impact on quality of life, patient satisfaction and better outcomes for the healthcare systems. The researchers recommended that specialists be trained in palliative care medicine in order to deal effectively with cases of terminal illness.[24]In a report by Coleman and colleagues[25] it was noted the psychosocial support has become very crucial to oncology care services and they recommended to European countries to integrate psychosocial support services and evaluations within routine oncology care for patients and their families. This should be done for all disease stages and survivorships as part of regular standard care. "Quality-of-life assessments" should be routinely included in cancer care settings, as a standardized way to estimate patients' needs, to inform treatment options and to monitor the quality of care. A biopsychosocial and patient-centred approach should be implemented in routine cancer clinical care in order to attain optimal results" says the

report.[25] This demonstrates the commitment of the developed world to improve palliative care and to integrate it early in the treatment and care continuum.

Mishra[26] noted that palliative care in India was very important for cervical cancer due to late diagnosis and presentation of cases which left palliative care as the main option of treatment. It was also noted that in developing countries palliative care is feasible as it requires less material resources and should be implemented within routine care. High rates of advanced disease, treatment failures, side-effects and recurrence due to poor follow-up are amongst other barriers to the adoption of palliative care approach within routine oncology care.[26] Herce and colleagues[23] in their rural Malawi study noted that palliative care integrated with routine treatment of HIV/AIDS, cancer and other serious chronic diseases was an important strategy for increasing access to the services as well as improving quality of health care outcomes. Regardless of the vast amount of information on the benefits and non-requirement of material resources, access to integrated palliative care remains limited in most developing countries at a time the global burden of chronic disease is growing unabatedly.[23] In sub-Saharan Africa (SSA) palliative care remains very limited with only 5% of those who need it accessing it despite some efforts to integrate it with routine treatment care programmes[23]. Qualitative research studies in SSA have shown that the greatest need of patients and their carers may be psychosocial, with basic socioeconomic necessities such as food, adequate shelter, school fees featuring as prominent needs[23-25]. There is little information on palliative care needs, knowledge and preferences in developing countries. In Zimbabwe not much is known about access and utilization of palliative care by cervical cancer patients. At the national level, some strides have been made and these include: integration of palliative care in the health system, mass activism for palliative care to be part of the National Health Strategy and adoption of some standard guidelines which are already in use. However, the country lacks a finalized and implemented palliative care policy which is the bedrock of any sustainable intervention.[2] Furthermore, the integration of palliative care with disease-modifying therapy for cervical cancer has not been evaluated in Zimbabwe. This study will investigate some of the issues and factors that influence access and use of palliative care by cervical cancer patients in Harare.

1.1.2 Social issues related to cervical cancer treatment

Social factors such as ethnicity were noted to influence equity in access of health services in a study of Arab countries by Kronfol[36]. Ethnic minorities are more vulnerable hence may be disenfranchised through professionals' views on suitability of people for treatment. Racism in public spaces may also pose an important barrier to accessing services.[36] Religion is another factor that plays an important role in health as noted in Arab countries and it influences certain specific health practices such as male and female circumcision, the practice of medicine and litigation.[36]

In Australia, up to 61.5% of cancer patients use alternative and complementary medicines during cancer treatment.[39] In Turkey, the use of traditional medicines amongst cancer patients ranged from 54.5% to 61%.[40, 41] In a Ugandan study, Mwaka and colleagues[38] noted that the use traditional medicines to treat cervical cancer had become popular among women due to barriers to modern biomedical care. Barriers to biomedical care and community beliefs of the effectiveness of traditional medicines were noted to encourage use of traditional medicines for cervical cancer treatment.[38] In some qualitative studies in South Africa and Ethiopia lay people have been noted to prefer traditional medicines for the treatment of cervical cancer.[42, 43] In Zimbabwe, while the use of traditional medicines for the treatment of many ailments has been reported,[44] little is known regarding treatment of cervical cancer using traditional medicines.

1.1.3 Health Equity concept

Health equity is related to service coverage which depends on the ability of the health service to interact with its target population, that is, the ability to transform the intention to serve people into providing a successful intervention for their health. Coverage, which can be defined as proportion of the target population that can receive or have received, the service, is a function of a variety of factors such as availability of resources including human resources, distribution of facilities, supply logistics, and the people's attributes to health and healthcare.[47] Addressing inequities in access to health services is a crucial step in the pathway to achieving universal health coverage. The relationship between service capacity and output defines service utilization and is a key health service attribute.[47]

Equity analysis can be carried out utilizing the WHO Priority public health conditions analytical framework, which has five levels namely: socioeconomic context and position, differential exposure, differential vulnerability, differential health outcomes and differential consequences.[48] Health equity analysis involves comparing mortality and morbidity outcomes for different subgroups. Equity concerns are mostly presented in terms of differences in socioeconomic status, though other differentials such as gender, age, ethnicity, education levels, occupation and geographical location are important to understand.[49] There are several methods to measure equity (horizontal and vertical) in health however rate differences or odds ratio from multivariate analyses were used in this study.[50] The unit of analysis for this study was the individual.

1.1.4 Cancer policies in Zimbabwe

In Zimbabwe, the Ministry of Health and Child Care is responsible for developing and rolling out policies and strategies that provide a guiding framework for health related interventions. In 2013, the MoHCC rolled out the National Cancer Prevention and Control Strategy (2013-2017) to provide guidance to all cancer related programmes in the country. However, the strategy outlined Equity as its number one guiding principle, yet the policy does not indicate measures meant to ensure equity in access of cancer preventive and control measures.[15] Another recent policy, the Zimbabwe Cervical cancer prevention and control strategy (2016-2020) also outlined equity as a key guiding principle to ensure equitable distribution of cervical cancer prevention and treatment services.[51] The main component of a health policy should include political, economic, social and cultural determinants of health in any country. Lifestyle, socializing and empowering determinants are also crucial with the latter linking individual and collective interventions.[52]

Health policies in Zimbabwe outline equity in access and distribution of healthcare services but do not mention components of health policies as reported by Navarro.[52] None of the current national cervical cancer policies indicate key determinants of equity in access, later provide mechanisms of addressing known barriers to access. Understanding that cervical cancer occurs in a complex social, political, cultural, environmental and economic context is critical in investigating the possible barriers and

promoters of access and utilization of treatment and palliation services.[53] Recent evidence from global studies suggests inequalities in access to and use of cancer care persist up until death.[38] Studies of palliative care use have concluded that older patients are less likely to receive these services compared to their younger counterparts.[54, 55] In Zimbabwe, inequities to healthcare access and utilization entrenched by age, social class, income, occupation, ethnicity, gender and place of residence are well documented.[56] However, there is a knowledge gap regarding inequities in access and uptake of cervical cancer treatment and palliation services in the country.

1.2 Rationale of the study

While several studies have been conducted on equity and factors influencing access and utilization of health services in general, not much research has been conducted in the area of cervical cancer treatment and palliation services. Zimbabwe has gone through major economic shifts over the past couple of years mainly the adoption of multicurrency regime[4,5] yet no research has been conducted to access the implications of this financial changes on access and utilization of cervical cancer treatment. Hence, this present research endeavor was identified to understand the pertinent issues related to treatment and palliative care of cervical cancer patients. Cervical cancer preventive services (screening and HPV vaccination) have been scaled-up recently in Zimbabwe and some studies have been conducted to assess patient access and utilization[58,71]. However, cervical cancer treatment and palliation services remain an under researched area in developing countries.

This present study was aimed at ultimately culminating in a model strategy to address individual, societal and health system barriers for cervical cancer treatment and palliation services in Zimbabwe. The few studies that have been conducted on cervical cancer treatment in developing countries have reported barriers to access and utilization[6,8,9,14] and not many have gone to the depth of developing contextually relevant model strategies to address the challenges. This study was therefore envisaged to take a further step to come up with strategies that may be used in programme improvement, policy and advocacy to improve access and utilization of cervical cancer treatment services in developing country contexts.

As a public health researcher with interests in emerging non-communicable diseases, the doctoral student visualizes that this study be aimed at contributing significantly to the understanding of one the most challenging diseases in Zimbabwe. This study was envisaged to initiate and lead to the development of skills in research, scientific publications, policy analysis and development of contextually relevant model strategies to solve contemporary health problems. The research was conducted to contribute to the fulfilment of researcher's career objective of developing evidence-based and sustainable public health services in developing countries and in particular for Zimbabwe.

1.3 Problem statement

Cervical cancer is a complex condition which requires integrated approaches to ensure adequate and equitable distribution of both preventive and curative services.[30] Zimbabwe has a female population aged 15-49 years of about 5 million who are at risk of developing cervical cancer.[2,59] Cervical cancer is a major cause of morbidity and mortality among women in the country with about 3,186 new cases having been diagnosed in 2018 with an estimated mortality rate of 20% from the condition. [1] Recent statistics indicate that cervical cancer is the most frequent cancer amongst women and the 2nd most frequent cancer amongst women aged 15-44 years. About 80% of cervical cancer cases are presented in late stages (IIB-IIIB) which are associated with poor prognosis and high mortality, yet this disease is preventable through health promotion, awareness, early screening and diagnosis, treatment and care.[6, 57] Despite the huge burden of cervical cancer and some notable efforts to improve screening services across the country, treatment and palliation care coverage remains very low.

In 2000, Chirenje and colleagues reported that about 77% of cervical cancer patients were engaged into treatment. Statistics from 2002-2003 WHO survey indicated screening coverage rate of 9.4% amongst women aged 25-64 years within 3 years.[57] Recent data from the Zimbabwe Demographic and Health survey revealed a cervical cancer screening coverage of 24% in Harare.[58] Opportunistic and organized cervical cancer preventive programmes are vaguely understood in Zimbabwe. Not much data on the proportions of patients with cervical cancer engaged into treatment and care has

been published publicly in Zimbabwe. Little is known on the pathway from diagnosis to actual engagement into treatment and care yet a myriad of studies have demonstrated poor survival for those with advanced disease.[2, 14, 26] While knowledge capital and institutional memory of HIV/AIDS, tuberculosis, malaria and more recently of cervical cancer screening interventions is a good starting point, understanding individual, societal and health systems factors that influence access and utilization of cervical cancer treatment and palliation care remains crucial.[2, 14, 26] This forms the basis of understanding the equity dimensions peculiar to cervical cancer as one of the leading public health challenges in Zimbabwe.[18, 57] Improving health outcomes is a policy agenda of any government and international organizations such as WHO and UN and as such without evidence to guide these policies, little or no progress can be realized in the Sustainable Development Goals' era.

The National Cancer Control Strategy was launched in 2013 to expand cancer prevention and control services in the country.[30] The Zimbabwe Cervical cancer prevention and control strategy (2016-2020) was recently finalized. Presently, cervical cancer treatment and palliative care services are largely centralized in major cities even though most women still live in the rural areas.[59] Regardless of the limited fiscal space the government of Zimbabwe is experiencing[60], cervical cancer treatment and care can be strengthened to reach the affected women across the country given the infrastructural improvements and programmatic knowledge capital from HIV/AIDS, TB, malaria and cervical cancer screening interventions. Furthermore, the government has demonstrated significant political will to improve the health of the people judging from the policies that have been implemented. In a recent review study of Europe and USA, it was reported that there exists a non-linear relationship between cancer outcomes and expenditure, citing other factors such as lifestyle as determinants of outcomes.[61] This doctoral research study was envisaged to provide evidence on the factors that leads to poor access and uptake of cervical cancer treatment and palliative care services in the Zimbabwean context. An optimal process of cancer care delivery consists of the use of new and existing diagnostic tests and treatment strategies of high quality and is effective, safe, patient centred, efficient and timely. Such a health system is highly recommended and all stakeholders in society will benefit.[30, 61]

Moreover, the macroeconomic dynamics partly associated with multicurrency regime resulted in freezing of posts in the public sector.[5, 60] The distribution of healthcare workers and facilities influences health service access and delivery and this is associated with socioeconomic characteristics of populations.[14]This has negative implications on cervical cancer service delivery as human resources are crucial in improving access and utilization of healthcare services.[61] The majority of women (52%) in Zimbabwe live in rural areas[59] and to date, little data exist on the factors associated with their access and usage of cervical cancer treatment and palliation services. The quality of services provided in healthcare institutions is to a great extent influenced by the motivation of healthcare providers.[62]

Ten percent of Zimbabweans are members of private medical aid schemes and this means that 90% of the population relies on out-of-pocket financing which has impoverishing consequences on the population which further reduces access to health care.[63] Therefore, health financing patterns is another probable source of inequity to cervical cancer services, though the extent of their influence is still not known in the context of Zimbabwe. This present study endeavoured to investigate determinants of access and utilization of cervical cancer treatment and of palliative care services, using the case of urban and rural Harare to provide evidence that can be used in policy formulation.

Cervical cancer is a condition which currently faces stigmatization and as such health education programmes targeted at communities are crucial to improve awareness in the country. Recent data reported shows that while 79% of women aged 15-49 years had heard about cervical cancer, only 13% has had a screening examination in Zimbabwe.[58] While generally cervical cancer awareness has improved over the past few years, there remain some unquantified barriers to accessing and utilizing cervical cancer treatment and care services across the country. Effective treatment and care programmes are also not possible without the support of political, traditional and other community leaders. The success that has been realized in combating HIV/AIDS can be attributed in part to the engagement of all stakeholders to promote awareness which in turn influence health seeking behaviours.[64] There are advantages of a holistic intersectoral

approach with regards to cervical cancer which includes improved awareness which can lead to de-stigmatization of sufferers, social support, behaviour change and early health seeking behaviours. However, such an approach requires significant resources which may require external donor funding, though sustainability challenges are probable in cases of global economic downturns.

Holistic approaches may also take some time to produce noticeable impact in the country at a time cervical cancer is becoming a major public health challenge. Scarcity of the information prevails on the level of awareness and support key community leadership has on cervical cancer treatment and palliative care. In Zimbabwe, Island Hospice is the pioneer in palliative care in the African continent and they have contributed significantly to the development and provision of palliative care in the country[31]. However, their efforts are challenged due to limited resources and recently they started piloting the integration of palliative care into oncology in collaboration with Ministry of Health and WHO. Literature on palliative care has also revealed some myths and misconceptions about approach and this has led to stigmatization in some African settings[23-25]. Specific advocacy work to raise cervical cancer treatment and care awareness at community level starting with the local and traditional leadership such as headmen, councilors, traditional healers and chiefs cannot be underestimated. Studies have shown the relationship between social support and health outcomes[65-67], though limited information exists regarding cervical cancer in Zimbabwe. While the integration of cervical cancer screening with reproductive health and HIV/AIDS programmes is imperative[2], treatment and palliative care services for cervical cancer are complex, hence existing programmes need to be investigated to establish synergistic linkages for optimal implementation and ultimately improve health outcomes.

1.4 Problem Justification

With reference to the background and problem statement, it is clear there are a myriad of grey areas regarding the determinants of access and utilization of cervical cancer treatment and palliative care services in Zimbabwe. The country has been going through numerous macroeconomic challenges for a couple of years now and this has generally negatively affected health service delivery and access to crucial health

services. How this has impacted on access and utilization of cervical cancer treatment and palliative care services across the country is largely unknown.

Some studies have found no relationships between cancer outcomes and health expenditure, citing societal and individual factors as prominent determinants.[53, 61]Hence, it is critical that in developing countries like Zimbabwe, substantial evidence be gathered on these factors that influence access and utilization of cervical cancer treatment and palliative care services to be later utilized to effectively inform health policy. The adoption of the multicurrency system in 2009 negatively affected health service access and utilization in Zimbabwe. Rising of costs of healthcare services and medicines which are mostly imported and the de-regulation of fees charged by specialist doctors are some of the potential causes of inequity in health service access. The impact of the multicurrency system on access and utilization of cervical cancer treatment and palliation services are vaguely understood. While the multicurrency regime stabilized and curbed hyperinflation, government austerity measures which resulted in freezing of posts including those of health professionals has had an influence on access and utilization of services particularly in public sector health institutions. Lack of resources due to economic challenges has also resulted in less capital expenditure in healthcare infrastructure, which is crucial in improving access and utilization.[2, 14, 60]In addition, due to limited resources, wealthy citizens have been accessing cervical cancer treatment services outside the country and it is unclear how this practice of medical tourism has been impacting local service development.

As one of the leading public health challenges in Zimbabwe, cervical cancer has been studied but some of this research have not added value to the diagnosis and management of the disease. The association of cervical cancer and HIV/AIDS also complicates the perceptions, beliefs and attitudes of people which in turn influence their health seeking behaviours, treatment and palliative care services. Opinion leaders such as traditional leaders, politicians, musicians and other community leaders play a significant role in influencing health seeking behaviour of people.[64]However, there is no information on how they have impacted or may impact cervical cancer treatment and palliative care services in Zimbabwe.

This study endeavoured to address the above knowledge gaps and clarify some of the scientific contestations related to cervical cancer treatment and palliative care services. The study was aimed at elucidating new information for planning to policy makers, health professionals, the donor community and the Ministry of Health and Child Care. In addition the study was aimed to provide information to academics and researchers on the determinants of equity in access and utilization of cervical cancer treatment and palliative care services in the country. This study was planned to assist in the understanding of equity in access and utilization of cervical cancer treatment and care. The study also investigated the current service responses in Harare to understand the gaps and limitations of programmes in addressing inequities in access and utilization of cervical cancer treatment and palliative care services. No study to date has been carried out in Harare to investigate the determinants of access and utilization of cervical cancer treatment and palliative care. Harare was the chosen setting for this study because cervical cancer services are relatively more available compared to other places in the country. The city is also faced with an increasing burden of cervical cancer diseases against a background of limited resources.[68]

1.5 Research Objectives

1.5.1 Primary objective
The overall aim of this study was to investigate equity in access and utilization of cervical cancer treatment and palliative care services amongst women aged at least 25 years in Harare.

1.5.2 Secondary objectives:
I.   To investigate individual, societal and health system determinants of access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

II. To investigate health system barriers impacting access and utilization of cervical cancer treatment and palliative care services in Zimbabwe.

III. To investigate model strategies that could be used to address individual, societal and health system barriers to cervical cancer treatment and palliative interventions.

1.5.3 Research Questions

i. What are the equities in access and utilization of cervical cancer treatment and palliative care services amongst women aged at least 25 years old in Harare, Zimbabwe?

ii. What are the individual, societal and health system determinants of access and utilization of cervical cancer treatment and palliative care services amongst women aged at least 25 years in Harare?

iii. How does the healtn system impede access to and utilization of cervical cancer treatment and palliative care services in Zimbabwe?

iv. How can model strategies to address barriers to cervical cancer treatment and palliative care be developed?

1.6 Theoretical Framework

This study was guided by the Andersen-Newman behavioral model of health service utilization. The theory postulates that access and utilization of health services are determined by individual, societal and health system factors.[34, 35] Health behaviours, such as obtaining access to cancer and other medical services, are complex and multifaceted.[14]This model is a conceptual basis for understanding human behaviour especially patient-physician interactions.[72] The theory not only examines individual behaviours but extends to public health resources.[34] This theoretical model was relevant to the investigation of equity in access and utilization of cervical cancer because recent iterations of this theoretical framework examine psychosocial factors as they describe attitudes toward healthcare providers as well as beliefs about the healthcare system.[34] Using this model predisposing factors (e.g education, occupation, and social networks), enabling factors (e.g income, health insurance and health personnel) and need factors (perceived and evaluated) were investigated to determine the barriers and facilitators of access and utilization of cervical cancer treatment and palliation services in Harare (See Figure 1.1 and 1.2) Access is defined as the means through which patients gain entry into the health system and continue with the treatment process. Utilization according to Andersen and Newman[34] can be characterized by the purpose; primary care has to do with stopping the illness before it starts, secondary care has to do with the treating of the illness to return the patient to original functional state. Tertiary care utilization refers

to the stabilization of long-term irreversible illness and palliative care refers to the provision of personal needs to a patient without doing anything for the underlying illness. This study focused on the secondary, tertiary and palliative care among women with cervical cancer.
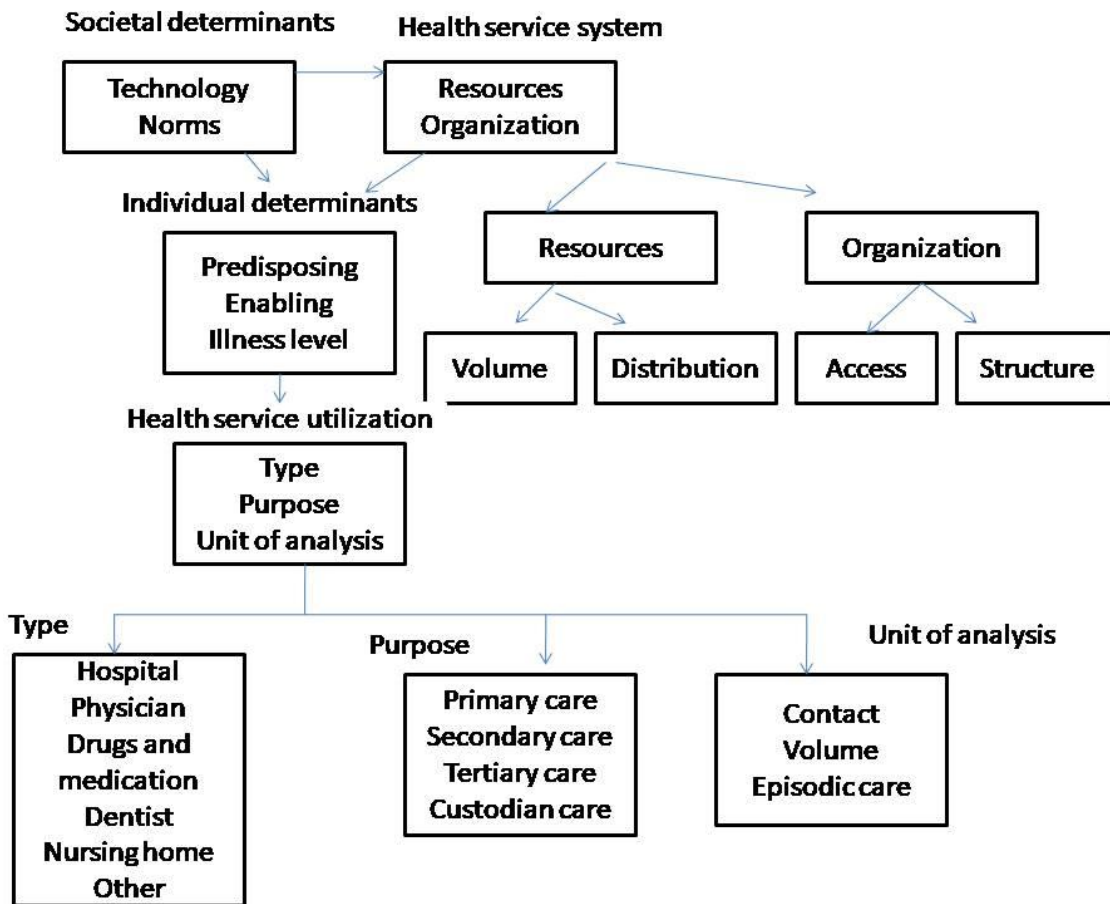
Figure 1.1: Andersen-Newman model of health service utilization[34]
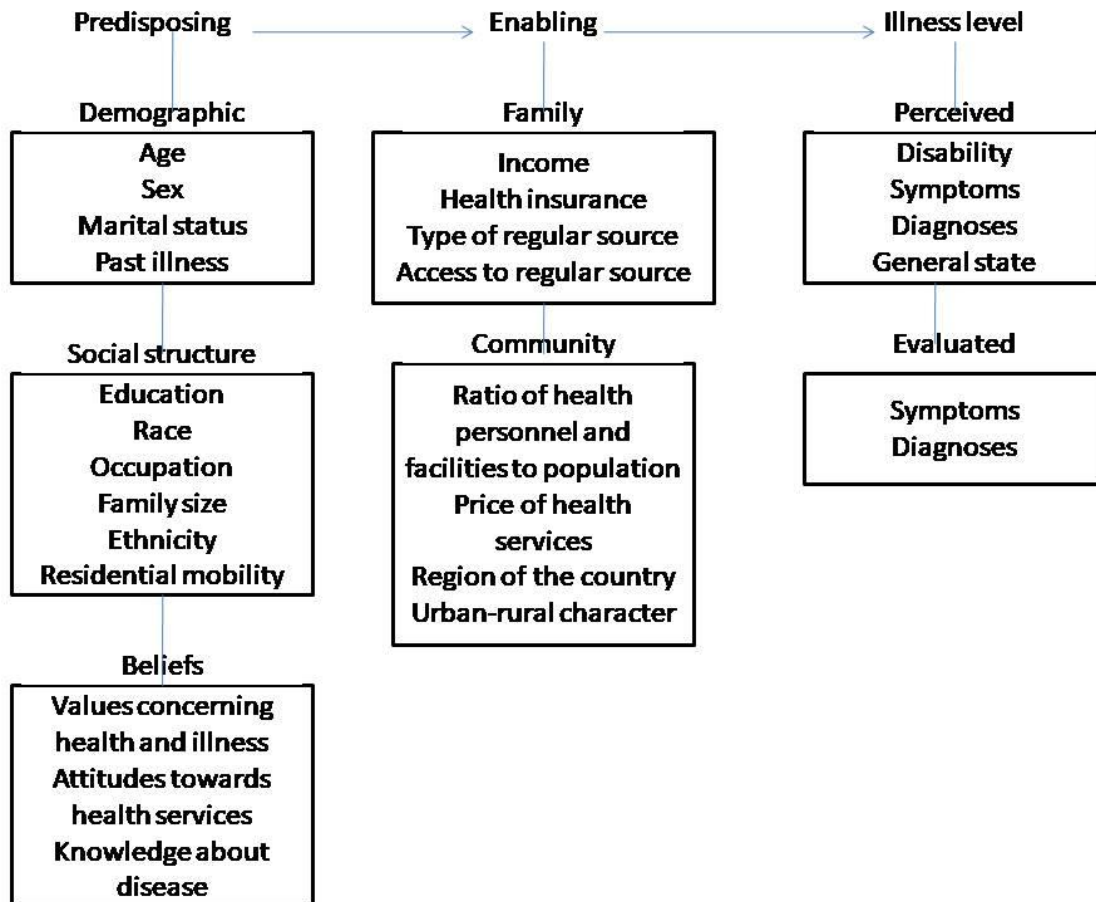
Figure 1.2: Individual determinants of health service utilization (Andersen-Newman Model) [34]

1.7 Methods

1.7.1 Research Designs

This study used a sequential explanatory mixed methods design of both quantitative and qualitative research methods to generate evidence. The priority of the design was on quantitative study and implementation was in a sequential manner (QUAN ⟶ qual) (see Figure 1.3). This design is characterized by collection and analysis of quantitative data followed by the collection and analysis of qualitative data with integration of the two methods at the interpretation phase of the study. The primary purpose of the sequential explanatory design was to use qualitative results to assist in interpreting and explaining the findings of a primarily quantitative study[34]. This study had two distinct phases, that is, phase 1(quantitative) and phase 2 (qualitative) (Figure 1.2).

Quantitative research involves the collection of data to quantify information and to statistically treat the information to support or refute alternate knowledge claims. Qualitative research is concerned with the subjective assessment of attitudes, opinions and behaviour.[74] Mixed methods have been argued to increase credibility of the research findings. Some scholars argue about the relevance of mixed methods in studying phenomena due to the differences in epistemological and ontological underpinnings of qualitative and quantitative research methods[34,74] However, both paradigms are meant to understand a phenomenon of interest and hence their application in a single study is beneficial for balanced research findings. The use of qualitative and quantitative methods has the tendency to neutralize the flaws of one method and increasing the benefit of another method. Hussein[75], also argued that it increases the credibility of research findings by increasing internal consistency and generalizability of the research outputs. Mixed methods are also a stronger research approach if conclusions are to matter in its application in practice.[74, 75] Qualitative methods are subjective and have limited verifiability, though they are crucial in understanding underlying issues such as barriers to cervical cancer treatment and palliative care access. Understanding deeper issues such as social, political, environmental and health system factors associated with cervical cancer treatment and palliative care services' uptake is more beneficial with qualitative techniques. On the other hand, though quantitative methods cannot determine perceptions, beliefs and assumptions, they can be done quickly relative to qualitative methods. Quantitative methods also enable the researcher to compare groups and organizations as well as allowing the measurement of degree of agreement or disagreement between respondents.[76] This study primarily used quantitative design in phase 1 and qualitative methods were used in phase 2 to interpret and explain some of the findings from surveys.

Phase 1

An analytical cross sectional survey approach was used to collect quantitative data and this study design is used in investigating the relationship between exposure and outcome simultaneously at a define time point.[77] Both exposure and outcome of interest

are studied at the same time on a randomly selected sample. The major advantages of using cross sectional studies is that they pose less ethical challenges as participants are neither deliberately exposed, treated or untreated. They are relatively cheaper to conduct compared to other observational studies and can be used to study multiple exposures.[77, 78] In this phase three surveys were conducted, that is, community based survey, health facility based (patient) survey and health worker survey.

Phase 2

Qualitative design was used to assist in interpreting and explaining of findings from the cross sectional surveys. The design was used to explain significant, non-significant, outliers and surprising results from the surveys. Cross sectional findings were used to guide purposive sampling for qualitative work in this phase of the study.[74] Qualitative work occurred after data collection and analysis of the cross sectional surveys. Both women and men were enrolled purposively for participation in this phase of the study. The findings of phase 1 and 2 were integrated at interpretation stage and the combined analyses were used to inform the model strategy for Zimbabwe. The proposed bi-phased study was conducted conducted over two years (2017-2018).
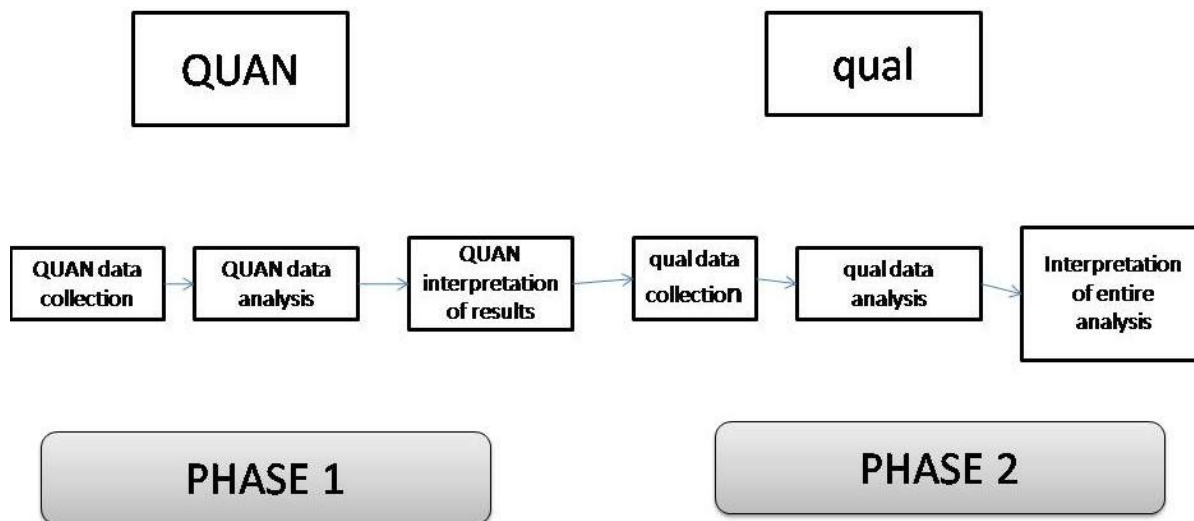
Figure 1.3: Sequential explanatory design[34]

1.7.3 Target population

The target population comprised of healthy women, women with or with a history of cervical cancer and health workers working in cervical cancer screening and treating

health facilities. Except for health workers other survey participants had to be aged 25 years or older to be eligible for enrolment into the study. The age range was informed by studies that have shown the incidence of cervical cancer is higher among women who are older than 30 years[57]. In Zimbabwe cervical cancer screening is recommended for sexually active females between 18 and 49 years old [51]. For that reason it was plausible to recruit participants aged a bit younger than 30 years, at least 25 years old, to ensure that some women with cervical cancer who could be younger than 30 years would be eligible for participation in this study. Healthy women who were resident in Harare (urban and rural) for at least one year were considered as potential participants. Cervical cancer patients or survivors were not necessarily from Harare since they were enrolled in Harare health facilities. Cervical cancer patients or survivors with histologically confirmed disease attending tertiary public health facilities and NGO run centres in Harare were eligible for participation in the study. These patients were selected from health facilities during their routine visits (outpatients) or from databases or records (in-patients) regardless of where they stayed.

1.7.4 Study Sites
Phase 1

Four areas in Harare were randomly selected for community based survey. Three of the sites were suburbs representing high (Glen View), medium (Cranborne) and low (Highlands) density areas from 138 suburbs in Harare urban. One of the study sites was a peri-urban community (Hopely) and it was selected randomly out of seven communities in Harare peri-urban . For patient or health facility based survey, histologically confirmed cervical cancer patients were enrolled from Harare Hospital, Parirenyatwa Hospital and Island Hospice and Cancer Association of Zimbabwe Clinic. For the health worker survey, participants were selected randomly from Harare Hospital, Parirenyatwa Hospital and Island Hospice and Cancer Association of Zimbabwe clinic . Staff registers were used as sampling frame from which respondents were selected to avoid bias by selecting only those on duty at the time of the survey.

Phase 2

Qualitative work was conducted in the same areas where survey data were collected. Participants from the phase 1 of the study were not necessarily the same as those in phase 2 though some were drawn from phase 1 based on their rich perspectives identified during the survey interviews. During phase1, the researcher identified potential participants for the qualitative study and their contact details were requested for follow-up in phase 2.

In-depth interviews were conducted in communities and health facilities, while focus groups discussions were held in the communities (Hopely and Glen Norah) and health facilities (Parirenyatwa Hospital). In Hopely and Glen View communities, private school classrooms were used for conducting the focus group discussions after obtaining permission from the principals of the institutions. Transport compensation was provided to participants to travel to the selected venues. With the exception of key informants, in-depth interview and focus group discussion participants were given an average of US$8 to compensate for their transport costs and time in addition to refreshments which were served during the interviews or discussions. Key informant interviews were conducted in communities, health facilities and in offices of participants.

1.7.5 Sample sizes
Phase 1

For the community based survey, 143 participants were enrolled, though the minimum sample size was 131 respondents based on the Dopson sample size calculator[6, 80] and after adjusting for respondent response rate. The enrolment of 143 respondents improved on the precision of estimates. The sample size had been calculated using assumptions for one primary outcome variables (knowledge about cervical cancer). Dopson sample size calculation was follows: formula n= z² pq/d²

- Where *n* is the required sample size
- *Z* is a test statistic (1.96)
- p= proportion of women with knowledge about cervical cancer in Harare is 91%.[58]

- q= 1- assumed proportion women with knowledge about cervical cancer(91%)
- d is the desired precision (5% and a confidence level of 95%)
- Taking the average respondent response rate in urban and rural settings for women of 96.2%.[58]

The health facility based survey was conducted amongst women with cervical cancer or a history of the disease and health care workers. A census of eligible women with cervical cancer who visited Harare Hospital, Parirenyatwa Hospital and Island Hospice and Cancer Association of Zimbabwe clinic between January and March 2018 and consented in writing to participate in the study was conducted. In-patients were interviewed after obtaining clearance from their doctors that they were stable and in good state to be interviewed. It was anticipated that a minimum of 80 women with cervical cancer patients would be enrolled at Parirenyatwa Hospital, Harare Central Hospital and Island Hospice within two months. These figures were anecdotal statistics of patient flow/admissions from the study health facilities. However, a total of 134 women with cervical cancer or with a history of the disease were finally enrolled, 36 from Harare hospital, 86 from Parirenyatwa hospital and 12 from Island Hospice and Healthcare Centre. This higher sample size meant better precision of estimates of variables from the study.

Health worker survey was conducted to investigate supply-side factors and all staff members working in the treating and palliative care health facilities were eligible for participation in the study. Information of staffing (working conditions, motivation, job satisfaction and training), infrastructure, funding sources, equipment and commodities availability were collected from health worker survey. A census of all the available between January and March 2018 and consenting health workers totaling 78 in the treating and palliative care health facilities was carried out. A total sample size of 355 participants was enrolled for the three surveys of which 143 of the participants were healthy women selected from communities, 134 were women with cervical cancer or a

history of the disease and 78 health workers were selected from treating and palliative care health facilities in Harare.

Phase 2

The sample sizes for the qualitative research were guided by the saturation principle and a total of 84 participants were enrolled for the study. Six focus groups with average of eight (8) participants each were convened in Hopely and at Parirenyatwa hospital. For in-depth and key informant interviews, 16 and 20 participants were enrolled respectively to achieve theoretical saturation[57,64]. In-depth interview participants were identified during community and health facility surveys while snowball sampling was used to identify key informants.

1.7.6 Sampling frame and sampling procedure.
Phase 1

The sampling frame for the community based survey was residential communities in urban and rural Harare. The respondents needed to have been resident in the selected communities for at least one year to be eligible. The random selection of the study sites provided adequate variation and information needed for the study. Multistage cluster sampling technique was used for the study[74,78, 81]. Firstly, all the 138 suburbs in Harare urban were stratified into high, medium and low density using data from City of Harare. Random selection using ballot approach was carried out to select three urban suburbs out of 138 in Harare urban to represent high, medium and low density suburbs. The 138 suburbs were stratified into high, low and medium density and their printed names were put into three ballots marked "High", "Medium" and "Low". One suburb was selected by the researcher and his research assistant from each ballot and the selected suburbs constituted study sites for the urban communities. The same approach was used to select one out of seven peri-urban communities in Harare. The selected study sites were: Highlands (low density), Cranborne (medium density), Glen View (high density) and Hopely (peri-urban community). A sample size of 143 respondents was achieved in the community survey and this improved on the precision of estimates of variables under investigation which are not fully understood[74,77-78]. Probability sampling

proportional to size of population was used to determine the subsample for each study site based on the Zimbabwe 2012 National Census results.[59] The subsamples achieved for Glen View (high density), Cranborne (medium density), Highlands (low density) and Hopely (peri-urban) were 31, 31, 31 and 50 respectively after applying probability sampling proportional to sizes on census 2012 data.

In each community the researcher/research assistants selected the first household to the north located at the boundary of the community and proceeded with randomly selecting other households in an anti-clockwise direction using a sampling interval that was determined apriori based on census data. Sampling interval were calculated by dividing the number of households in that community by the subsample size for that area using formula (k/n) where k is the number of households and n is the subsample size[77-78]. The sampling intervals ranged from 3 in Highlands to 18 in Glen View. Only one respondent was eligible for participation per household and where more than one household member was eligible, the Kish grid approach was used to select only one.[81] This approach is a method of selecting members within a household to be interviewed. It uses a pre-assigned table of random numbers to find the person to be interviewed. The number of eligible women in the household was determined and a random number was chosen to select a particular woman for interviewing. All interviews were allocated a number (1-150) and a Kish grid sheet was completed in all households with more than one eligible respondent. On the form the youngest eligible household member was assigned position 1 followed by second youngest as 2 etc. The number of interview was looked up in the list that was updated by the researcher/research assistants after every interview and where that number (or last non-zero number for numbers above 10) intersects with the number of eligible respondents in household, there was a random number in that cell which would be the number of the respondent to be interviewed. For instance if a household had 3 eligible respondents and the interview to be conducted is the 3rd interview the researcher would look at the 3 (yellow) on the rows and 3 in the columns (yellow) and the cell where they would meet is a 3 (red) meaning that the 3rd youngest respondent would be eligible for participation after obtaining written consent (see Figure 1.4). If the selected respondent was not available a call back would be arranged and up to three call backs would be made before a replacement could be

considered. In the event that the selected respondent refused to consent and there was still more than one eligible respondent in the household the Kish approach would be repeated excluding the non-consenting respondent.[81]

To ensure representation of participants in each socioeconomic stratum, each suburb selected contributed a sub-sample of participants determined by the sample size and the population sizes reported in Census 2012[59] i.e 31 participants from each suburb selected (Highlands, Cranborne and Glen Norah) and 50 from per-urban community (Hopely). Random selection of participants in each of the selected suburbs/communities also ensured even distribution of baseline characteristics including socioeconomic characteristics. The proportions of participants in each socioeconomic stratum were validated using ZDHS 2015 data and no significant discrepancies were obtained after the validation process.

For health facility based survey, histologically confirmed women with cervical cancer or survivors were randomly selected from health facility records or referred by health workers who had knowledge of their confirmed diagnoses. Out and in-patients from Harare Central Hospital, Parirenyatwa Hospital and Island Hospice facilities in Harare were eligible to participate in the study. The researcher obtained the assistance of health workers in the participating health facilities to identify histologically confirmed cervical cancer patients or survivors. During the data collection period, health workers were sensitized to the objectives of the study and their assistance was obtained to identifying cervical cancer patients using medical records. Patients were also sensitized by their health workers and asked for their consent whether they would want to participate in the study. Patients who agreed verbally to participate were then referred to the researcher or his assistant for informed consent and interviews/discussions were conducted with those who consented in writing to participate in the study. This process was done for outpatients as well as in-patients. The researcher/research assistants also verified the diagnoses of the patients during the interviews/discussions to ensure that only the eligible participants were enrolled for the study. It was possible that some patients would refuse to consent and some were too ill to participate.In the overall study 12 women with cervical cancer refused to participate as they were experiencing pain

due to the disease or treatment. Eight women with cervical cancer were excluded from the study as they were not in stable conditions or mentally challenged as certified by their clinicians to endure a 45 minute interview. Women with cervical cancer or a history of the disease were selected regardless of their place of residence. Women with cervical cancer, who were terminally ill, mentally challenged and refused to provide consent were not be eligible to participate in the study.

The health worker survey was conducted in the same health facilities where cervical cancer patients will be selected and the facilities were Harare hospital, Parirenyatwa hospital and Island Hospice and Healthcare. A census of all health workers was conducted and a short structured questionnaire in electronic format was administered by the researcher. Health workers who were not around during the entire period of the study (January – March, 2018) were excluded from the study. The researcher worked with the schedules of the health workers and ensured that the interviews happened within the shortest time not taking more than 30 minutes with each participant.

Eligible people	Household							
	1	2	3	4	5	6	7	8
1	1	1	1	1	1	1	1	1
2	1	2	1	2	1	2	1	2
3	1	2	3	1	2	3	1	2

4	1	2	3	4	1	2	3	4
5	1	2	3	4	5	3	4	5
6	1	2	3	4	5	6	3	6
7	1	2	3	4	5	6	7	4
8	1	2	3	4	5	6	7	8
9	1	2	3	4	5	6	7	8
10 or more	1	2	3	4	5	6	7	8

Figure 1.4: Kish grid sheet used in the selection of eligible women participants in households in the community survey [81]

Phase 2

Purposive sampling approach was used to select women (healthy women and women with cervical cancer or a history of the disease) and men participants for the qualitative research of this study. The researcher identified potential participants with desired characteristics during phase 1 surveys[74]. The number of in-depth, key informant interviews and focus group discussions were guided by the theoretical saturation principle. Saturation is a process that ensures that adequate and quality data has been collected to support a study. Theoretical saturation is reached when successive interviews in a population with diverse characteristics and experiences yields no new concepts. Some scholars have shown that theoretical saturation is reached after a range of 20 to 30 interviews or 4 to 6 focus groups.[57, 64]. Key informants were also recruited for face-to-face interviews and the participants include health professionals (oncology nurses, radiotherapists, general practitioners, gynecologists, radiation oncologists, pathologists and physicians), key personnel in the Ministry of Health and Child Care, policy makers, community leaders, traditional healers, prophets, pastors, academics and key personnel in non-governmental organizations (NGO) involved in cervical cancer programmes in Harare. Participants for in-depth interviews were

identified as well as selected community and patient surveys based on special characteristic which included knowledge of subject matter and special experience with the disease. Focus groups comprised of different composition of women and men participants purposively selected (see table 1) to enrich the study through diverse discussions. Selection of participants was conducted in such a way as to ensure wider age range, different residential areas, different experiences and socioeconomic circumstances. Key informants were selected purposively from different settings i.e community, health facilities, universities, MoHCC, NGOs and WHO country offices. They were selected based on knowledge of the subject under investigation, public behaviors and views and experience in the field of cervical cancer in different capacities.

1.7.7 Methods of data collection
Phase 1

For the community and health facility based patient surveys, one validated structured questionnaire was administered by the researcher/research assistants to women participants. The health worker survey used a short validated structured questionnaire which was administered to both men and women participants by the researcher. All questionnaires were administered by the researcher to allow for probing and verification of issues during the interview process. By conducting face-face interviews, the researcher/research assistants were able to probe the participants to validate information and this was crucial for the research outcomes especially to inform phase 2[74,76]

Survey data was collected by the researcher using smartphones programmed with *SurveytoGo* software (Dooblo, Israel). Structured questionnaires programmed in electronic format were used by the researcher/research assistants to collect data from participants for the analytical cross sectional surveys. Electronic data collection allowed one structured questionnaire to be administered in the community and health facility based (cervical cancer patients) surveys respectively. A different and short structured questionnaire was administered in electronic format by the researcher to health workers in English language. The structured questionnaire for community and health facility

based participants was administered by the researcher/research assistants in the language most appropriate to the participant (English or Shona).The questionnaires were administered in not more than 45 minutes for each participant. There was no data entry for surveys because of the use of electronic data collection methods. The *Surveytogo* software which was used for data collection saved the data collected automatically in a cloud server and the researcher downloaded the data files from the server using a laptop/desktop in Excel format. The Excel data file was converted to *STATA* file by importing it into the software and analyses were conducted using *STATA* version 14 software (StataCorp, Texas). The use of electronic data collection methods allowed the researcher to review data in real-time and collection of geo-coordinates for verification and validation purposes.

Phase 2

Qualitative data was used in the interpretation and explaining of analytical cross sectional study results. Twenty (20) key informant interviews, 16 in-depth interviews and 6 focus group discussions with an average of 8 participants each were carried to collect relevant data for this study (See Table 1 and Figure 1.5 below). Purposive sampling technique was applied to select participants and results from the phase1 surveys were used to guide participant selection. Data from in-depth and key informant interviews were collected using interview guides, while for discussion guides were used for FGDs. These tools were informed by the findings of the cross sectional surveys in phase1. Draft data collecting tools were developed for phase 2 however; they were only finalized after the analysis of data from phase 1 of the study. Interviews and discussions were audio-recorded using voice recorder and the researcher also took notes. For focus groups the researcher engaged a trained research assistant to help with audio-recording, note taking and moderating the focus groups.

Table 1.1: Distribution of participants for the collection of qualitative data

Data collection type (Qualitative)	Description of participants	Number of participants
Key informant interviews	Health professionals(oncology nurse, , general practitioner, gynecologist, pathologist o, radiologist and physician), Dire ncologistctor of Family Health (MoHCC), WHO expert , traditional healer, prophet, pastor, academic and programme managers of Cancer Association of Zimbabwe , PSI-Zimbabwe and Island Hospice	20
In-depth interviews	Women (healthy)	3
	Men (including partners)	3
	Women diagnosed of cervical cancer or a history of cervical cancer.	4
	Men with partners diagnosed of cervical cancer	3
	Caregivers for women with cervical cancer	3
Focus group discussions	Men and healthy women	7
	Men partners and caregivers of women with cervical cancer.	8
	Women with cervical cancer or a history of the disease.	7
	Women diagnosed of cervical cancer or history of cervical cancer and healthy women.	10
	Women diagnosed of cervical cancer and men with partners with cervical cancer	7

	Combined group (healthy men and women, women with cervical cancer and men with partners affected with cervical cancer)	9

The above table (Table 1.1) shows the disaggregation of participants for the qualitative inquiry of the study (phase 2). A total of 84 participants were enrolled in the qualitative segment (phase 2) of this study. For in-depth and key informant interviews, 16 and 20 participants were enrolled respectively. For FGDs, 48 participants were engaged in 6 different groups with an average group size of 8. Interviews and discussions were terminated when saturation had been reached.

The researcher engaged and worked with five (5) experienced research assistants (with valid ethics training certificates) in the pretesting of data collection tools and data collection particularly the surveys. One research assistant with training in qualitative research was retained after the surveys and assisted in moderation, note taking and audio-recording during focus group discussions in phase 2 of the study. The research assistants were trained in aspects of the study including objectives of the study, ethical issues and data collection using electronic devices.

1.7.8 Validation of data collection tools
Phase 1

To ensure validity and reliability of the questionnaires, the tools were reviewed, pretested and validated before being used for the study. The instruments were reviewed by Supervisors of this PhD study, to determine face and content validity of the instruments. At Ethics review stages, the validity of the instruments were also tested by the reviewers and their comments were used to adjust the instruments accordingly. The instruments were also pretested on a total of 50 participants (20 healthy women, 10 cervical cancer patients and 20 health workers) in Chitungwiza based on literature and data analysis was conducted to validate the tools[86]. The data from the pretesting was not included in the main study.. Chitungwiza hospital and the surrounding community were used for pre-testing the data collection tools and they are located about 26 km from Harare. Factor analysis and principle component analysis (PCA) were conducted

to test the validity of the questionnaires using pretesting data. This method was most useful on Likert scale items of the questionnaires. Cronbach alpha analysis was conducted by the researcher using pretesting data collected from the field to establish the internal consistency reliability of the questionnaires. A Cronbach alpha coefficient (α) ≥0.7 was considered acceptable for each of the two instruments[86]. In cases where the Cronbach alpha coefficients were less than 0.7, the questionnaires were adjusted by removing some questions in a systematic manner until alpha coefficients greater than or equal to 0.7 were obtained. These analyzes were conducted using *STATA* version 14 software (StataCorp, Texas) and the results of the validation process were included in the main research (see Chapter Two).

Phase 2

To ensure trustworthiness of the qualitative inquiry in this study, the researcher sought to satisfy the four criteria of Guba's construct.[87] In addressing the credibility, the researcher demonstrated and ensured that the true picture of the phenomenon under investigation was presented. To allow transferability, the researcher shared sufficient detail of the context of the fieldwork, to allow readers the ability to decide whether the prevailing environment was similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting. To meet the dependability criterion the researcher strived to provide a concise methodological approach about the study to enable future investigators to repeat the study. Finally, to achieve confirmability, the researcher took steps to demonstrate that findings emerge from the data and not his own predispositions.[87]

1.8 Data Analysis
Phase 1

Data analysis was conducted using *STATA®* version 14 software (StataCorp, Texas) by the researcher to yield descriptive statistics and to compare and establish the nature of relationships between variables. Univariate analysis was used to generate descriptive statistics and bivariate analysis was used to identify significant independent factors for multivariate logistic regression models. Multivariate binomial logistic regression models

were used by the researcher to identify the individual, societal and health system determinants of access and utilization of cervical cancer treatment and palliative care services and factors associated with knowledge about causes, prevention and treatment of cervical cancer in Harare, Zimbabwe (also see Table 1.2). Complicated interactive relationships have been noted between race/ethnicity and other variables like poverty and levels of education.[78, 84]Furthermore, bivariate analyses of variables may incur confounding. These confounders were taken into consideration during study design by stratification of community study sites into high, low, medium density and rural areas and during the analysis stages. To reduce contamination and improve on data, quality check questions were included in the structured questionnaires and probing techniques were also be used to ensure consistency in the data collected. Pre-testing of the data collection tools and subsequent validations of the tools also reduced chances of contamination during the actual data collection. In addition, the application of multivariate analysis such as binomial logistic regression models controlled for confounders in the analysis of the study data to generate evidence. Goodness of Fit tests was conducted for the binomial logistic regression models, to check for violation of model assumptions and parsimonious models were considered in this study.[68, 69, 74] Findings from this phase informed qualitative tools and the issues that were explored in phase 2 of the study.

Phase 2

Transcription of audio-recordings was done by the trained research assistant and these were reviewed by researcher. During transcription, the research assistant did not have access to questionnaire results[74.83]. Transcripts were identified by the unique identifier previously assigned to each participant (and stated by each participant at the beginning of the FGD/interview) rather than by any personal information. Unique identifiers were used to link the questionnaire and the interview, only after the conclusion of transcription.

All audio-recorded data from FGDs, in-depth interviews and key informant interviews was transcribed and translated verbatim into English. Any relevant non-verbal communications was included in the transcripts. Following review of transcripts by the

researcher, interview summaries were then written for each FGD/interview. The interview summary was a descriptive and analytic synopsis of the FGD/interview. The researcher conducted inductive thematic analysis of the interview summaries to come up with a provisional coding framework[74, 83]. All in-depth interviews/key informant interviews and FGDs were then coded line by line on using *Dedoose* software using the provisional coding framework. Coding was done in *Dedoose* software to identify interview themes and code the interview transcripts. Transcripts were then coded using the modified coding framework; care was taken to identify any additionally emerging codes.[74,83] Generated thematic codes were processed in *Dedoose software* to produce final outputs for the phase 2 (see Table 1.2). Thematic analysis which is the process of identifying patterns or themes within qualitative data was used in analyzing qualitative data. The process involved six steps based on literature and the steps were:

Step 1: Become familiar with the data,

Step 2: Generate initial codes,

 Step 3: Search for themes,

Step 4: Review themes,

Step 5: Define themes,

Step 6: Write-up.

The goal of a thematic analysis is to identify themes, i.e. patterns in the data that are important or interesting, and use these themes to address the research or say something about an issue.[93]

Findings of the phase 1 and 2 were integrated at interpretation stage and qualitative findings helped to explain and interpret significant, non-significant, outliers and surprising results from the quantitative study (see Figure 1.5, Table 1.2). The findings of phase 1 and 2 were used to develop a model strategy to address key individual, societal and health system barriers to cervical cancer treatment and palliative care access and utilization in Zimbabwe.

Table 1.2: Data analysis plan by objective

Objective	Research question	Data sources	Variables	Methods of analysis
1. To assess access and utilization levels of cervical cancer treatment and palliative care services amongst women aged at least 25 years in Harare	i. What are the access and utilization levels of cervical cancer treatment and palliative care services amongst women aged at least 25 years old in Harare, Zimbabwe?	1.Questionnaires 2.In-depth interviews 3.key informant interviews 4.Focus group discussions	1. Proportion of women in Harare reporting accessing and using cervical cancer treatment and palliative services in Harare. 2. Proportion of women in Harare reporting that they would have access and use cervical cancer treatment and palliation services. 3. Proportion cervical cancer patients using treatment and palliative services in Harare.	Frequencies, Chi-squared using *STATA* version 14 Thematic analysis using *Dedoose*
2. To investigate individual, societal and health system determinants of access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.	ii. What are the individual, societal and health system determinants of access and utilization of cervical cancer treatment and palliative care services amongst women aged at least 25 years in Harare?	1.Questionnaires 2.In-depth interviews 3.key informant interviews 4.Focus group discussions	1. Socioeconomic and demographic characteristic of cervical cancer patients and healthy women in Harare. 2. Attitudes ,beliefs, perceptions on cervical cancer treatment and palliative services in Harare 3. Capacities of health facilities (human resources, infrastructure, commodities, funding, policies/guidelines) in Harare.	Frequencies, Chi-squared, logistic regression models using *STATA* version 14 Thematic analysis using *Dedoose software*

| 3. | To investigate how service (treatment and palliative care) delivery models influence potential inequities in access and utilization of cervical cancer treatment and palliative care services in Zimbabwe. | iii. How do cervical cancer treatment and palliation service delivery models influence potential inequities in access and utilization in Zimbabwe? | 1.Questionnaires

2.In-depth interviews

3.key informant interviews

4.Focus group discussions | 1. Distances and costs to the nearest heath facility or cervical cancer treating centres in Harare.

2. Distribution of treating and palliative care facilities in Harare.

4. Service referral systems for cervical cancer treatment and palliation services in Harare.

4. Average time to engagement into treatment and palliative care from time of diagnosis in Harare.

3. Attitudes, beliefs and perceptions of treatment and palliative services in Harare. | Frequencies, Chi-squared using *STATA version 14*

Thematic analysis using *Dedoose software*. |
| 4. | To develop model strategies that addresses individual, societal and health system barriers and how it may be adopted in Zimbabwe to improve cervical cancer treatment and palliative interventions. | iv. What are the model strategies that may be adopted in Zimbabwe to address individual, societal and health system barriers related to cervical cancer treatment and palliative care? | 1.In-depth interviews

2.key informant interviews

3.Focus group discussions | 2. Model strategies that could developed to address identified barrier at each of the 3 levels. | Thematic analysis using *Dedoose software*. |

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                    ┌─────────────────────────────┐
                    │          Surveys            │
                    │ Community and patient (n=277)│
                    │    Health worker (n=78)     │
                    └─────────────────────────────┘
                                  │
                                  ▼
Phase 1             ┌─────────────────────┐
                    │    Data analysis    │
QUAN                └─────────────────────┘
                                  │
                                  ▼
                    ┌─────────────────────┐
                    │      Findings       │
                    └─────────────────────┘
                                  │
                                  ▼
         ┌──────────────────┐         ┌──────────────┐
         │  FGD (6 x 8=48)  │─────────│  KII (n=20)  │
         └──────────────────┘         └──────────────┘
                  │
                  ▼
         ┌──────────────────┐
         │    IDI (n=16)    │
         └──────────────────┘
                  │
                  ▼
                    ┌─────────────────────┐
                    │    Data analysis    │
Phase2              └─────────────────────┘
                                  │
qual                              ▼
                    ┌─────────────────────┐
                    │      Findings       │
                    └─────────────────────┘
                                  │
                                  ▼
                    ┌─────────────────────┐
                    │   Integration and   │
                    │  interpretation of  │
                    │       results       │
                    └─────────────────────┘
```
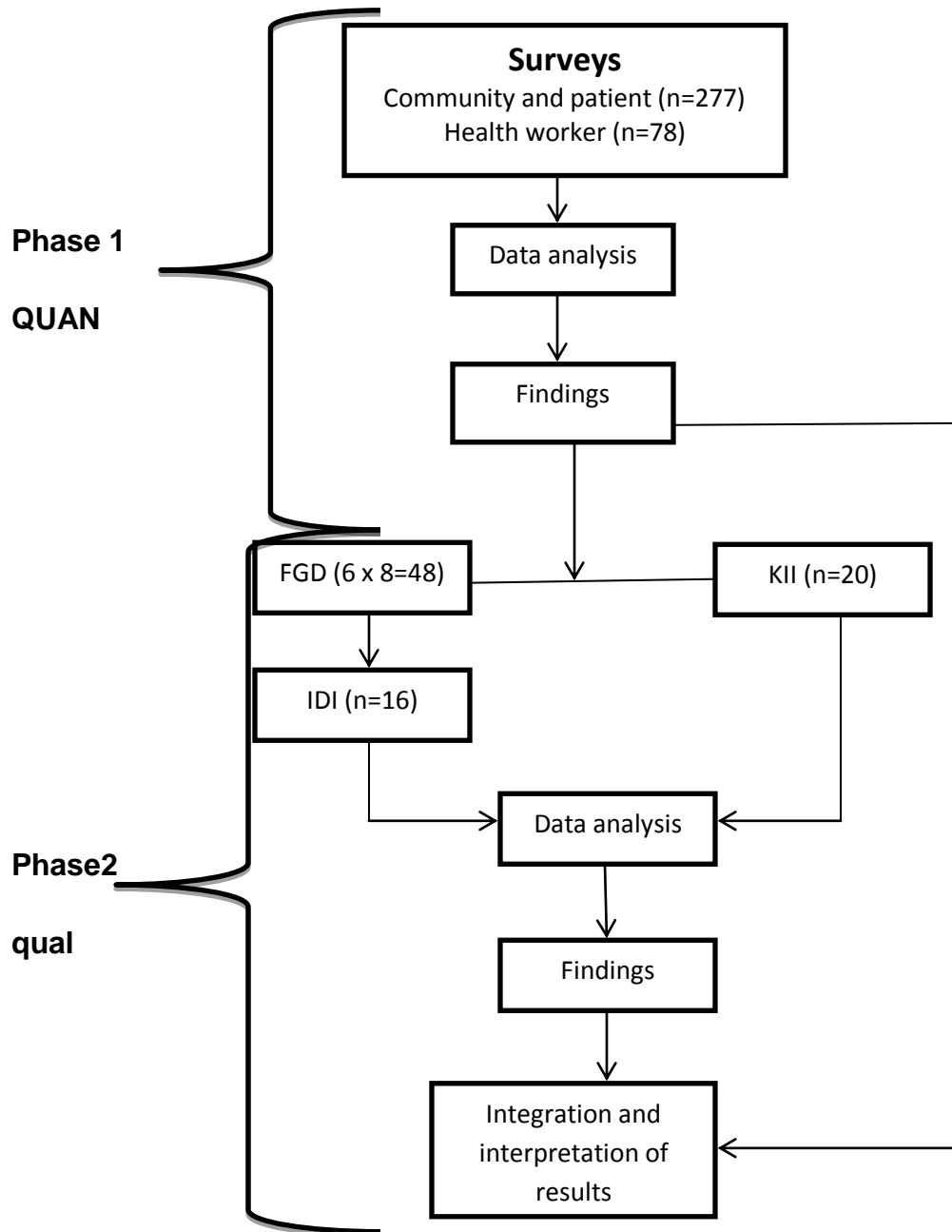
Figure 1.5: Study flow schematic diagram

1.9 Measures to ensure research rigor

Phase 1

This quantitative study may have incurred sampling and non-sampling errors like any other research study. While non-sampling errors may be impossible to avoid and

difficult to assess statistically, the study design ensured that they were kept very minimal. Several measures were put in place to ensure good quality data was collected. These measures include: designing of understandable and clear questionnaires in English and Shona languages, incorporation of a clear sampling strategy, use of validated questionnaires in electronic formats and inclusion of check questions in structured questionnaires to ensure consistency. Extensive data analysis for the pilot interviews was done to ensure that good quality tools for collecting reliable and accurate data from the respondents were developed. Adequate training in data collection and interview techniques were obtained by the researcher and research assistants before field work commenced. Allowable sampling errors were set at 5% and all quantitative variables were reported with 95% confidence interval limits.[80] An independent statistician was consulted to validate the data collected from the pilot phase before data collection took place. Data from the pilot phase was not included in the main study to reduce contamination and this data had been collected from a community that was far away from the main study sites to minimize confounding.

Phase 2

The qualitative study was guided by the Guba's model[87] to ensure the trustworthiness of the findings. However, since the purpose of this phase was to assist in interpreting and explaining findings from phase 1, most of the work that was informed by those findings.

1.10 Ethical Considerations

Ethics approvals were sought from the Medical Research Council of Zimbabwe as this study met the criteria for human subject research. This study methodology had been designed to address the following ethical principles: respect for persons, beneficence and justice.[85] Institutional ethical reviews were sought from the University of Pretoria Ethics committee, Harare Central Hospital ethics committees, Joint Parirenyatwa and University of Zimbabwe ethics committee (JREC). Permissions to conduct the study were sought prior to the submission of application for ethical approval from the following institutions: Chitungwiza Hospital, City of Harare Health Department, Ministry of Health and Child Care and Island Hospice and Healthcare.

This study had the following ethics approvals (including the relevant approval reference numbers):

1. University of Pretoria, Faculty of Health Sciences Research Ethics Committee (**REC 487/17**)
2. Harare Hospital Ethics Committee (**HCHEC 271017/77**)
3. Joint Parirenyatwa and University of Zimbabwe Research Ethics committee (**JREC 33A/18**)
4. Medical Research Council of Zimbabwe (**MRCZ/A/ 2271**)

1.10.1 Risks and Benefits to Participants

This study posed minimum risk to the participants as no invasive procedures or blood or tissue samples were collected from participants. Participants were engaged in survey interviews, in-depth interviews, FGDs and key informant interviews. The questionnaires, interview and discussion guides did not include questions of a sensitive nature. For health facility based interviews or discussions the researcher had a contingency plan to discontinue patients with signs of psychological trauma due to the interview or discussion and would refer participants to health workers(nurse, doctor or clinical psychologist) to help them with counseling. Prior arrangements were made with management of health facilities to ensure that participants requiring counseling would be provided at the facility, though no incident occurred to warranty such interventions. The researcher was guided by the policies of the health institutions with regards to dealing with patients who would experience psychological trauma. Terminally ill-patients in hospital or palliative care and those not certified by their doctors as fit to sustain a 45-60 minute interview/discussion were not eligible for enrolment in the study. For community based participants, prior arrangements were made with local health facility managers to refer participants who would need counseling. All community based participants were given information sheets with contact numbers of local health facilities or professionals they would contact should there be need of counseling after the interviews/discussions.

This study did not contain any direct benefits to the participants however; the results from this study are important in understanding the determinants of access and utilization of cervical cancer treatment and palliative care services that may improve current and

future programmes. Information from this study may also influence the national cancer policies aimed at reducing the morbidity and mortality of cervical cancer amongst women.

1.10.2 Informed Consent and Participant Rights

To participate in this study the researcher sought written consent. In community survey, permission to select and interview household members was sought from household heads. In health facility based surveys permission to interview patients and health workers was sought from management of the facilities. All consenting participants were given full details of the study including risks and their rights to pull out during any stages of the interviews/discussions. The participants chose the language of their preference i.e English or Shona.

Signed informed consent forms were kept separately from questionnaires, interview transcripts and audio-recordings. Signed consent forms were stored securely at all times in locked document storage facilities such as lockable folders, or filing cabinets. Only authorized research team members have access to the signed consent forms.

1.10.3 Data Privacy and Confidentiality

Identifying information such as locality names, household name, and hospital numbers were collected in the study. However, non-identifying codes were used to name interviews for the purposes of coding audio-recordings and transcripts. In phase 2, interviews were named based on locality or health facility names and number assigned by the researcher e.g GlenView_IDI_1 for an in-depth interview done in Glen View suburb and assigned number 1 as it was interview number and it would be unique for that community. At the start of the recording of the interview (and for each segment if the recording was not continuous) the interviewer would specify the locality name and number, whether it was an in-depth interview, a FGD or a key informant interview, and the number of the participant/FGD.

Focus group discussions, in-depth interviews and key informant interviews were audio-recorded with a digital voice recorder. All digital audio files and any notes taken during FGDs and interviews were stored securely on Dropbox. Audio files and notes were

defined by the unique identifier previously assigned to each participant rather than by any information that could identify the participants. The unique identifier (or identifiers, in the case of FGDs) used to define audio recordings and notes were the same identifier(s) used to describe questionnaire responses. Only authorized research team members have access to the Dropbox folder containing the recordings and notes. Once audio files have been stored on Dropbox and their quality were confirmed, the original files on the voice recorder were erased.

University of Pretoria supervisors, researcher and local supervisor in Zimbabwe had access to the data containing identifying characteristics. However; identifying characteristics were not be used in any of the research report or publications. For stored data, all confidentiality and privacy measures were upheld. All paper-based documents such consent forms and filled in Kish grid sheets used in community survey were kept under key and lock and were only be accessible to the researcher and supervisors. All important documents (paper or electronic) for this study will be stored for a minimum of fifteen years (until 2033) at the University of Pretoria, School of Health Systems and Public Health. All electronic data files and software were password coded and will only be accessible by people involved in the study (researcher and supervisors). At all stages of the interviews and discussions participants were assured of confidentiality and protection of their private data.

1.11 Thesis Structure

This thesis is presented in eight chapters, of which six of the chapters are peer-reviewed articles emanating from this research study.

- **Chapter one:** Presents the introductory part of the study and it includes study rationale, problem statement, study justification, motivation and detailed methods. This chapter also highlights extensive literature that was reviewed to guide this study. The literature reviewed was on access to cervical cancer preventive services, treatment and palliative care global, African and Zimbabwe perspectives.

- **Chapter two:** Presents an original paper published in *Global Journal of Health Science.* The article covers the validation of the structured questionnaires used in the three surveys (community, patient and health worker surveys).

- **Chapter three**: Presents an original paper published by *BMC Public Health*. The article covered sociodemographic disparities in access and uptake of cervical cancer screening, treatment and palliative care among women.

- **Chapter four:** Presents the determinants of access and utilization of cervical cancer treatment and palliative care services among women with the disease. This chapter is in the format of a manuscript under peer review with *BMC Public Health.*

- **Chapter five:** Presents knowledge about cervical cancer, its causes, risk factors, prevention and treatment among women with the disease. This study also explored factors associated with knowledge of causes and prevention of cervical. This chapter is in the format of a manuscript under review with *BMC Women's Health* where it was accepted for publication.

- **Chapter six:** Presents how health system barriers are impacting on access and utilization of cervical cancer and palliative care among women in Harare, Zimbabwe. This chapter is in the format of a manuscript under review with *BMC Health Services Research*.

- **Chapter seven**: Presents the model strategies that could be implemented in Zimbabwe to address individual, societal and health system barriers to accessing and utilizing cervical cancer treatment and palliative care amongst women. This chapter is in the format of a manuscript under review with *Pan African Medical journal*.

- **Chapter eight:** Presents the overall general conclusion of the research, recommendations and areas of future research.

The references of each chapter are presented at the end of the respective chapter. This chapter references and those of chapter eight are in the Vancouver system accepted by the Faculty of Health Sciences, School of Health Systems and Public Health at the University of Pretoria. However, for other chapters, two to seven the references are in

the styles specified by the respective journals where they were published or were submitted for publication.

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CHAPTER TWO

Introduction

This chapter is the initial step in the formulation of this research study to validate structured questionnaire tools for use in survey data collection. The aim was to determine whether the developed tools were scientifically valid and would be reliable tools to use to investigate access and utilization of cervical cancer treatment and palliative care in Harare, Zimbabwe. This chapter shows that the developed tools were valid and reliable for use in the context of Zimbabwe and could be used in similar settings to understand complex concepts like access to health services.

2.0 DESIGN AND VALIDATION OF QUESTIONNAIRES INVESTIGATING ACCESS AND UTILIZATION OF CERVICAL CANCER TREATMENT AND PALLIATIVE CARE.

Abstract

Background: Standardized tools to evaluate access and utilization of cervical cancer treatment and care remain scarce in developing countries. The objective of this study was to validate questionnaires to investigate access and uptake of cervical cancer treatment and palliative care.

Materials and Methods: We designed and validated two questionnaires for patient and community and health worker surveys to determine the main constructs of each of the draft questionnaires. Pilot data was collected randomly amongst 50 patient and community participants and 14 health workers respectively in Chitungwiza, Zimbabwe. Content and face validity were assessed qualitatively from expert evaluations. Construct validity, reliability and internal consistency testing were conducted using exploratory factor analysis and Cronbach's alpha correlation coefficient respectively.

Results: Twelve (12) experienced researchers, based on convenience, reviewed the questionnaires and validated their draft constructs based on experience and literature. Each of the questionnaires was sub-divided into 4 separate mini-questionnaires respectively. All the eight mini-questionnaires were analyzed independently and Kaiser-

Meyer-Olkin coefficients ranged from 0.5-0.9 and Bartlett's Sphericity tests were all significant, p<0.001, showing promising to very good constructs. Patient and community questionnaire had 15 meaningful constructs while the health worker questionnaire had 13. Cronbach's alpha (α) coefficients for internal consistency reliability testing of all the final constructs were greater than the minimum acceptable threshold of 0.70.

Conclusion: This analysis revealed the validity and the reliability of questionnaires that can be used to evaluate access and utilization of cervical cancer treatment and palliative care in countries affected by the disease.

Key words: Cervical cancer, access, utilization, construct, questionnaire, validity, reliability, exploratory factor analysis, Cronbach's alpha.

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2.1 Background

Cervical cancer is the fourth most commonly diagnosed cancer amongst women worldwide and the most prevalent cancer in Zimbabwe's female population (GLOBOCAN,2018). About five million (60%) of the 15-49 year-old Zimbabwean female population is at risk of cervical cancer. (Nyakabau, 2014). Despite the increasing availability of prevention and screening programmes, morbidity and mortality rates remain very high due to limited, centralized treatment services (Nyakabau, 2014; Kuguyo et al., 2017). While access and utilization of treatment and care for cervical cancer remains a huge challenge predominantly due to limited resources (Kuguyo et al., 2017), standardized tools to measure them remain limited in Africa. Understanding service access and utilization patterns is the first step towards evidence-based programme improvement and formulation of relevant national policies. Generally, access to healthcare is a complex and multidimensional concept which has three main dimensions namely: affordability, physical accessibility and acceptability of services (Sundaresan et al., 2016). A study had defined access to health care as the timely use of personal health services to achieve the best health outcomes (Margolis et al., 1995). The difficulties in measuring access and utilization of health services are largely due to complexity of the concepts, subjectivity and contextual differences in understanding (Sundaresan et al., 2016). Assessment of access and utilization of health care services are also further complicated by the need to integrate evidence from both the supply (health system) and demand sides (patients/community).

Some standardized tools have been developed to evaluate access and uptake of other health services such as malaria prevention interventions, HIV/AIDS, family planning and other sexual reproductive health services (ZDHS, 2015). These tools have been used to assess access and utilization of health services or interventions from the demand side with little attempt to integrate the supply side. Furthermore, these tools have failed to capture full breadth of the ideas enshrined in access and utilization concepts and their psychometric attributes remain unknown. Another weakness of the tools used in population-level surveys is that some proxies are used to measure access and

utilization with no data on items and scorings available publicly. No studies have been conducted to test and validate tools that may be used to evaluate access and utilization of cervical cancer treatment and care in Zimbabwe.

We conducted this study to address the identified gaps by developing and validating some of the constructs that may be used to measure access and utilization of cervical cancer treatment and care in developing countries. Demographic and socioeconomic variables were adopted from Zimbabwe Demographic and Health Surveys (ZDHS) of 2015 for the patient and community survey questionnaire (ZDHS, 2015). This tool was validated and used for several rounds of the DHS surveys in the country. The ZDHS wealth quintile asset variables were simplified by adopting the approach from previous work done [7] to shorten the questionnaire for ease of administration. Variables to measure access and utilization of cervical cancer treatment and care were adopted from ZDHS and literature (Bruni et al., 2016; Nyakabau, 2014; Kuguyo et al., 2017; Sundaresan et al., 2016; Margolis et al., 1995; ZDHS, 2015; Andersen and Newman,2005).

Several approaches have been developed and used to design and validate psychometrically sound questionnaires (Parsian and Dunning, 2009; Atkinson et al., 2011; Osborne et al., 2013; de Jager Meezenbroek et al., 2012; Yu and Richardson, 2015; Besnoy et al., 2016). In Australia, Parsian et al (2009) reported the development and validation of a questionnaire to measure spirituality using content, face validity, construct validity using factor analysis, reliability and internal consistency testing using test-retest and Cronbach's alpha correlation coefficient. In another Australian study development of a tool to measure health literacy was done through consultative process involving workshops. The resultant tool was then validated using confirmatory factor analysis and item response theory (Osborne et al., 2013). In Netherlands, a questionnaire to measure spirituality was validated using Cronbach's alpha testing, factorial and convergent validity testing approaches (de Jager Meezenbroek et al., 2012). A four factor, 20 item questionnaire used to measure student online readiness in university freshmen was confirmed to be valid after exploratory factor analysis and Cronbach's alpha correlation coefficient approaches in USA (Yu and Richardson, 2015).

A three factor brief pain assessment was validated to be superior to a one-factor model using confirmatory factor analysis by Atkinson et al (2011) in New York. A one factor model; Traits, Aptitudes, and Behaviors Score (TABS) tool was validated in southeastern USA for use by teachers to refer or nominate gifted students without bias using exploratory and confirmatory factor analyses (Besnoy et al., 2016).

This paper describes the conceptualization, psychometric development and validation of the new questionnaires based on approaches in literature. We endeavored to develop tools that could be used for the assessment of access and utilization of cervical cancer treatment and palliative care from population-level surveys through to programme improvement and policy formulation.

2.1 Methods

The methods used in the development and validation of the two study questionnaires included:

- Translational validity: content validity and face validity.
- Construct validity: exploratory factor analysis.
- Reliability test: internal consistency (Cronbach's alpha)

The process of validating the questionnaires is illustrated in Figure 1. The initial phase of the tool development involved extensive literature review of relevant publications to identify important domains related to the measurement of access and utilization of cervical cancer treatment and palliative care. A consultative process followed with cancer specialists, public health experts, policy makers and some patients to develop draft constructs. Validated tools used in recent surveys in Zimbabwe were also used to guide the development of draft constructs for both questionnaires [6].The ideas from literature, consultations and existing tools were used to develop the constructs and items for the drafts questionnaires. The draft tools were then tested after obtaining written consent from patients, community members and health workers in Chitungwiza, Zimbabwe in cross sectional surveys to identify meaningful and psychometrically valid constructs. The draft patient and community survey questionnaire consisted of four

mini-questionnaires, 13 constructs and a total of 140 items (excluding participant socioeconomic and demographic characteristics. Health worker survey questionnaire consisted of four mini-questionnaires, 6 constructs and 116 items (excluding health facility characteristics).
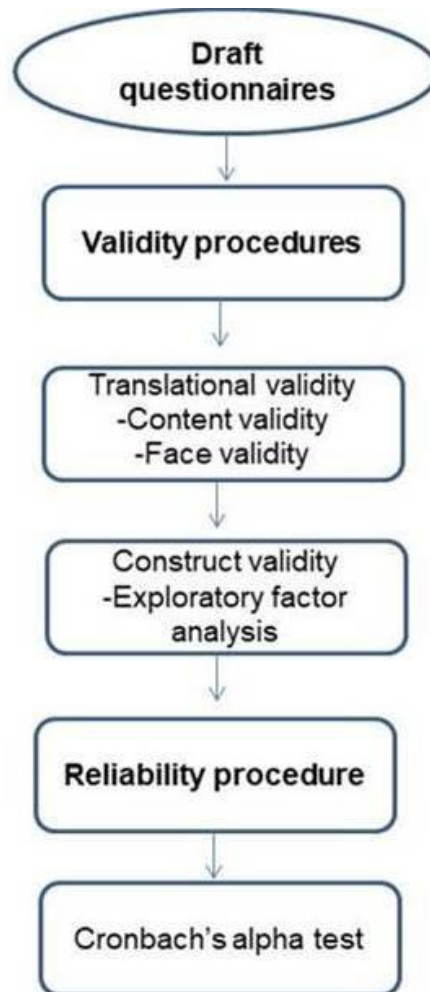
Figure 2.1: A flow chart depicting the process used to validate patient, community and health worker questionnaires (Parsian & Dunning, 2009)

2.2.1 Translation validity

Content validity

Content validity was conducted to examine if the content of the two study questionnaires were appropriate and relevant to the study purpose. Content validity

shows a complete range of attributes under study and it is usually carried out by at least seven (7) experts (Parsian and Dunning, 2009). To estimate the content validity of the two questionnaires, we defined the conceptual framework for access and utilization of cervical cancer treatment and palliative care using literature and seeking expert opinions. For this study the health utilization model (Andersen and Newman, 2005), was used as the conceptual framework. At least 12 purposively selected experts in the areas of research, public health, oncology, health policy, gynaecology and biostatistics were chosen to review the two questionnaires with 140 and 116 items, respectively. The experts reviewed the appropriateness and relevance of questions to answer the research questions for the study. The validity of each questionnaire was based on the qualitative comments or suggestions for improvements from the reviewers.

Face validity

Face validity shows the appropriateness of a questionnaire to the purpose of the study and content area. Though this is the easiest validation process, it is the weakest as it measures the appearance of questionnaire in terms of feasibility, readability, consistency of style and formatting, and the clarity of the language used (Parsian and Dunning, 2009; DeVon et al.,2007). In order to access the face validity of each of the two draft questionnaires in terms of readability, translations, contextual appropriateness of questions, length of questionnaire, formatting and flow of the tools, at least 12 purposively selected experts (oncologist, gynaecologist, public health specialists, social scientist and researchers) provided their evaluations through comments and suggestions for improvements. Secondly, a five member team of trained research assistants also reviewed and pre-tested the questionnaires through mock interviews and validity was determined by their qualitative evaluations.

Construct validity

Construct validity refers to the degree to which an item on a questionnaire or data collection tool relates to the theoretical construct. It is used to determine how independent variable (construct) relates to the proxy dependent variable (indicator) (Parsian and Dunning, 2009). Cognitive interviewing, after obtaining consent, was

conducted by administering questionnaires, eliciting responses to questions, and collecting additional information from respondents about how they understood the questions and how they selected their responses. The approach helps the researcher to be able to elicit the right data from the questions being asked (O'Sullivan and Rasmussen, 2017). This was done amongst 13 randomly selected participants in Harare until no more modification of the tools was required. When an indicator has multiple items, factor analysis is imperative (Parsian and Dunning, 2009) and for this study, exploratory factor analysis was applied to validate the draft constructs in the two questionnaires. The sampling for the exploratory analysis was 50 for the patient and community questionnaire and 12 for the health worker tool based on literature (Parsian and Dunning, 2009; DeVon et al., 2007).

Factor analysis is broadly used to summarize data so that relationships and patterns can be better understood (Yong and Pearce, 2013). It is a useful technique during questionnaire development and validation as it groups up items into common factors; interpret each factor on the basis of item loading and summarizing items into smaller items. Therefore, a factor is a list of items that can be clustered together (Bryman and Cramer, 1991). Loadings measure the relationship between an item and its factor and are used to identify items that could be lumped into a factor based on their magnitude. Unrelated items, those with low factor loadings, do not define a construct and should be deleted from the tool (Parsian and Dunning, 2009). Exploratory factor analysis (EFA) is applied to explore complex patterns within datasets and testing predictions. There are some conditions that need to be satisfied for EFA to be valid and these include:

I. data must be normally distributed;
II. no outliers;
III. factor should have at least 3 items, though this depends on the design of the study;
IV. variables under factor analysis should have at least 5-10 observations

In the analysis factors, we extracted factors based on two criteria; Kaiser's criteria and scree plots made in *STATA* version 14 (StataCorp LLC, Texas). Orthogonal varimax

rotations were also conducted to produce factor structures that are uncorrelated to provide easier interpretation of results, and more parsimonious solutions (Brett et al., 2010). Factor analysis, like any other scientific method has its limitations which include: challenges in naming factors, some factors may be loaded onto others making interpretation difficulty, need for large sample sizes and using singular datasets collected at specific time points, and which if collected at different points, cannot be combined for factor analysis (Yong and Pearce, 2013).

Sample size adequacy for the questionnaires for factor analysis was assessed using KMO statistic and the estimates ranged from 0.5-0.9 (see Tables 1-4). The KMO statistic values lie between 0 and 1, with values closer to 1 showing that factor analysis is appropriate. Zero value indicates that the sum of partial correlations is larger than the sum of the correlations, indicating dispersion in the pattern of correlations, thus rendering factor analysis inappropriate for analysis (Chakraborty, 2016). KMO estimates ≥ 0.5 are acceptable, 0.5-0.7 are mediocre, 0.8-0.9 are great and ≥0.9 are superb (Kaiser, 1974). On running factor analysis, factor extraction was conducted based on Kaiser's criterion of eigenvalues ≥1 and scree plots (see Figure 2) to determine the number of factors to be retained for each questionnaire. Items with communalities <0.5 were deleted from the factor solutions (Parsian and Dunning, 2009). Some researchers recommended that a factor is reliable if it has at least three items (Castello and Parsian, 2005).

We conducted EFA on data collected randomly during pilot testing using each of the two draft questionnaires based on the approach above. Given the complexities of measuring access and utilization of health services in general and the several hypotheses under investigation in the study, the two draft questionnaires had many variables to fully understand demand (patients/communities) and supply side issues (health workers) based on literature and the theoretical framework (Andersen-Newman health model). This necessitated us to analyze the data in mini-questionnaire formats based on the draft constructs to avoid Heywood case in factor analysis (Castello and Parsian, 2005). Heywood case or negative variance estimates are common errors in factor analysis and given their impossibility their causes need to be understood. Some of the causes of

Heywood case include outliers, non-convergence, empirical underidentification, structurally misspecified models or sampling fluctuations (Castello and Parsian, 2005; Kolenikov and Bollen, 2012). Furthermore, our approach made interpretation of outputs easier and resulted in meaningful factor models.

2.2.2 Reliability testing

Upon completion of the validity procedures, internal consistency reliability testing was conducted on each of the meaningful constructs derived from the two questionnaires. Reliability is defined as the ability of a tool to measure an attribute and how well the items fit together conceptually (Parsian and Dunning, 2009). In tool design and validation, reliability is important but it is not sufficient to validate the tool and it is possible to have a reliable but invalid tool. Some researchers have recommended that reliability testing be conducted on validated tools. Two estimators are reported in literature to measure reliability: test-retest reliability and internal consistency reliability (Parsian and Dunning, 2009; DeVon et al.,2007). The most commonly used method is the internal consistency reliability and this was used to test the two questionnaires in this present study.

Internal consistency is a measure of inter-item correlation within a tool and how well the item fit together within that instrument. The total score of the items is also determined to measure the overall internal consistency of the questionnaire. Split-half reliability and Cronbach's alpha correlation are the two approaches that can be used in determining internal consistency. However, Cronbach's alpha correlation is the most commonly used method as it also averages all the possible split-half estimates (Parsian and Dunning, 2009; DeVon et al.,2007).

Cronbach's alpha was estimated for each of the meaningful constructs in the mini-questionnaires of both tools designed to measure access and utilization of cervical cancer treatment and palliative care. The total scores for each mini-questionnaire were also computed to obtain overall internal consistency alpha coefficient estimates (Parsian and Dunning, 2009; DeVon et al.,2007).

2.3 Results

2.3.1 Content validity

Experts reviewed the two questionnaires and evaluated them as clear and appropriate to the subject under investigation. Based on their qualitative evaluations, the tools were determined validity in terms of their content.

2.3.2 Face validity

Experts, research assistants and participants who evaluated the questionnaires reported that they were understandable and acceptable for the intended target audience.

2.3.3 Factor analysis

After excluding binary and string variables and applying Kaiser's criterion, all the questionnaires were acceptable for factor analysis (Brett et al., 2010), see Tables 1 - 4. Using the guidance of Hair et al (1998) for reported that factor loadings ≥0.4 were important, we applied the same criteria to retain items in factor solutions. Meaningful factors were ultimately retained for each questionnaire based on literature and the subject under investigation.
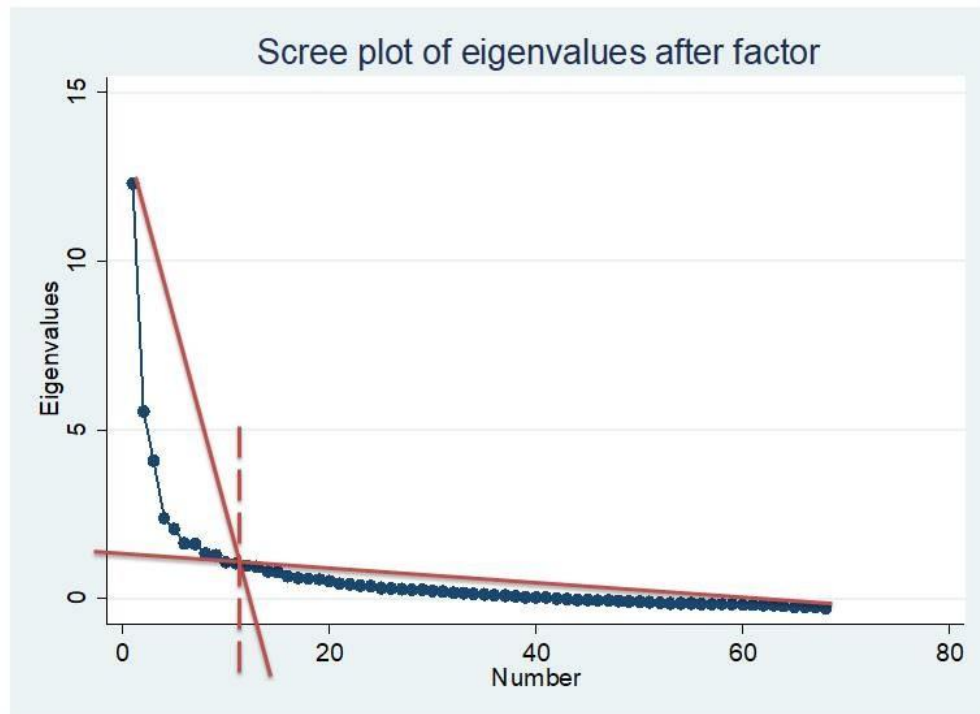
Figure 2. 2: Scree plot retaining 11 factors in a questionnaire.

The figure above (Figure 2.2) shows a scree plot of questionnaire with 11 meaningful factors based on eigenvalues (Parsian& Dunning, 2009).

2.3.4 Internal consistency reliability testing

Finally, once all the meaningful factors and items had been selected for each mini-questionnaire, we applied Cronbach's alpha correlation for internal consistency testing and all questionnaires had estimates ≥ 0.7. The estimates showed that the questionnaires had high correlations amongst items and were consistently reliable. Some researchers have recommended alpha estimates ≥0.9, though others suggested that alpha ≥0.7 is acceptable for new instruments (Parsian and Dunning, 2009; DeVon et al., 2007). We used 0.7 as our threshold in this study given that we were testing newly developed tools.

Table 2.1: Summary results from 15 factor solution of the final Patient and Community questionnaire from factor analysis and internal consistency testing for each factor.

Items	KMO	Bartlett's test (p value)	Alpha (α)
	0.7607	<0.001	0.75
1. Knowledge of cervical cancer			
a. Knowledge about cervical cancer causes and treatment			0.80
b. Sources of information			0.70
c. Knowledge of palliative care			0.80
d. Knowledge of cervical cancer treatment			0.70
2. Access to cervical cancer treatment and palliative care	0.7150	<0.001	0.79
a. Access to treatment and palliative care			0.94
b. Health facilities that provide treatment and palliative care			0.70
c. Health facilities that treat cervical cancer in Harare			0.73
3. Utilization of cervical cancer treatment and palliative care	0.9016	<0.001	0.84
a. Utilization of cervical cancer treatment and palliative care			0.89
b. Challenges faced in accessing health services			0.75
c. Access to cervical cancer screening			0.89

Items	KMO	Bartlett's test (p value)	Alpha (α)
4. Perceptions, attitudes and beliefs about cervical cancer treatment and palliative care	**0.8132**	**<0.001**	**0.78**
a. Attitudes			0.88
b. Availability of treatment and palliative care services			0.82
c. Quality of care			0.70
d. Perceptions about treatment services abroad			0.86
e. Beliefs			0.70

The table above shows the questionnaire items from factor analysis and their KMO statistic and Cronbach's alpha coefficients which were acceptable based on literature- also see Table 2.3 (Appendix 1) (Parsian and Dunning, 2009; DeVon et al.,2007).

Table 2.2: Summary results from 13 factor solution of the final Health Worker questionnaire from factor analysis and internal consistency testing for each factor.

Items	KMO	Bartlett's test (p value)	Alpha (α)
1. Health worker characteristics	**0.532**	**<0.001**	**0.72**
			0.72
a. Professional development			
b. Profession training			0.71
c. Quality of care			0.70
d. Working conditions			0.78
e. Perception of cervical cancer strategies and policies			0.71

2. Health facility characteristics	**0.639**	**<0.001**	**0.79**
a. Characteristics of cervical cancer service providers			0.87
b. Perceptions about provider quality of services			0.71
3. Service characteristics	**0.5**	**<0.001**	**0.70**
a. Cervical cancer services			0.70
b. Cervical cancer service referrals			0.70
4. Infrastructure, equipment and drugs capacity	**0.538**	**<0.001**	**0.79**
a. Availability of basic services, equipment and drugs.			0.84
b. Hygiene, sanitation and waste management capacity			0.70
c. Supply of basic services, equipment and drugs.			0.70
d. Availability drugs for treatment of cervical cancer.			0.91

Table 2.2 shows the questionnaire factor analysis items together with KMO statistic and Cronbach's alpha coefficient which were all within acceptable limits -also see Table 2.4 (Appendix 2) (Parsian and Dunning, 2009; DeVon et al.,2007).

2.4 Discussion

The integrity of any research data collection tool depends on accuracy of the measure being used particularly in the context of assessing complex phenomena such access and utilization of cervical cancer treatment and palliative care services. This study demonstrated the validity and reliability of the patient and community and health worker questionnaires to conduct both demand and supply side evaluations in the context of cervical cancer treatment and care services. The scientific approaches used in this study were rigorous and appropriate for the intended purposes. Face validity, while being the lowest form of validity was crucial in the administration of the tools amongst cervical cancer patients, healthy women in communities and health care workers. Content validity, which was measured qualitatively in this study, assisted in determining the relevance of content of both questionnaires to the concepts of access and utilization of cervical cancer treatment and palliative care. Exploratory factor analysis helped in assessing the theoretical constructs of the two questionnaires and meaningful factors were the ultimate outcomes of this analysis based on recommended best practices [(Parsian and Dunning, 2009; Castello and Parsian, 2005). Cronbach's alpha (α) internal consistency reliability reached the acceptable threshold for both questionnaires. This demonstrates that the two questionnaires could be used confidently in clinical and public health practice to determine access and utilization of cervical cancer treatment and palliative care. These tools could also be used for programme improvement and policy formulation. The tools may be used to understand cervical cancer treatment and care gaps in order to design packages of interventions to address the limitations.

Understanding access and utilization of health care services is a fundamental public health priority though these concepts are difficult to measure given their complexities. However, this study provided psychometrically valid questionnaires to specifically measure access and utilization of cervical cancer treatment and palliative care. While it is plausible to extrapolate these tools to other cancers or disease areas, care must be taken to ensure their appropriateness given the differences in disease specific issues.

However, to strengthen scientific rigor, the researchers recommend further research using a bigger sample. Furthermore, the researchers endeavor to conduct extended

analysis using structural equation modeling and confirmatory factor analysis on a larger sample with diverse population that includes healthy women, cervical cancer patients and health care workers to support wider generalizability of the tools.

2.5 Conclusion

This study showed that patient and community and health worker questionnaires were validity and reliability and can be used to evaluate access and utilization of cervical cancer treatment and palliative care in countries affected by the disease. While a plethora of approaches have been developed and used in validating questionnaires in different fields of research, this present study presents a systematic and simplified approach that can be adopted by researchers investigating complex concepts.

Ethics approval and consent to participate

This study was carried out as part of a PhD degree at the University of Pretoria and was approved by several ethics committees/bodies:

5. University of Pretoria, Faculty of Health Sciences Research Ethics Committee (**REC 487/17**)
6. Harare Hospital Ethics Committee (**HCHEC 271017/77**)
7. Joint Parirenyatwa and University of Zimbabwe Research Ethics committee (**JREC 33A/18**)
8. Medical Research Council of Zimbabwe (**MRCZ/A/ 2271**)

All participants in this study were consented in writing before interviews. Consent forms were administered by the researchers in the language of the participant's preference i.e English or Shona (local language spoken by majority of people in Zimbabwe).

Competing interests

The authors declare that there are no competing or potential conflicts of interest.

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CHAPTER THREE

Introduction

This chapter shows some differences in socio-demographic characteristics among women accessing and utilization cervical cancer screening, treatment and palliative care services in Harare. The section revealed few variations in access and usage of screening, treatment and care services by women explained by socio-demographic factors suggesting the involvement of other factors. This chapter sets the tone towards the understanding of the major sources of inequities in access and uptake of cervical cancer treatment and palliative care in Zimbabwe which are explored in subsequent chapters.

3.0 SOCIO-DEMOGRAPHIC INEQUITIES IN CERVICAL CANCER SCREENING, TREATMENT AND CARE AMONGST WOMEN AGED AT LEAST 25 YEARS: EVIDENCE FROM SURVEYS IN HARARE, ZIMBABWE.

Abstract

Background

Cervical cancer is the most commonly diagnosed cancer among women in Zimbabwe; however; access to screening and treatment services remain challenged. The objective of this study was to investigate socio-demographic inequities in cervical cancer screening and utilization of treatment among women in Harare, Zimbabwe.

Methods

Two cross sectional surveys were conducted in Harare with a total sample of 277 women aged at least 25 years. In the community survey, stratified random sampling was conducted to select 143 healthy women in Glen View, Cranborne, Highlands and Hopely communities of Harare to present high, medium, low density suburbs and peri-urban areas respectively. In the patient survey, 134 histologically confirmed cervical cancer patients were also randomly selected at Harare hospital, Parirenyatwa Hospital and Island Hospice during their routine visits or while in hospital admission. All consenting participants were interviewed using a validated structured questionnaire programmed in *Surveytogo* software in an android tablet.

Data was analyzed using *STATA* version 14 to yield descriptive statistics, bivariate and multivariate logistic regression outcomes for the study.

Results

Women who reported ever screening for cervical cancer were only 29%. Cervical cancer screening was less likely in women affiliated to major religions (p<0.05) and those who never visited health facilities or doctors or visited once in previous 6 months (p<0.05). Ninety-two (69%) of selected patients were on treatment. Women with cervical cancer affiliated to protestant churches were 68 times [95% CI: 1.22 to 381] more likely to utilize treatment and care services compared to those in other religions (p=0.040). Province of residence, education, occupation, marital status, income (personal and household), wealth, medical aid status, having a regular doctor, frequency of visiting health facilities, sources of cervical cancer information and knowledge of treatability of cervical cancer were not associated with cervical cancer screening and treatment respectively.

Conclusion

This study revealed few variations in the participation of women in cervical cancer screening and treatment explained only by religious affiliations and usage of health facilities. Strengthening of health education in communities including churches and universal healthcare coverage are recommended strategies to improve uptake of screening and treatment of cervical cancer.

Key words: Cervical cancer, inequity, socio-demographic, screening, access, treatment, stratified random sampling, Harare.

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3.1 Background

Cervical cancer is the most commonly diagnosed cancer amongst women and accounts for 18.2% of all cancers in Zimbabwe yet it is preventable [1]. At least 5 million (60%) women aged at 15-49 years risk contracting cervical cancer in their life time in the country [6]. Recent data has shown that a total of about 3,186 new cases ofcervical cancer were diagnosed in 2018 and the mortality rate was 20% [1]. Cervical cancer burden is increasing in Zimbabwe, predominantly due to high prevalence of HIV/AIDS and limited screening and treatment services [4].The past few years have seen increases in the number of cervical cancer screening facilities offering free services across the country especially in urban areas; however these services remain limited in rural areas where 66% of the women reside [4, 5]. Zimbabwe conducted an HPV vaccination pilot intervention which started in 2014 and was targeted at girls 10-14 years in schools to reduce the risk of cervical cancer [4]. However, given the impracticalities of covering the entire female population with vaccination the nation will continue relying on cervical cancer screening and treatment of pre-cancerous lesions to prevent the disease. In addition, cervical cancer diagnosis, staging and treatment remain centralized and the associated direct and indirect costs remain unaffordable to the majority of patients [4, 6-7]. Inequities in cervical cancer screening and treatment in Zimbabwe have been reported anecdotally but not much is known on their magnitude and influencing socioeconomic factors.

The United Nations Declaration of Human rights Article 25 states that: "Everyone has the right to a standard of living adequate for the *health* and well-being of himself and of his family, including food, clothing, housing and *medical care* and necessary social services" [8]. In pursuance of this international declaration Zimbabwe's health policies have been developed to ensure equity over the years. The National Cancer Strategy in Zimbabwe (2013-2017) outlined equity as its number one guiding principle yet the policy did not indicate measures meant to ensure equity in access of cancer preventive and control measures [9]. Another recent policy, the Zimbabwe Cervical Cancer Prevention and Control Strategy (2016-2020) outlined equity as a key component to ensure equitable distribution of cervical cancer prevention and treatment services [10]. Disparities in healthcare access and utilization entrenched

by age, social class, income, occupation, ethnicity, gender and place of residence have been documented [11].

Several studies have reported factors associated with uptake of cervical cancer screening in different contexts. The main factors reported were: education, income levels, marital status, age, employment and area of residence contrary to study findings [12-24]. However in Zimbabwe, some researchers found that financial independence among women and living in mining and resettlement areas were associated with uptake of cervical cancer screening [24]. Studies from across the world have also reported different determinants of cancer treatment uptake and these included: age, ethnicity, socioeconomic class, income, health insurance status, marital status, area of residence [25-29]. One study in Ethiopia revealed that cervical cancer screening was significantly associated with being at urban area, age 30-49 years, having annual household income of more than 30,000 ETB and college and above level of education [30]. There is a knowledge gap regarding inequities in the uptake of cervical cancer screening and treatment in Zimbabwe. Our present work was an imperative starting point to building evidence in the developing context for use in policy and design of interventions.

3.2 Methods

3.2.1 Data sources

Two cross sectional surveys were conducted in Harare between January and April 2018 to gather data for the study. The first survey was community based, where 143 women aged at least 25 years were randomly selected from stratified communities. Based on the Dopson sample size calculator [3, 31] the minimum sample required for the survey was 140 participants. Harare communities were stratified into low, medium and high density and peri-urban area and probability proportional to size sampling was conducted to determine the subsample for each stratum using census data [5]. Using the ballot approach one community was randomly selected from the list of communities or suburbs that had been grouped into their respective strata based on City of Harare data. The selected suburbs were Glen View (high density), Cranborne (medium density), Highlands (low density) and Hopely (peri-urban area). The subsamples achieved were 31 for each suburb and 50 for the rural area which exceeded the required minimum sample size of 140, thereby improving on the

precision of estimates. In communities, households were selected randomly by selecting a reference household and going around in an anti-clockwise direction maintaining a sampling interval of 7-10 households in high density and rural area and 3-5 households in medium and low density suburbs. At household level, when more than one woman was eligible for participation, the Kish grid approach [32] was used to select a respondent in that household. Interviews were conducted after obtaining written consent from the potential participant.

For patient survey, histologically confirmed cervical cancer patients or survivors at least 25 years old were selected using health facility records. All confirmed cervical cancer patients or survivors who visited participating health facilities between February and April 2018 were considered for participation in the study after obtaining written consent. The subsamples for Harare Hospital, Parirenyatwa Hospital and Island Hospice were 36 (27%), 86 (64%) and 12 (9%) respectively and these were proportional to the flow of cervical cancer patients based on 2017 data from the facilities. The minimum sample size required for the patient survey was 80, and this was based on the flow of patients in 2017. However, a total of 134 participants were enrolled in the study to increase the precision of estimates from the study given the different disease stages, treatments and backgrounds of the patients. Out and in-patients from Harare Central Hospital, Parirenyatwa Hospital and Island Hospice in Harare were eligible to participate in the study after consenting in writing. The researchers sought the assistance of health workers in the participating health facilities to identify histologically confirmed cervical cancer patients and to confirm treatment. During the data collection period, health workers were sensitized about the study. Patients were sensitized by their health workers and asked if they would want to participate in the study. Patients who agreed verbally to participate were then referred to the researchers for informed consent and interviews. This process was done for outpatients as well as in-patients. The researchers also verified the diagnoses of the patients during the interviews to ensure that only eligible participants were enrolled for the study. Patients were selected regardless of their place of residence. Patients who were terminally ill, mentally challenged or confused and refused to consent were not eligible to participate in the study.

3.2.2 Data collection methods

Both the community and patient surveys used a similar validated structured questionnaire, administered by the researchers in the most appropriate language to the participant, which was either English or Shona. This approach allowed for probing and verification of issues during the interview process. Survey data were collected electronically using smartphones/tablets programmed with *SurveyToGo* software. This software saved the collected data automatically in a cloud server and the researchers downloaded the data files in *csv format* from the server using a laptop. The *CSV* data file was imported to a file in *STATA* software and was used for our data analysis. The use of electronic data collection methods allowed the researchers to review data in real-time and collection of geo-coordinates for verification and monitoring sampling processes in the field.

3.2.3 Variables

The socioeconomic equity variables used in the models were province of residence categorized as Manicaland, Masvingo, Midlands, Mashonaland Central, Mashonaland East, Mashonaland West and Harare, education (primary, secondary, higher and none), religion (Roman Catholic, Protestant, Pentecostal, Apostolic sect and Other), occupation (unemployed, professional, self-employed and other), marital status (married/co-habiting, never married, widowed and divorced or separated), personal income (no income, <US$200, 200-400 and ≥430), household income (no income, <US$600, 600-1000 and ≥1200) medical aid status (yes and no) and wealth (poor, middle and rich). The categories for the variables used in the models were based on the number of observations obtained and meaningfulness based on literature [12-30].The selection of the variables in the model was also based on literature and validated tool used in the study [12-30, 37]. Confounding variables adjusted for in the logistic regression model were head of households' occupation and education and participants' area of residence (categorized as urban and rural areas) and these were based on literature [12-30]. The outcome variable for cervical cancer screening utilization was "*ever screened for cervical cancer*" and this referred to at least one screening session regardless of the method used. This variable was self-reported, though they were follow-up questions about name of facility and the date of the last screening to validate uptake of screening services. The outcome variable for cervical cancer treatment utilization was defined as any administered treatment modality: surgery, chemotherapy and radiotherapy used singly or in

combination and these were established from medical records and health professionals.

3.2.4 Data analysis

Univariate and bivariate analyses were conducted to yield descriptive statistics. Chi-squared test was used to determine significance of differences in proportions among different groups of participants. The groups were based on history of cervical cancer screening and treatment utilization at the time of the survey. Multiple logistic regression models were used to determine the socio-demographic factors associated with screening and utilization of treatment of cervical cancer using binary outcome variables. The logistic regression models were used to estimate the odds of uptake of screening and treatment services for cervical cancer by healthy women and women with cervical cancer respectively in each socioeconomic group. The models allowed us to identify the disparities in the uptake of screening and treatment services by healthy women and patients compared to reference groups respectively. A p-value of <0.05 at 95% CI was considered statistically significant. Data analyses were conducted using *STATA* version 14 software (StataCorp LLC, Texas).

3.3 Results

The mean age of participants in both the community and patient surveys was 43 years (SD=13.4). The mean age of women who participated in the community survey was 35 years (SD=8.6) while those who reported ever screening had a mean age for 37 years (SD=9.1). The proportion of women in the community survey who reported ever being screened for cervical cancer was only 29%.The majority (79%) of the participants who reported ever screening for cervical cancer were less than 45 years of age. Eighty-six percent of the community survey participants who reported ever screened for cervical cancer were from urban areas while 14% were from the peri-urban area. By further disaggregating the urban areas, 48% of women were from low density, 29% from medium density and only 9% from the high density area. Ninety-three percent of the participants who ever screened for cervical cancer were Shona while 7% were from other minority ethnic groups. With regards to marital status of the study participants, the majority (74%) of the women reporting ever screened for cervical cancer were married. Seventy-one percent of the women had secondary education and 93% of the heads of households with women who reported

ever screening for cervical cancer had at least higher education. More than half (52%) of the participants who reported ever screening for cervical cancer were affiliated to Protestant and Pentecostal churches. Thirty-three percent of the women who reported ever screening for cervical cancer screening were unemployed. The proportions of women who ever screened for cervical cancer who had no personal and household income were 48% and 50% respectively. Eight one percent of these women were poor while 60% reported being on medical aid (health insurance).

Table 3.1 (see Appendix 3) shows that the mean age of women who received cervical cancer treatment was 53 years (SD=12.7) and 45% of the patients were Harare residents. Fifty-one percent of the patients who were treated lived in urban areas compared to 49% who resided in rural areas. The majority (96%) of the cervical cancer patients who received treatment were Shona and this is reflective of population. Close to half of the patients who received cervical cancer treatment (48%) were widows probably due to HIV-related deaths and 33% were married or had partners. More than half (54%) of the patient who had received treatment had secondary education while 46% of their household heads had at least higher education. Forty percent of the patients who were treated were household heads. The majority (65%) of the patients who were treated for cervical cancer were unemployed while 16% of their households were also unemployed. Fifty-seven percent and 55% of the treated patients had no personal and household income respectively. Only 24% of the patients who received treatment were on medical aid while 76% were not. Thirty-two percent of the treated patients were poor while more than half (52%) were rich.

There were significant differences in proportions of women who ever screened for cervical cancer and those who never screened (p<0.05) with respect to urban (low and high density) and peri-urban residence,affiliation to protestant, Pentecostal and other religions, household head's secondary and higher education, household head's professional occupation status, incomes of less than US$200 and US$430 or more, having no household income and household income less than US$600. The proportions of cervical cancer patients on treatment and those not treated differed significantly (p<0.05) with respect to high density residence, affiliation to protestant and other religions, household heads with no education, and in professional occupation status.

Table 3.2 (see Appendix 4) shows the differences in cervical cancer screening and treatment by different socioeconomic groups based on logistic regression model outcomes. Women affiliated to Roman Catholic, Protestant, Pentecostal and Apostolic sect religions were less likely to uptake screening services compared to those in other religions (p<0.05). Women who visited health facilities or consulted doctors once or never six months prior to the survey were less likely to use screening services for cervical cancer (p<0.05). Age, education, occupation, marital status, medical aid status, income (personal and household), wealth, sources of cervical cancer information, having regular doctor and knowledge of treatability of cervical cancer were not associated with uptake of cervical cancer screening after controlling for household heads' occupation, education and area of residence area of residence directly related to income, education level, medical aid. Women with cervical cancer who were affiliated to Protestant churches were 68 times [95% CI: 1.22 to 381] more likely to utilize treatment and care services compared to those in other religions (p=0.040).Province of residence, education, occupation, ethnicity, marital status, income (personal and household), wealth, medical aid status, sources of cervical cancer information and knowledge of treatability of cervical cancer were not associated with utilization of cervical cancer treatment and care after controlling for household heads' occupation, education and area of residence.

3.4 Discussion

This study investigated the socio-demographic inequities in uptake of cervical cancer screening and treatment among healthy women and those with cervical cancer aged at least 25 years old. Non-participation in cervical cancer screening was associated with affiliations to Roman Catholic, Protestant, Pentecostal and Apostolic sect religions. Healthy women who never visited health facilities or doctors or only visited once were less likely to screen for cervical cancer. Age, education, occupation, marital status, medical aid status, income (personal and household), wealth, sources of cervical cancer information, having regular doctor and knowledge of treatability of cervical were not associated with uptake of cervical cancer screening services after controlling for confounders. Utilization of treatment for cervical cancer was positively associated with affiliation to Protestant churches.. Province of residence, education, occupation, Shona ethnicity, marital status, income (personal and household), wealth, medical aid status, sources of cervical cancer information and knowledge of

treatability of cervical cancer were not associated with utilization of cervical cancer treatment and care after controlling for household heads' occupation, education and area of residence. The study of socio-demographic inequities of cervical cancer screening and treatment is an important research endeavour in the context of Zimbabwe and other similar contexts. In our study context inequity is define as unfair and systematic disparities in the usage of cervical cancer screening and treatment services by groups already disadvantaged with respect to health [35]. We have shown that belonging to major religious affiliations and using health facilities less frequently is associated with non-participationin cervical cancer screening. Over the past few years there have been great strides by the government and its partners to scale-up free screening and treatment of pre-cancerous lesions across the country. A number of screening sites using the VIAC approach have been set up across the country [4, 34]. These facilities are however still centralized at provincial and district levels, although the majority of women are domiciled in rural areas which may be far from service centers [4, 5]. Our work did not find any disparities in uptake of cervical cancer screening by urban women compared to their peri-urban counterparts. This finding is not supported either by a systematic review conducted in 67 countries where rural residence was a determinant of non-participation in screening for cervical cancer [23].The National Cervical cancer prevention and control strategy (2016-2020) was a result of efforts to reduce cervical cancer burden in the country. However, its implementation has remained poor due to limited resources as suggested by recent reports [4, 6]. Despite these efforts, screening uptake has not improved significantly from 2015 when the ZDHS reported 24% [33] while our study found 29% ever screened for cervical cancer in Harare. This suggests low uptake or perhaps underutilization of the cervical cancer screening interventions. While service fees are a major barrier to uptake of health services [7, 11-13], the provision of free screening services was implemented to improve access to all women who may be at risk. Our results suggest that there are potentially additional underlying issues driving low screening utilization. This research found religious affiliations and usage of health facilities as determinants of participation in cervical cancer screening similar to some earlier work done in Zimbabwe on general health service uptake [11]. In the African context this may suggest the underlying roles of social norms influencing uptake of screening services in healthy women [12, 14, 21-22, 24]. Some religions, where the majority of women in Zimbabwe are affiliated, influenced non-participation

in screening services suggesting that belief systems may be important determinants of uptake of preventive interventions [33]. Our findings contrast the results from several other studies done in both developed and developing countries [12-24]. Some Denmark researchers reported basic education, low income and being unmarried very similar to Zim population as determinants of non-participation in cervical cancer screening services, while our study did not find any associations [15]. Some researchers reported low family disposable income, low education and non-cohabiting influencing non-usage of screening by Swedish women [16] but our work found only religious affiliations and utilization of health facilities as determinants in context of Harare. A plethora of studies conducted in many countries and at different time points clearly pointed out age, education, income, marital status, employment, family income, ethnicity and wealth as major socio-demographic determinants of inequities to cervical cancer screening [12-24] but our study suggested only religion and usage of health facilities. Findings from another Zimbabwean study [24] were not in agreement with our results suggesting dynamisms in the screening determinants over time and/or other factors influencing cervical cancer screening. However, our work found only two out of the myriad of determinants of screening reported in literature.

While screening for cervical cancer services are fairly increasing in coverage in Zimbabwe, treatment of confirmed cases has remained challenged [4, 6]. We have demonstrated that religion was associated with inequities in the uptake of cervical cancer treatment.. Our work found that the majority of socio-demographic factors (age, race, occupation, low socioeconomic class, income, ethnicity, region of residence, health insurance status and wealth) except for religion reported in literature [25-30] were not associated with utilization of cervical cancer treatment in our context. Some studies have reported high costs of treatment for cervical cancer as a major barrier [4, 6-7], however; we found that income both personal and household as well as wealth were not associated with receipt of treatment.A study in USA had found no effect of marital status on receipt of treatment for cervical cancer though single patients had low survival chances [29] and this was not supported by our work. As opposed to cervical cancer screening which was associated with religious affiliations and usage of health facilities, utilization of treatment for cervical cancer was only associated with one religious affiliation (Protestant) and no other

socio-demographic factor reported in literature [25-30]. It is also plausible that inequities in both uptake of screening services and treatment of confirmed cervical cancer in the Zimbabwean context may be potentially entrenched by behavioral, societal and health system factors. These factors may be directly related to socioeconomic factors. Behavioural factors such as knowledge of cervical cancer, attitudes towards the disease, values concerning health and illness and perceptions of need of routine screening and treatment may be important to meditate on. Societal factors may include social norms about routine screening and treatment, technologies, social networks/support for screening and treatment uptake, beliefs about cervical cancer, misconceptions about the disease and its treatment. There are a plethora of potential health system determinants and these may include: number and distribution of screening and treating centres, health worker knowledge and skills, organization of health service delivery, physical infrastructure, policies and supportive laws [36, 38]. Further research work involving mixed method designs is imperative to fully understand the drivers of inequities in the developing countries.

The strengths of our study lie in several aspects, mainly that a robust cross sectional design was conducted. The design involved stratification of known confounding variables i.e area of residence and socioeconomic classification in the surveys. The patient survey was based in quaternary health facilities providing treatment and care for cervical cancer in Zimbabwe. The use of multivariate analyses allowed for meaningful associations to be identified given that confounding variables were adjusted for. More importantly, this study used a structured questionnaire that we designed and validated for use in developing country contexts [37]. In addition this study improved the methods of other studies cited in that it had two groups of participants, healthy women and those with cervical cancer in different study settings and comparisons of the factors associated with screening and treatment at the same time point gave a better picture of the status of wider cervical cancer interventions in the country. This makes the findings of this research a good starting point in improving policy and programmes. However, this research being a cross sectional design prevented causal inferences to be established. Furthermore, cervical cancer screening status was self-reported from healthy women who had been selected randomly in the communities. Self-reported data may be biased as there is no way of verification. However, our validated tool [37] had follow-up questions on "*Last date of*

screening" and "*Name of health facility where last screening was conducted*" in order to validate the screening status. For the patient survey, only participants from public health facilities and an NGO facility were recruited as two private health facilities providing cancer treatment declined to grand permission for this study. However; the majority of cervical cancer patients in Zimbabwe are treated in public health facilities and the inherent bias of conducting this study in these facilities was minimal. Small sample sizes can also compromise statistical precision.

3.5 Conclusion

Our study revealed few variations in the participation of women in cervical cancer screening explained by religious affiliations and usage of health facilities. While our results suggested that receipt of cervical cancer treatment was only associated with protestant religious affiliation there may be indirect relationship through stage of presentation which in turn influences treatment modalities. Behavioral, social/societal and health system factors may be better in explaining inequities in uptake of cervical cancer prevention and treatment interventions in developing countries. Further investigation of these factors is crucial in order to design effective policies and interventions at a time cervical cancer burden is increasing in resource-limited settings. The design of targeted interventions to improve participation in preventive measures and usage of treatment services for cervical cancer is implied.

List of abbreviations

AIDS   Acquired immunodeficiency syndrome

HIV   Human immunodeficiency virus

HPV   Human papilloma virus

NGO   Non-governmental organization

VIAC   Visual inspection with acetic acid cervicography

ZDHS   Zimbabwe demographic and health survey

Declarations

Ethics approval and consent to participate

This study was carried out in partial fulfillment of the requirements of a PhD degree at the University of Pretoria and was approved by several ethics committees/bodies:

9. University of Pretoria, Faculty of Health Sciences Research Ethics Committee (**REC 487/17**)
10. Harare Hospital Ethics Committee (**HCHEC 271017/77**)
11. Joint Parirenyatwa and University of Zimbabwe Research Ethics committee (**JREC 33A/18**)
12. Medical Research Council of Zimbabwe (**MRCZ/A/ 2271**)

All participants in this study were consented in writing before interviews. Consent forms were administered by the researchers in the language of the participant's preference i.e English or Shona (local language spoken by majority of people in Zimbabwe).

Consent for publication

Not applicable

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare no conflict of interests.

Funding

Authors' contributions

OT: researcher, concept and study design; WK and AMN: concept and study design, clinical oversight, critical revision and editing; WM: concept design, critical revision and editing; GD: PhD Co-supervisor, concept design, critical revision and editing; SJHH: PhD Supervisor, concept and study design, critical revision and editing; BSP, critical revision and editing. All authors reviewed and approved this manuscript.

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CHAPTER FOUR

Introduction

The previous chapter revealed few socio-demographic characteristics associated with limited access to cervical cancer screening, treatment and palliative care among women in Harare, Zimbabwe. This chapter will explore other determinants of access to treatment and care among women with cervical cancer apart from socio-demographic factors which did not explain much of the known variations. Chapter four will reveal individual, societal and health system determinants of access and uptake of cervical cancer treatment and palliative care.

4.0 DETERMINANTS OF ACCESS AND UTILIZATION OF CERVICAL CANCER TREATMENT AND PALLIATIVE CARE SERVICES IN HARARE, ZIMBABWE.

Abstract

Background
Cervical cancer treatment and care services have remained largely centralized in Zimbabwe thereby entrenching inequities to access amongst patients. The objective of this study was to investigate the determinants of access and utilization to treatment and care by women with cervical cancer in Harare, Zimbabwe.

Methods
A sequential explanatory mixed methods design was used. In phase 1, three surveys (namely community, patient and health worker) were conducted with sample sizes of 143, 134 and 78 participants respectively. Validated structured questionnaires programmed in Android tablet with *SurveytoGo* software were used for data collection during the surveys. Univariate, bivariate and multivariate logistic regression analyzes were conducted using *STATA®* version 14 to generate descriptive statistics and identify determinants of access to cervical cancer treatment and care. In phase 2, 16 in-depth interviews, 20 key informant interviews and 6 focus groups were conducted to explain quantitative data. Participants were purposively selected and saturation principle was used to guide sample sizes. Manually

generated thematic codes were processed in *Dedoose* software to produce final outputs for qualitative study.

Results

Knowledge of causes (p=0.046), perceptions of adequacy of specialists (p<0.001), locus of control (p=0.009), service satisfaction (p=0.022) and walking as a means of reaching nearest health facilities (p<0.001) were associated with treatment or perceptions of access by healthy women. Perceptions of access to treatment amongst health workers were associated with their basic training institution (p=0.046), health service quality perceptions (p=0.035) and electricity supply status in their respective health facilities (p=0.036).Qualitative findings revealed health system, societal and individual factors as barriers to accessing treatment and palliative care.

Conclusions

The findings of this study revealed that heath system and societal level factors were more important than individual level factors. Significant investments across all the pillars of the health system should therefore be prioritized as a starting point.

Key words: Cervical cancer, access, determinants, treatment, palliative care, inequity, health system, sequential mixed methods, Zimbabwe.

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4.1 Background

Cervical cancer treatment and care which include services such as radical surgery, radiation and chemotherapy as well as palliative care are still largely centralized in Zimbabwe [1, 2]. In the health facilities where treatments are available, costs are exorbitant and the referral systems are challenged to afford women with advanced cervical cancer high level of care. Paucity of treatment and care services for cervical cancer in Zimbabwe, has promoted medical tourism to countries such as South Africa, India, China and Europe by the affluent members of society [2]. This has a negative impact on perceptions, acceptance and utilization of health services in Zimbabwe which in turn entrenches inequities [3]. However, determinants of access to treatment for cervical cancer in their various dimensions: individual, societal and health system levels; are less understood in Zimbabwe.

In 2000, Chirenje et al [4] reported that 77% of women diagnosed with cervical cancer (1995-1997) were engaged into treatment using radiotherapy. However,no recent data exists on the proportions of women with confirmed cervical cancer who are being engaged into treatment and care. While knowledge about the disease, its risk factors and screening programmes has improved over the past few years a huge information gap exists about treatment and palliative care interventions in the country. Fallala & Mash [6] in their Bulawayo, Zimbabwe study noted that of the 10.8% women who tested positive to visual inspection with acetic acid cervicography (VIAC), 61.1% received immediate treatment while 38.9% were either delayed or referred to a Gynaecologist. There is no evidence of a system to follow-up on these 38.9% to ensure that they got into treatment and care. Lack of a system to follow-up patients predisposes women to high risk of late stage disease presentation which is associated with increased morbidity and mortality in developing countries like Zimbabwe [1, 2]. The provision of treatment and palliative care services is still very limited in the country. Several factors were noted by Pomerai et al [5] to influence knowledge about cervical cancer. These include lack of prioritization of the disease by health workers and Ministry of Health and Child Care, lack of a clear case definition of the disease as well as limited funding from global donors. This study was envisaged to address some of the knowledge gaps and setting a foundation for further research in cervical cancer treatment and palliative care in Zimbabwe.

4.2 Methods

4.2 1. Study Design

This study used a sequential explanatory mixed methods design of both quantitative and qualitative research methods to generate evidence [7-10]. The priority of the design was on quantitative nature of the study and the implementation was in a sequential manner QUAN $\longrightarrow$ qual. This study was primarily based on a quantitative design in phase 1, while qualitative methods were used in phase 2 to interpret and explain some of the findings from surveys. In phase 1, analytical cross sectional survey approach was used to collect quantitative data and this study design was used in investigating the relationship between different variables and access to treatment as a dependent variable. [8, 9] In this phase three surveys were conducted, that is, a community based survey, a health facility (patient) based survey and a health worker survey. In phase 2, qualitative design was mainly used to explain significant, non-significant, outliers and surprising results from the surveys [7, 10]. The findings of phase 1 and 2 were integrated at interpretation stage and a combined analysis was utilized to generate evidence for this study

4.2.2 Target population, sample sizes and data collection

The target population for Phase 1(quantitative surveys) consisted of three groups: 1) healthy women 2) cervical cancer patients or survivors (previous history of cervical cancer) aged 25 years or older and 3) health workers directly involved in cervical cancer screening, diagnosis and treatment. The age range was informed by studies and anecdotal evidence from health facilities that have shown the incidence of cancer being higher amongst women who are older than 30 years [4, 6]. In Zimbabwe cervical cancer screening is recommended for sexually active females between 18 and 49 years old [6]   and for that reason it was plausible to recruit participants aged at least 25 years old for this study. Group 1 consisted of 143 healthy women who were resident in Harare (urban and rural) for at least one year and were randomly selected. Multistage stratified random sampling was used in which four areas in Harare were selected for community based survey to represent each of the following: high, medium, low density suburbs and rural areas. The three suburbs were selected from a total of 138 suburbs in Harare urban. One of the study areas was a rural community and it was selected randomly out of seven communities

in Harare. The Kish grid approach was used to select one respondent in households with more than one eligible respondent as it is the most commonly used technique in surveys in Zimbabwe [11]. Group 2: One hundred and thirty-four (134) cervical cancer patients or survivors with histologically confirmed disease were also randomly selected at Harare and Parirenyatwa hospitals as well as from the Island Hospice and Cancer Centre. Patient and community survey sample sizes were based on Dopson sample size calculator [4, 12]. Patients were selected from health facilities as they made treatment or review visits (outpatients) or from databases or records (in-patients) regardless of where they were resident. This is because the chosen health facilities were quaternary facilities that treat and care for patients from across the country and for this study it was important to reduce bias by selecting patients regardless of where they stayed. Group 3: For the health worker survey, 78 participants were selected randomly from the health facilities from which cervical cancer participants were drawn. Staff registers were used as the sampling frame from which participants were selected to avoid bias by selecting from those on duty at the time of the survey. Validated structured questionnaires were used for data collection for surveys. Questionnaires were programmed in *SurveytoGo* software in an Android tablet to allow for electronic data collection.

The Qualitative part of the study (phase 2) was conducted in the same areas where survey data were collected. A total of 84 participants were purposively selected based on desired characteristics for the study. Six focus groups with an average of 6 participants each were conducted in the communities and health facility (Parirenyatwa Hospital). For in-depth and key informant interviews 16 and 20 participants were enrolled for participation based on theoretical saturation principle [13]. During phase 1, the researcher identified some potential participants, based on desired characteristics and sensitized them about enrolment in phase 2 of the study. All in-depth interviews and FGDs were conducted in communities and health facilities. In communities, church premises were used for conducting focus groups after permission from church elders was obtained. Key informant interviews were conducted in health facilities and in offices of participants. Interview and discussion guides were used for qualitative data collection and responses were audio-recorded after obtaining written consent.

4.2.3 Data analysis

Quantitative surveys

Data analysis were conducted using *STATA®* version 14 software by the researcher to yield descriptive statistics and to compare and establish the nature of relationships between variables. Univariate analysis was used to generate descriptive statistics and bivariate analysis was conducted to identify significant factors for multivariate logistic regression models. Multivariate binomial logistic regression was conducted to identify individual, societal and health system determinants of access and utilization of cervical cancer treatment and palliative care services in Harare.

Qualitative study

Transcription and translation of audio-recordings were undertaken by the researcher and his assistants. Transcripts were identified by the unique identifier previously assigned to each participant (and stated by each participant at the beginning of the FGD/interview) rather than by any personal information. Unique identifiers were used to link the questionnaire and the interview only after the conclusion of transcription. All in-depth interviews, key informant interviews and FGDs were coded manually line by line by the researcher using *Dedoose software* after creation of codes based the research questions and literature. Manually generated thematic codes were processed in the same software to produce final outputs for the phase 2. Findings of the phase 1 and the phase 2 were integrated at interpretation stage in which case qualitative findings assisted in explaining and interpreting significant, non-significant, outliers and surprising results from the quantitative study.

4.3 Results

4.3.1 Quantitative results

Table 4.1 (see Appendix 5) shows that the majority (45%) of women who received treatment for cervical cancer were resident in Harare. The proportion of women who reacived treatment unemployed (65%), had no personal income (57%), no household incme (55%) and no medical aid (76%). Proportion of cervical cancer patients who were treated was 69% while proportion of healthy women who had the perception of access to treatment if diagnosed of the disease was 80%.

Table 4. 1: Determinants of access and utilization of cervical cancer treatment and care from healthy women and patient surveys

Participant type	*Healthy women with perceptions of access to treatment if diagnosed of cervical cancer (n=70)		Cervical cancer patients treated (n=92) [N=134]	
Variables	OR , (95% CI)	p value	OR, (95% CI)	p value
Individual factors**				
Knowledge of prevention	0.34 (0.06 to 1.88)	0.218	2.50 (0.53 to 11.97)	0.248
Knowledge of causes	**6.18 (1.03 to 37.14)**	**0.046**	**0.13 (0.02 to 0.68)**	**0.016**
Perception of availability of treatment services	1.08 (0.36 to 3.23)	0.889	1.89 (0.65 to 5.54)	0.244
Affordability of treatment services	0.50 (0.17 to 1.43)	0.197	1.57 (0.45 to 5.59)	0.480
Locus of control regarding cervical cancer	0.97 (0.39 to 2.42)	0.949	**2.90 (1.30 to 6.45)**	**0.009**
Perception of threats from cervical cancer	1.42 (0.61 to 3.28)	0.412	0.49 (0.15 to 1.57)	0.229
Perception on medical tourism	2.25 (0.95 to 5.34)	0.064	0.91 (0.42 to 1.97)	0.819
Usage of health services in last 6 months	1.74 (0.55 to 5.45)	0.344	-	-
Societal factors**				
Perception of availability of prevention technologies (HPV vaccination and screening)	0.82 (0.45 to 1.50)	0.521	0.91 (0.42 to 1.97)	0.777
Perceptions of availability of equipment	0.97 (0.36 to 2.58)	0.946	0.51 (0.21 to 1.22)	0.129
Social support	0.54 (0.18 to 1.68)	0.291	0.28 (0.07 to 1.15)	0.078
Beliefs	0.19 (0.02 to 1.77)	0.145	0.70 (0.07 to 6.76)	0.758
Attitudes	1.53 (0.37 to 6.25)	0.555	0.24 (0.03 to 1.83)	0.168
Health system factors**				
Perception of training of Health Professionals	2.19 (0.73 to 6.60)	0.162	0.88 (0.08 to 9.32)	0.912
Perceptions of adequacy of specialists	**10.77 (3.10 to 37.32)**	**<0.001**	**7.32 (1.53 to 35.06)**	**0.013**
Quality of care	-		0.19 (0.03 to 1.45)	0.110
Satisfaction	-		**27.15 (1.61 to 458.85)**	**0.022**
Accessibility of health facilities**				
Distance from nearest health facility				
		0.759		

Less than 10km	1.46 (0.13 to 16.64)	-	1.24 (0.29 to 5.26)	0.775
21 to 40 km	Ref		Ref	-
Mode of transport to nearest health facility				
Walking	**0.08 (0.03 to 0.24)**	**<0.001**	0.21 (0.03 to 1.80)	0.155
Public transport	0.75 (0.13 to 4.51)	0.015	0.21 (0.02 to 1.93)	0.169
Private car	Ref	-	Ref	-
Time to travel to nearest health facility				
30 or less minutes	0.87 (0.31 to 2.43)	0.794	1.50 (0.29 to 7.70)	0.624
31 to 60 minutes	-	-	0.83 (0.12 to 5.63)	0.848
90 or more minutes	Ref		Ref	-

*For healthy women, proxy indicator of access to treatment was used based on their perceptions of whether they would access treatment services for cervical cancer if diagnosed. **Model 1 controlled for disease stage for patients and religion and ethnicity for healthy women, *** Model 2 controlled for financial barriers for patients and religion and ethnicity for healthy women. Bold shows factors that are significant (p<0.05).

Table 4.2 above shows that knowledge of causes of cervical cancer was negatively associated with receipt of treatment by patients (p=0.046) and positively correlated with perceptions of access to treatment by healthy women (p=0.016). However, knowledge of prevention of cervical cancer did not influence uptake of treatment or perceptions of access thereof. Locus of control with regards to cervical cancer was positively associated with uptake of treatment amongst patients (p=0.009) but was not associated with perceptions of access to treatment amongst healthy women. Receipt of treatment and perceptions of access to it were not associated with any societal factors. Perceptions of adequacy of specialists were positively associated with uptake of cervical cancer treatment (p<0.001) and perceptions of access to it amongst healthy women (p=0.013). Service satisfaction was correlated with receipt of treatment services amongst cervical cancer patients (p=0.022). Walking as a means of reaching nearest health facilities was negatively associated with perceptions of access to treatment for cervical cancer amongst healthy women (p<0.001).

Table 4.3 (see Appendix 6) shows that the mean age of health workers was 37 years (SD=10), with majority of health workers being below 50 years of age (92%). Average number of years of experience in health profession was 12 years (SD=10). Fifty-four percent (54%) of the respondents were from Parirenyatwa hospital, 33%

from Harare Hospital, 12% from Island Hospice and 1% from Cancer Centre. In multivariate analysis, after controlling for all factors (Table 4.3), perceptions of access to cervical cancer treatment from health worker's perspective were associated with their basic training institution (p=0.046), health service quality perceptions (p=0.035) and electricity supply status in their respective health facilities (p=0.036). However, challenges faced in seeking treatment by patients were slightly insignificant (p=0.066).

4.3.2 Qualitative results

Access to cervical cancer treatment and care

Qualitative interviews and FGDs suggested that most cervical cancer patients were not able to access treatment and care services from health facilities due to multidimensional barriers. This is shown by what some participants had to say:

"….*because we must remove the barriers and one of the barriers is cost and the other one is accessibility*". -Senior Gynaecologist from Harare Hospital, key informant

"At Karanda hospital they did a biopsy after 2 weeks her results were out and then she was referred to Parirenyatwa hospital that's when we came in March and the doctors were on strike…"- Caregiver from Goromonzi,23 years

Cost of diagnosis and treatment

Quantitative results from the community and patient surveys revealed that affordability was not associated with perceptions of access to treatment or uptake of treatment. However, the majority of participants in the In-depth, FGDs and key informant interviews cited the high costs of cervical cancer treatment as the biggest barrier to accessing services. The direct costs that were reported were incurred during diagnosis, staging and treatment stages, with diagnosis and staging costs causing most of the impediments to getting treatment. One junior oncologist (key informant) reported that:

"In terms of costs I would estimate that staging and radiation therapy is about US$2000 and chemo-radiation including staging is around US$2500".

Cost of biopsies

While the collection of the biopsy samples may be done in some public hospitals, the processing of the samples and investigations are done in specialized laboratories by pathologists. Qualitative findings suggest significant barriers in accessing treatment due to lack of access to biopsy histological investigations. Most respondents reported challenges in accessing the histological investigations due to limited number of doctors who can perform the procedure, long turnaround times for results from public health laboratories and the high costs involved which presents a barrier to treatment uptake. One VIAC nurse/Midwife reported that:

"Histology is done at Lancet Laboratories (private laboratory) so depending on the specimen that was taken they pay from US$36 upto US$56 and one may not be able to pay for their specimen."

Cost of staging

Based on the FIGO guidelines [15], cervical cancer must be staged to inform the treatment modalities. Staging involves laboratory investigations, X-rays, ultrasound scans and at times CT scans. These procedures are mandatory before a patient can be commenced on treatment. Most respondents alluded to the challenges of accessing these services due to high costs, limited availability and the time it takes to get all the investigations together for a decision to be made on a treatment plan. This was revealed by in the statement below:

"….I paid for scan and x-rays which were US$20 and US$65 respectively. When I came here I had another scan done which was US$65 and from there you realize the costs are going up" -Patient from Kwekwe, 45 years

Cost of laboratory investigations

Laboratory investigations are conducted for diagnosis, staging and during the treatment and care continuum. Some respondents reported challenges in accessing laboratory tests due to limited capacity of treatment at such health facilities to conduct some investigations efficiently. In addition there were also the high costs of the laboratory tests not to mention the frequency with which they are requested before, during and after treatment. A 45 year old patient from Kwekwe reported that:

"Blood tests were US$45 because they were done twice. I had 25 days for radiotherapy treatment and on the last day I was told I needed more blood and for four pints I was told it would cost me US$220 and I no longer had any money so I managed to buy two pints"

Cost of transport

Qualitative findings suggest that lack of transport or high transport costs were frequently reported barriers to accessing treatment for cervical cancer in Harare. Most of the patients treated at Parirenyatwa Hospital come from far places, outside Harare and this translated into huge transport costs. One 41 year old caregiver from Mabvuku has this to say:

"Lack of money is also a problem because some people stay far away from hospitals so some may not even have money for transport".

Cost of palliative care related services

Our findings reveal that even palliative care services is very expensive cost of money and this burden is laid on the patient and her family. Some of the palliative care services include blood transfusion, pain medication, palliative radiotherapy and chemotherapy and visits made by palliative care stuff from Island Hospice. Another 45 year old patient from Mutoko reported that:

"When I got back I was in Mutare, after four days I fell ill again and got admitted at Mutare General Hospital and was given two pints of blood, advised to buy Ranferon tablets and some drugs to stop the bleeding"

Opportunity costs

Qualitative findings reveal a number of opportunity costs namely loss of ability to bear children, loss of income, loss of employment and loss of property or savings and these were mentioned by some respondents. A 49 year old Chiredzi patient reiterated that:

"Sometimes one doesn't go to work and has no means of getting any money to go to the hospital that is why some get to the point of dying because they don't have money".

Acceptability factors and ability to seek

Qualitative results showed a number of acceptability barriers which negatively influenced the ability to seek treatment services by patients. The most commonly cited factors were health worker's negative attitudes, misconceptions about cervical cancer and its treatment, lack of knowledge about radiotherapy, alternative interventions (spiritual and traditional), cultural beliefs, family influences and partner attitudes or perceptions. One respondent mentioned that:

"Radiotherapy, in our community people are very hesitant as they have their own way of thinking because they don't know what really happens. Some say the moment you undergo radiotherapy they put heavy metals on your body and your chest so your veins will not function well so they believe it is better for one to die at home than go for radiotherapy" - Patient from Chiredzi, 49 years

Approachability factors and ability to perceive

Cervical cancer treatment and palliative care services were reported by most interviewees as scarcely publicized even in health facilities. Most of the focus has been on screening and treatment of pre-cancers but there is little awareness on cervical cancer treatment. Despite some awareness campaigns on cervical cancer lack of knowledge still exists in communities and amongst health care workers which reduces the ability to perceive treatment services by people. Cervical cancer and its treatment is shrouded with many misconceptions that were reported by many respondents. One 39 year old survivor from Mabvuku mentioned that:

"….like I mentioned earlier on it is because of lack of awareness so because the cancer doesn't bring symptoms at an early stage so one will be thinking that health wise they are ok."

Availability and accommodation and ability to reach

Many patient respondents reported travelling great distances to access treatment in Harare at Parirenyatwa Hospital. Some of the interviewees reported being put on long waiting lists for treatment while some cited health worker strikes and radiotherapy machine breakdowns as barriers to their accessing treatment. These affect the availability of treatment and patients' ability to reach treatment facilities. A WHO official (key informant) reported that:

"I was discussing with the director about chemotherapy in Harare that he went there and saw hundreds of women waiting and they were waiting for one machine, which breaks down here and there."

Appropriateness factors and ability to engage

Qualitative results showed that there is no follow-up system for cervical cancer patients in the treatment and care continuum. Even during diagnosis stages, patients may present at many different health facilities as "new patients" to get second opinions or just an act of denial of their cervical cancer diagnosis. The health system relies on patients presenting themselves at the treating facilities for diagnosis, staging and treatment or to get follow-up reviews after their treatments. Some respondents reported missing their treatment/procedures due to challenges mostly lack of finances, beliefs, misconceptions or family influences. All these factors negatively affect the patient's ability to engage with healthcare services. One key informant from Harare Hospital explained that:

"The problem that we have is that if we suspect a patient has cervical cancer we may see her last the day that we would have suspected her of cervical cancer, that follow up routine is not coming out to say the person we have referred to our outpatient department (OPD) for us to know that the patient has done the biopsy and their results. We tell them to come back with their health cards but they don't come back." -VIAC nurse from Harare Hospital, key informant

4.4 Discussion

There is considerable evidence that access and usage of cervical cancer treatment and palliation care services is a challenge and therefore uptake is low. Data from surveys revealed that 69% of cervical cancer patients interviewed at health facilities

were on treatment, while 80% of healthy women in communities perceived that they would access treatment if diagnosed of cervical cancer. These figures are consistent with what was reported in 2007, where 77% of diagnosed cervical cancer patients were treated with radiation [4]. While these figures seem high and perhaps encouraging, what remains unknown is the proportion of women with cervical cancer who are not presenting at health facilities for treatment. Furthermore, qualitative findings suggest a myriad of barriers to treatment. These barriers are multidimensional and most patients are not getting to the point of histological diagnosis/confirmation or staging due to supply and demand side barriers. Our findings are supported by some recent studies which reported that patients with advanced disease were less likely to pursue further investigations for staging and some refused treatment [16, 17].

In bivariate analysis, patient and community surveys revealed that residence in high density suburbs, belonging to other religions (other than the most common ones: Pentecostal, Protestant and Apostolic sect), and having a head of household with no formal education was associated with not being treated. However, being affiliated to protestant churches and having a household head in professional category were associated with treatment for cervical cancer. However, in multivariate analysis no socio-demographic factors were associated with receipt of treatment. These findings are supported by other studies in similar context [18, 19]. Most respondents in the qualitative research mentioned financial barriers as the major hindrances to accessing diagnosis, staging and treatment services. Having medical aid was also reported by some respondents as a facilitating factor to accessing healthcare services, though there was no statistical significance in the survey. These findings suggest that health system factors (few treating centres, lack of infrastructure, lack of commodities such as drugs, limited number of radiotherapy machines, frequent breakdowns of radiotherapy machines, high costs of services , few specialists, lack of standardized guidelines, lack of health information system, lack of patient follow-up system and bureaucratic referral system) and social factors (lack of knowledge, fear, stigma, misconceptions, family influences, attitudes, beliefs, influence of traditional and spiritual healers) may play a major role in influencing poor treatment uptake compared to individual factors. Other researchers found that the cost of medication prescribed for cervical cancer was one of the barriers to adherence [20].

In the USA, young women with no health insurance and low socioeconomic status were likely to delay treatment for breast cancer [16]. In another study the researchers found no association between affordability (individual factor) and uptake of cervical cancer screening [21].

Knowledge of causes of cervical cancer was negatively associated with treatment uptake however; it was positively associated with perception of access to treatment among healthy women. Qualitative findings showed that more factors than knowledge seem to influence treatment utilization and these may include beliefs, attitudes, misconceptions about cervical cancer and its treatment, economic factors, health system factors, family, traditionalists' and spiritualists' influences. In addition, our qualitative findings suggest that those women who knew more about cervical cancer had presented late and had more knowledge because of their experiences with advanced disease. In addition, there are a number of misconceptions around radiation therapy which may present a barrier to patients especially with advance disease. One of the misconceptions is that radiation therapy quickens death hence some patients refuse this treatment modality until they have advanced disease when they become desperate. This is supported by findings in a Moroccan study that showed that patients with advanced disease were more likely to refuse further investigations and treatment itself [28]. These factors do not affect healthy women as they did not have the disease yet and the factors that affect sufferers were not present. Some researchers reported that patients with a lack of knowledge were at risk of patient delay for treatment [22]. Generally, many studies have shown that knowledge, availability or lack of it influenced access to healthcare services [23, 24]. Knowledge of prevention did not influence either treatment uptake or perception of access to it suggesting that there is little awareness of prevention of cervical cancer. Our qualitative results suggest that there are limited awareness campaigns about cervical cancer prevention and some health workers have limited knowledge of cervical cancer hence may not be effective in educating communities. Lack of knowledge about cervical cancer as a preventable disease was also reported in our qualitative interviews and focus group discussions as evidenced by misconceptions that cancer is a "*death sentence*" and that it is caused by evil spirits hence could not be prevented or treated.

Locus of control with regards to cervical cancer was positively associated with uptake of treatment amongst patients but was not associated with perceptions of access to treatment amongst healthy women. Some researchers have defined locus of control as to the extent to which an individual perceives events and actions in his or her life as a consequence of their own behaviour, ability or characteristics (internal control) [25]. Other studies have reported association between internal locus of control and uptake of cervical cancer screening [26]. Lack of association of locus of control and perceptions of access to cervical cancer could be explained by lack of knowledge and the mere fact of absence of disease in the respondents. Qualitative findings suggest that locus of control is crucial to seeking treatment early and uptake of treatment given the barriers associated with cervical cancer treatment. Quantitative results showed no influence of societal factors on receipt of treatment and perceptions of access to cervical cancer treatment. However; qualitative results suggest that societal factors play a significant role in the form of beliefs, attitudes, misconceptions, social support from families and partners, family influences and influence of alternative interventions' providers (traditional healers and prophets). Most patients who reported receiving treatment had the support of their families, partners and caregivers.

Perceptions of adequacy of specialists were positively associated with uptake of cervical cancer treatment and perceptions of access to it amongst healthy women. The provision of health services rely on having a health workforce. Some studies have reported that sufficiency and distribution of health workforce is crucial in improving access to healthcare. Lack of trained health workers compromises the quality of services that can be provided [27]. Health worker survey findings suggested shortage and sub-optimally distributed health workers for the treatment and care of cervical cancer. In a South African survey, researcher found that affordability and other patient level factors (acceptability, accommodation, and accessibility) were less important predictors of access to cervical cancer screening than availability of physicians in the population [21]. Qualitative findings revealed shortages of oncologists, oncology nurses, gynaecologists, radiographers, pathologists and pharmacists for the provision of quality services. Lack of knowledge amongst healthcare workers about case definition and management of suspected cervical cancer was another barrier to accessing early treatment. A Malawian study

reported that health workers not formally trained in cervical cancer prevention were unlikely to be responsive, fair and efficient to achieve the best outcomes [27]. This finding is consistent with our qualitative results. The Zimbabwean government has been unable to hire and train more health workers in general due to limited fiscal space in the last few years and this has been affecting treatment and care of cervical cancer patients [1, 2].

Our findings indicated that service satisfaction was correlated with receipt of treatment services amongst cervical cancer patients. This means that most patients who were treated were satisfied with the services they were provided. Qualitative results also suggested that most patients who were treated reported being satisfied with the services. These findings could be due to few treatment centers in Zimbabwe to compare with and also the fact that most patients present late with severe symptoms of bleeding and pain and the treatment they are given which is usually palliative is perceived as satisfactory. Most respondents reported that to them treatment meant alleviation of their pain and symptoms even if the primary condition was not treatable. The general perception was that cancer is untreatable and it is a "*death sentence*" such that any attempt to treat symptoms mostly pain and bleeding (palliative care) were well received despite the barriers they countered. All patients who received treatment had gone through many processes to access treatment and by the time they were engaged into treatment their hope was low. Some studies have shown that satisfaction with cervical cancer services was associated with knowledge of visual inspection with acetic acid (VIA) screening test, with women who knew about this procedure *apriori* being less satisfied when they were tested. Distance to the health facilities was also found to be associated with level of satisfaction with women who travelled more than five kilometers reporting higher satisfaction levels [28]. These findings are consistent with our present work with regards to satisfaction as most patients travelled great distances to get treatment to Parirenyatwa Hospital, one of the two treating centers in Zimbabwe.

Walking as a means of reaching nearest health facilities was negatively associated with perceptions of access to treatment for cervical cancer amongst healthy women. In a US study transport to health facilities was found to influence access to cervical cancer screening in urban settings [29]. Results from our qualitative study revealed that the second most frequently reported barrier to treatment was transport and its

associated costs as most patients had to travel to treating facilities. Perceptions of access to cervical cancer treatment from health worker's perspective were associated with their basic training institution, health service quality perceptions and electricity supply status in their respective health facilities. Challenges faced in seeking treatment by patients were slightly significant to perceptions of access to treatment. These findings are supported by qualitative study which suggested that health system factors were more important to accessing treatment by cervical cancer patients.

This study deserves the justice of mentioning its limitations; that it was conducted in Harare and some findings may not be generalizable to the whole country hence interpretation should be conducted carefully.

4.5 Conclusion

There are numerous prevailing multi-dimensional barriers to accessing cervical cancer treatment and palliative care in Zimbabwe. Our findings revealed that heath system and societal factors were more important that individual level factors. The major of the health system factors that presented as barriers to treatment were few treatment centers, lack of infrastructure, lack of commodities such as drugs limited number of radiotherapy machines, frequent breakdowns of radiotherapy machines, high costs of services and few specialists. The main social barriers found were lack of knowledge, fear, stigma, misconceptions, family influences influence of traditional and spiritual healers. However, social support was noted as important facilitating factor that was reported by most patients who received treatment. Individual level factors that were revealed were financial challenges which affected transportation to health facilities and the ability to pay for diagnostics, staging and treatment procedures most of which required payment upfront. Most patients in Zimbabwe rely on out-of-pocket financing as only 10% are on medical aid coverage [30]. Those with medical aid coverage reported better access to treatment in the qualitative study. In general, a paradigm shift is imperative in the Zimbabwean health system if access to cervical cancer treatment and palliative care are to be improved to reduce high mortality and morbidity rates in the country. Health policies to address the challenges faced by patients are crucial in an endeavor to afford them their basic right to health as enshrined in the International Declaration of Human rights [31]. Investments in

infrastructure, health information systems, equipment and their servicing, human resources, development of standardized guidelines and regular health worker trainings will go a long way to address some of the challenges bedeviling cervical cancer treatment programmes. Strategies to subsidize or remove user fees for the diagnosis, staging and treatment may go a long way to improve access to treatment in a country where the majority of people are living in poverty. Health education and promotion interventions cannot be underestimated to address the societal factors impeding treatment while reinforcing facilitating factors like social support. Overall, multi-sectoral approaches are implied to address all the multifaceted barriers in order to improve cervical cancer treatment and palliative care access which will translate to better outcomes in a resource-limited context.

List of abbreviations

FGD	Focus Group Discussion
FIGO	International Federation of Gynaecology and Obstetrics
SD	Standard deviation
VIAC	Visual inspection with acetic acid cervicography
WHO	World Health Organization
ZDHS	Zimbabwe demographic and health survey

Declarations

Ethics approval and consent to participate

This study was carried out in partial fulfillment of the requirements of a PhD degree at the University of Pretoria and was approved by several ethics committees/bodies:

13. University of Pretoria, Faculty of Health Sciences Research Ethics Committee (**REC 487/17**)
14. Harare Hospital Ethics Committee (**HCHEC 271017/77**)
15. Joint Parirenyatwa and University of Zimbabwe Research Ethics committee (**JREC 33A/18**)
16. Medical Research Council of Zimbabwe (**MRCZ/A/ 2271**)

All participants in this study were consented in writing before interviews. Consent forms were administered by the researchers in the language of the participant's preference i.e English or Shona (local language spoken by majority of people in Zimbabwe).

Consent for publication

Not applicable

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare no conflict of interests.

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Introduction

This chapter presents knowledge, attitudes, beliefs and practices of women to cervical cancer, its prevention and treatment. This chapter is a follow-up section from chapter four and it explores knowledge of causes, risk factors, prevention and treatment of cervical cancer and associated factors among women affected by the disease.

5.0 CERVICAL CANCER KNOWLEDGE, ATTITUDES, BELIEFS AND PRACTICES OF WOMEN AGED AT LEAST 25 YEARS IN HARARE, ZIMBABWE.

Abstract

Background

Cervical cancer is the most common cancer and a major cause of morbidity and mortality among women in Zimbabwe yet it is preventable, early detectable and highly curable. The objective of this study was to investigate knowledge, attitudes, beliefs and practices towards cervical cancer, its prevention and treatment in Harare, Zimbabwe.

Methods

Sequential explanatory mixed methods approach consisting of analytical cross sectional survey and a qualitative inquiry was used. Study population consisted of women with cervical cancer, health workers and other stakeholders who are involved in cancer control programmes. Patient survey data were collected using validated structured questionnaire in *Surveytogo* software in an android tablet. Qualitative study used key informant interviews to understand survey findings better. Data analyses for the survey involved univariate and multivariate analyses using *STATA* version 14. For qualitative study, themes in transcripts were coded and analyzed using *Dedoose* software to generate evidence for the study.

Results

Participants reported different levels of knowledge of causes (23%), risk factors (71%), prevention (72%), screening (73%) and treatment (80%). Participants had relatively higher knowledge with regards to risk factors, prevention, treatment and screening, though suboptimal for women with diagnosed cervical cancer. Knowledge of causes and prevention of cervical cancer were associated with different socio-demographic factors namely; age, income, wealth, radio listenership and watching TV. Most women participants reported positive attitudes and beliefs about cervical cancer. Relatively high proportion of women (48%) reported having a regular doctor they consult and 66% of women with cervical cancer reported screening at least once in their lifetime.

Conclusions

This study revealed that knowledge of causes and prevention of cervical cancer was associated with high socioeconomic status. Despite relatively high levels of knowledge of cervical cancer risk factors, prevention, screening and treatment, specific knowledge of cause remained suboptimal. While access to regular doctors and utilization of screening services was high among women with cervical cancer the majority had presented with locally advanced disease (IIB-III. This may suggest poor early treatment behaviors, health system and societal barriers. Strengthening of health education through the packaging of messages targeting the wider society using different delivery channels is thus recommended. Investments in the health system to improve cervical cancer treatment coverage is also imperative in low-income settings.

Key words: Cervical cancer, attitudes, beliefs, practices, knowledge, prevention, risk factors, Harare, treatment, sequential explanatory mixed methods.

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5.1 Background

Cervical cancer, the fourth most common cancer worldwide [1] with 85% of the cases occurring in low-income countries is a global concern [1,2]. Paradoxically, cervical cancer is a potentially preventable disease, yet it affects millions of women across the world [2]. In Zimbabwe, recent reports have revealed that in 2018 about 3,186 new cases of cervical cancer were diagnosed and mortality was 20% [1]. Statistics from the Zimbabwe National Cancer Registry report of 2016 revealed that the most common cancer among black women was cervical cancer account for 33% [3]. Recent data has also shown that about 79% of people are aware of cervical cancer [4] however; there is limited specific knowledge of its causes, risk factors, prevention and treatment.

In Zimbabwe, previous researchers reported that cervical cancer knowledge and understanding was poor despite the high morbidity and mortality of the disease. This lack of knowledge coupled with misconceptions about the disease and its treatment leads to poor health seeking behaviours [5]. Researchers in Uganda revealed that knowledge about cervical cancer prevention was relatively high and attitudes on screening encouraging. However, specific knowledge on the disease and its causes and screening were low [6]. In a Tanzanian study, less than 50% of nurses studied had adequate knowledge about cervical cancer and there was significant association between their knowledge levels of causes, HPV transmission and age amongst them [7]. Ahmed et al [8] reported that market women had a fair knowledge of cervical cancer and its screening; however, there was poor knowledge of risk factors. India has the highest burden of cervical cancer in world and researchers have reported poor awareness of cervical cancer and its prevention [9]. Knowledge deficit was associated with non-adherence to cervical cancer screening amongst nurses in a Japanese study [10].

Some researchers reported levels of education and economic status as determinants of knowledge of causes, risk factors, prevention and treatment of cervical cancer [11]. A recent study conducted in Nigeria reported that major reasons for screening using Pap smear were health worker recommendations and fear of contracting the disease. Reasons for not taking the screening intervention were lack of awareness and non-recommendation by health workers. Prior counseling by health workers and knowing someone who had cervical cancer increased knowledge and uptake of Pap

smear test. However, level of education influenced knowledge of cervical cancer but not uptake of Pap smear [12]. Visanuyothin and colleagues in their study in Thailand reported that perceived barriers and knowledge of the disease and its treatment were predictors of cervical cancer screening adherence after adjusting for occupation, marital status, number of children and health insurance status in the model [13]. Researchers in Zimbabwe recently reported high knowledge of factors that caused cervical cancer amongst women from traditional churches, positive attitudes towards Pap smear test but low screening rates [1]. In 2015, the Zimbabwe Demographic and Health Survey reported that women who ever screened for cervical cancer in Harare were only 24 % [4]. This study sought to bridge the information gap on the factors associated with knowledge of cervical cancer causes and prevention in the country.

5.2 Methods

5.2.1 Study design

A sequential explanatory mixed methods design was used to generate evidence for this study. This design comprise of both quantitative and qualitative methods, with the quantitative study being the major study. Qualitative inquiry was conducted to aid deeper understanding of issues, explain surprising and unexpected results from the quantitative surveys [25]. A health facility based survey was conducted between January and April 2018 among women with cervical cancer. The second phase of the study consisted of a qualitative inquiry with key informants. These participants included health workers directly involved in cervical cancer control, WHO officials, Ministry of Health policy makers and NGO programme managers. Key informants were selected using snowball sampling technique [25, 26].

5.2.2 Target population

The study population consisted of women with cervical cancer, health workers and other stakeholders who are involved in cervical cancer interventions in Zimbabwe.

5.2.3 Sample sizes

In the health facility based survey, 134 women with histologically confirmed cervical cancer were selected in a census at Island Hospice, Harare and Parirenyatwa Hospitals between January and April, 2018. This sample size was based on the follow of patients in these health facilities based on data from the previous year, 2017. A minimum of sample size of 80 had been determined before the study based on 2017 data; however 134 women with cervical cancer were ultimately enrolled to improve on precision of estimates. In the qualitative study the sample sizes were guided by the saturation principle [14]. The final sample size achieved for key informant interviews was 17 participants. The key informants comprised of gynaecologist, oncologist, oncology nurse, general nurses, physician, radiographers, medical physicists , midwives and pathologist directly involved in the treatment and care of cervical cancer patients.

5.2.4 Study settings

The health facility study sites were: Parirenyatwa Hospital, Harare Hospital and Island Hospice. The treating health facilities serve people from across the country; however, most of the patients recruited in this study were resident in Harare communities. All participants in the survey were aged at least 25 years (and no maximum age limit) and consented in writing before being enrolled in the study. Some of the key informants for qualitative study were selected from the same study sites as the survey. They were selected based on special characteristics such as knowledge of cervical cancer and unique experiences in the treatment of cervical cancer.

5.2.5 Data collection methods

For the survey, a validated structured questionnaire [24] was administered by the researchers. The questionnaires had been programmed in *SurveytoGo* software (*Dooblo*, Israel) in android tablets. Electronic data collection allowed real time uploading of data, better quality control and reduced the time of data processing as there was no need for manual data entry. For the qualitative study, key informant interview guide was used for data collection. This study being a sequential mixed methods design, the qualitative tool was designed based on the outputs from the quantitative study analysis. The purpose of the qualitative study was to explain surprising results, outliers and put stories to data or associations in the survey.

5.2.6 Quantitative analysis

Data analysis for the survey was conducted using univariate and multivariate methods. Univariate analyses were conducted to obtain proportions with respect to knowledge of causes, risk factors, prevention and treatment amongst participants. Since Likert scales were used on some variables, the responses were compressed to generate binary variables "Yes" and "No" for the univariate and bivariate analyses. The multivariate analysis outcome variables were also converted into binary variables as criteria for conducting logistic regression analysis. Logistic regression analysis was conducted to identify factors that were associated with correct knowledge of causes, prevention and treatment. The confounding variables that were adjusted for in the multivariate analysis were: sources of cervical cancer information and head of household's occupation, education, radio listenership, watching TV, reading newspapers and accessing internet for general information. The identification of these confounders was based on literature from similar studies. All statistical analyses were conducted using *STATA* version 14 (*StataCorp*, Texas).

5.2.7 Qualitative analysis

A total of 17 key informants were enrolled for the qualitative research. Participants were selected based on specific characteristics relevant to the research question and to ensure diversity of perspectives to strengthen the study outcomes.

All audio-recorded key informant interviews were transcribed verbatim. The transcripts were coded manually line by line by the researchers using *Dedoose software* (SocioCultural Research Consultants, Los Angeles) after creation of codes based on the research questions and quantitative findings. Manually generated thematic codes were processed in the same software to produce final outputs. Findings from survey and qualitative study were integrated at interpretation stage in which case qualitative findings assisted in explaining and interpreting results from the survey.

5.3 Results

5.3.1 Quantitative findings

A total of 134 participants responded to the survey and these were women with cervical cancer. The mean age of participants enrolled in the survey was 52 years (SD=12.2).

Table 5. 1: Knowledge of cervical cancer causes, risk factors, prevention, screening and treatment among women with cervical cancer in Harare.

Question/variable	Women with cervical cancer [N=134]) (%) Correct answer
Causes HPV as the cause of cervical cancer	31 (23)
Prevention Correct prevention methods (early screening and treatment, male circumcision, eating healthy, use of condoms, sticking to one sexual partner, and abstinence from sex)	95 (71)
Risk factors HI/AIDS	10 (7)
STIs	50 (37)
Multiple sexual partners without protection	22 (16)
Uncircumcised partner	7 (5)
Poor personal hygiene	1 (1)
Use of herbs or traditional medicines in vagina	8 (6)
Screening Hospitals/clinics in my community offer screening for cervical cancer for free	98 (73)
HIV testing is optional when being screened for cervical cancer.	98 (73)
Treatment of cervical cancer Treatment modalities for cervical cancer (surgery, radiotherapy and chemotherapy)	107 (80)

Table 5.1 shows that women with cervical cancer had poor knowledge with respect to the causes of the disease. Only 23 % of the respondents specifically reported HPV as the cause of cervical cancer. Seventy-three percent (73%) of participants had knowledge of at least one risk factor of cervical cancer. Cervical cancer patients had better knowledge about the availability of free screening services at local hospital or health facility and HIV testing being optional during screening. Eighty percent (80%) of women with cervical cancer knew about treatment modalities about the disease.

Table 5.2: Attitudes, beliefs and practices towards cervical cancer, its screening and treatment among women with cervical cancer in Harare.

Questions	Women with cervical cancer [N=134] (%) Yes
Attitudes	23 (17)
Cervical cancer treatment is for people with money/finances	1 (2)
Cervical cancer treatment procedure is embarrassing	131 (98)
Screening is important for early treatment of cervical cancer	
Beliefs	
Cervical cancer treatment saves lives	133 (99)
Cervical cancer treatment gives a woman and their family peace of mind	133 (99)
Cervical cancer treatment gives a woman control over her health.	133 (99)
Cervical cancer treatment is not painful	70 (28)
Cervical cancer treatment has no side-effects.	83 (69)
Cervical cancer treatment is for all women regardless of background	128 (95)
Cervical cancer cannot be treated	11 (8)
Cervical cancer patients do not survive long even when treated	7 (5)
Cervical cancer is best treated with herbs/traditional medicines	14 (10)
Cervical cancer is best treated using spiritual means performed by prophets and pastors.	14 (10)
Cervical cancer treatment is best done abroad	73 (54)
Health professionals abroad provide better care for cervical cancer patients.	45 (33)
Cervical cancer patients treated abroad have better survival chances	39 (29)
Practices	64 (48)
Do you have a regular doctor whom you see when you require health services?	
Women ever screened for cervical cancer	127 (95)
Women screened at least once in their life time	88 (66)

In Table 5.2 overleaf, the majority (98%) of women reported that screening was important for early treatment of cervical cancer. Only 17% and 2% of women had negative attitudes that cervical cancer treatment was for people with money and the treatment was embarrassing respectively. With regards to beliefs, the majority of women had positive beliefs, however; 52% and 33% believed that cervical cancer treatment abroad was better and health workers abroad provided better treatment and care respectively. In addition, 29% of participants believed that patients treated abroad had better survival outcomes compared to those treated locally. Women who had access to a regular doctor were relatively high, 48%. However, participants who reported ever screening for cervical cancer in their lifetime were 95%. Proportion of participants who reported screening at least once in their lifetime was relatively high, 66%.

Table 5.3 (see Appendix 7) shows that knowledge of causes of cervical cancer was negatively associated with being aged 45 years or more (p=0.004), having no income (p=0.007), income less than US$600 per month (p=0.015), being in the middle class wealth quintile (p=0.032), watching TV daily (p=0.007) and between once and 6 times per week (p=0.045). Factors positively associated with correct knowledge of causes were listening to the radio daily (p=0.001) and between once and 6 times per week (p=0.010). Factors positively associated with cervical cancer prevention knowledge were listening to the radio daily (p=0.022) and between once and 6 times per week (p=0.018).

5.3.2 Qualitative findings

Theme 1: Drivers of limited of knowledge about cervical cancer causes, risk factors, prevention and treatment.

Results from our survey suggested limited specific knowledge about cervical cancer in communities and among patients. Drivers of lack of knowledge that emerged in the qualitative study included: limited awareness programmes in communities, infancy of cervical cancer awareness programmes, donor priorities to infectious diseases (vertical interventions), lack of knowledge amongst health workers,

negative attitudes towards cervical cancer and misconceptions. The following quotes show some of the drivers of lack of knowledge reported:

> "*You walk into a rural health facility and you ask nurses about cervical cancer or cancer in general but they have no clue of what it is but we are asking people in the community to go to the clinic where the nurses don't know anything about cancer*"- Cancer Centre Midwife, key informant.

> "*We also talked of education I don't think we are reaching enough in terms of education because we just give health education to those that would have visited the health centre and we don't have outreach programmes that help us reach the communities*",-Harare Hospital VIAC nurse, key informant

> "*………the minute you get into the realm of cancer there is fear of the unknown…..*so people are *in a comfort zone where they don't want to delve*" -Harare Pathologist, key informant.

Theme 2: Drivers of low usage of early treatment services

Key informant interviews pointed out some of deterring factors resulting in low usage of early treatment leadiing to late disease presentations. Some of the factors reported by most respondents were: lack of knowledge, belief that cervical cancer was not treatable, misconception that cervical cancer was caused by witchcraft or avenging spirits, fear of the unknown, limited screening services, health worker negative attitudes, lack of funds for transport, negative attitudes towards screening and social norms such as a person should only use the health facility when they are sick or in pain and the need for husband or partner approval or financial support to visit the health facility to be screened. Some of the respondents had this to say:

> "*It is fear of the unknown and lack of knowledge, those are the two things that are really hampering the campaign against cancer of the cervix*"- Harare Pathologist, key informant

> "*I think there is very little awareness of the population about cervical cancer. I think it's something which was not actively talked about to the community as much was HIV or TB*".-Harare Senior Gynaecologist, key informant

5.4 Discussion

Despite relatively high knowledge of risk factors, prevention and treatment, knowledge of cause remains suboptimal. Women with cervical cancer had low knowledge of causes of the disease with only 23% reporting HPV as the cause. Seventy-three percent (73%) of participants had knowledge of at least one risk factor of cervical cancer. Cervical cancer patients had better knowledge about the availability of free screening services at local hospital or health facility and HIV testing being optional during screening. Eighty percent (80%) of women with cervical cancer knew about treatment modalities of the disease. Majority (98%) of women reported that screening was important for early treatment of cervical cancer. Only a few participants reported negative attitudes towards treatment of cervical cancer. With regards to beliefs, the majority of women had positive beliefs, however; 54% and 33% believed that cervical cancer treatment abroad was better and health workers abroad provided better treatment and care respectively. Only 29% of participants believed that patients treated abroad had better survival outcomes compared to those treated locally. Women who had access to a regular doctor were relatively low, 48% while 95% of participants reported ever screening for cervical cancer in their lifetime. A relative low number of women with cervical cancer (66%) reported screening at least once in their lifetime. Its not low Knowledge of causes of cervical cancer was negatively associated with being aged 45 years or more (p=0.004), having no income (p=0.007), income less than US$600 per month (p=0.015), being in the middle class wealth quintile (p=0.032), watching TV daily (p=0.007) and between once and 6 times per week (p=0.045). Factors positively associated with correct knowledge of causes were listening to the radio daily (p=0.001) and between once and 6 times per week (p=0.010). Factors positively associated with cervical cancer prevention knowledge were listening to the radio daily (p=0.022) and between once and 6 times per week (p=0.018).

Causes

Knowledge about the causes of cervical cancer was low among cervical cancer patients. This finding suggests that there is still limited awareness or health education with regards to the basic information on cervical cancer. The assumption would be that cervical cancer patients because of their condition would tend to be

exposed more to information or have positive attitude towards information about their condition. However, findings suggest that this may not be so. About 72% of women with cervical cancer were able to report at least one risk factor of cervical cancer (HPV, HIV/AIDS, STI, poor personal hygiene, multiple sex partners without protection, sex with uncircumcised partner, and use of herbs in the vagina). However, HPV as a cause of cervical cancer was only reported by a small proportion of participants, 23%, confirming that specific knowledge about the cause of this condition is still limited in Zimbabwe. Our findings suggest relatively high knowledge of risk factors of cervical cancer as compared to other studies. In an Ethiopian study, only 42% of participants reported at least one risk factor of cervical cancer [11]. Researchers in Nigeria reported knowledge of risk factors as low as 15.6% in a recent study [12].In Tanzania, multiple sexual partners and history of HPV infection as risk factors for developing cervical cancer were reported by 47.4% and 43.1% of respondents respectively [7].

Knowledge of causes of cervical cancer reported was associated negatively associated with being aged 45 years or more (p=0.004), having no income (p=0.007), income less than US$600 per month (p=0.015), being in the middle class wealth quintile (p=0.032), watching TV daily (p=0.007) and between once and 6 times per week (p=0.045). However, listening to the radio frequently was positively associated with knowledge of causes of cervical cancer. These results suggest that knowledge of causes of cervical cancer is associated with socioeconomic status. The findings also suggest that awareness or health education programmes may be biased towards radio programmes or that the packaging of messages is appropriate for radio audience. Programmes in television may not be properly packaged to influence knowledge of causes but may be reinforcing fear, stigma, myths and misconceptions in the population. Our findings support those of Mitiku & Tefera [11] who found that better income was associated with knowledge of cervical cancer. A Nigerian study reported age as an important determinant of cervical cancer knowledge however our results contrast these findings [19]. Our results did not find any association of knowledge of causes with levels of education and this directly contrast those of a similar study in Zimbabwe, which suggested that knowledge of cervical cancer was associated with having at least secondary education [33].

Prevention

There was suboptimal knowledge of cervical cancer prevention reported among women with cervical cancer in our study, 71%. This suggests that lack of prevention knowledge for cervical cancer may be a possible risk factor for disease incidence. Mukama et al [6], in Uganda reported a relatively lower knowledge of preventive measures (62%). The factor associated with preventive knowledge was listening to the radio frequently. These results also suggest that radio programmes may be a better platform for disseminating cervical cancer awareness and education. Packaging of messages for cervical cancer could be targeting radio audience. These findings contrasts those of Ayinde [19] who reported that married women were more likely to be aware of cervical cancer compared to single women. Our study contrast the findings from a Ugandan study which revealed that living in peri-urban and urban areas, having a higher monthly income and having had an HIV test were associated with knowledge about cervical cancer prevention [6].

Treatment

Our study revealed that knowledge of treatment was suboptimal among women with cervical cancer (80%). The expectation is that all patients would know at least one modality of treatment for their condition given that most would have interfaced with different levels of care before they present at treating facilities. This suggests limited or lack of information or awareness especially from health workers. It is imperative that awareness or health education be biased towards risk factors, causes and prevention so that few people eventually develop the disease which is costly to treat and is a significant threat to life. As revealed in the qualitative phase of this study, there are still some gaps in the packaging of awareness or health education interventions for cervical cancer. Lack of knowledge about treatment may lead to misconceptions which may affect health seeking behaviours among women [6-11]. In our setting, cervical cancer treatment is marred with myths and misconceptions though only a small proportion (8%) of the respondents did not believe that the disease was treatable. To our knowledge, this study is the first to report knowledge levels with regards to treatment of cervical cancer in our context. There is generally little information about the knowledge of treatment in developing countries with most studies focusing on primary and secondary interventions for cervical cancer.

Attitudes

Generally, women participants in our study had positive attitudes towards cervical cancer, its screening and treatment. The majority agreed that early screening was important for early treatment however; a few women reported that cervical cancer treatment was for people with money and treatment procedures were embarrassing. These negative attitudes have an influence on the uptake of treatment services [6]. Low screening uptake and poor health seeking behaviours may be explained by the negative attitudes towards treatment despite positive attitudes towards screening itself [6]. Our qualitative findings also reported negative attitudes as a barrier to both preventive and curative interventions for cervical cancer.

Beliefs

Cervical cancer treatment is marred with many beliefs, myths and misconceptions. Most participants had positive beliefs with regards to cervical cancer, its screening and treatment. However, a relatively high proportion believed that treatment, care of health workers abroad and survival outcomes for those treated abroad were better. These findings may suggest relatively low levels of confidence in local health services or local capacity for cervical cancer treatment. Medical tourism has been reported to have a negative effect on the perceptions and development of local health service delivery [27].

Practices

Our study showed that women with cervical cancer had relatively high access to regular doctors for health services. This may be explained by their chronic condition which motivates them to seek medical attention from private doctors or health facilities or from multiple health facilities. The majority of participants (95%) had been screened for cervical cancer . Relatively high proportion of patients had screened for cervical cancer at least once in their life time, 66%. These findings may suggest gaps in early treatment seeking behaviors among women suspected or diagnosed with cervical cancer or health system barriers. Despite the relatively high levels of awareness of cervical cancer, its risk factors, prevention and treatment, our study showed relatively low knowledge levels of causes. High usage of screening for cervical cancer among patients was also revealed in this study and this is surprising

since the ZDHS (2015) reported only 24% of healthy women had ever screened for cervical cancer in their lifetime [4]. These results are unexpected given the fact that the majority of cases are presented in locally advanced stages (IIB-IIIB). Our qualitative study explained some of the reasons of low screening uptake among them: lack of knowledge, beliefs that cervical cancer was not treatable, misconception that cervical cancer was caused by witchcraft or avenging spirits, fear of the unknown, limited screening services and negative health worker attitudes. Lack of funds for transport and negative attitudes towards screening and poor health seeking behavior with a common attitude that a person should only use health facilities when they are sick or in pain could be contributing to low cervical cancer screening uptake in our settings. Social norms that necessitate women to seek husband or partner approval or financial support to get screened may also explain low uptake of screening services. Considering other low-income settings, in Nigeria uptake of screening services was reported to be as low as 23% and this was not surprising given the low levels of awareness of cervical cancer [12]. Again in Tanzania, a study amongst nurses revealed low screening uptake, only 15%, using the Pap smear technique [7]. Surprisingly in a similar study in Japan, a high-income country, only 14% of nurses had screened for cervical cancer in the previous 2 years [10]. In contrast in Thailand, Visanuyothin and colleagues reported a high Pap smear uptake of 77% amongst women in a recent study [13].

This study encountered some limitations which would deserve to be accounted for in interpreting the findings. Firstly, this study was conducted in Harare, the capital city of Zimbabwe where cervical cancer awareness, screening and treatment services are largely available compared to other parts of the country. Therefore, the results of this study may not be generalizable to other contexts and a follow-up national study would be imperative in future. Secondly, the study was conducted at a time health workers had series of strikes and therefore there may have been selection bias in the characteristics of patients who were scheduled for reviews or treatments particularly at Parirenyatwa and Harare Hospitals. This study comprised of a cross sectional survey whose outcomes cannot be used to infer causal relationships. Lastly, this study used qualitative inquiry which are prone to bias and whose findings are not generalizable beyond the study settings. However, this study had its own strengths; firstly this study used mixed methods with a diverse study population to

understand the subject under investigation better. Most studies cited have used either qualitative or quantitative methods and for policy recommendations mixed methods provide better outcomes [25, 28]. Secondly, this study, to the best of our knowledge, is the first in Zimbabwe to comprehensively investigate knowledge, attitudes, beliefs and practices about cervical cancer, its screening and treatment. Many previous studies focused on primary and secondary prevention of cervical cancer but there is a general paucity of information on tertiary interventions in the contexts of low-income settings.

5.5 Conclusions

This study revealed that knowledge of causes and prevention of cervical cancer was associated with high socioeconomic status. Despite high levels of knowledge of cervical cancer risk factors, prevention, screening and treatment, specific knowledge of causes has remained supotimal. High levels of access to regular doctors and utilization of screening services were shown among women with cervical cancer despite the majority of the patients presenting with locally advanced disease. Strengthening of health education through the packaging of messages targeting the wider society using different delivery channels such as community campaigns, mobile phone messages and health workers is thus recommended. An investment in health systems to improve universal coverage of cervical cancer treatment services is also an important step in low income settings. This may increase early uptake of treatment interventions against cervical cancer in the country.

List of abbreviations

AIDS	Acquired immunodeficiency syndrome
FGD	Focus group discussion
HIV	Human immunodeficiency syndrome
HPV	Human papilloma virus
NGO	Non-governmental organization
SD	Standard deviation
STI	Sexually transmitted infection

| VIAC | Visual inspection with acetic acid cervicography |
| ZDHS | Zimbabwe demographic and health survey |

Declarations

Ethics approval and consent to participate

This study was carried out in partial fulfillment of the requirements of a PhD degree at the University of Pretoria and was approved by several ethics committees/bodies:

1. University of Pretoria, Faculty of Health Sciences Research Ethics Committee (**REC 487/17**)

2. Harare Hospital Ethics Committee (**HCHEC 271017/77**)

3. Joint Parirenyatwa and University of Zimbabwe Research Ethics committee (**JREC 33A/18**)

4. Medical Research Council of Zimbabwe (**MRCZ/A/ 2271**)

All participants in this study were consented in writing before interviews. Consent forms were administered by the researchers in the language of the participant's preference i.e English or Shona (local language spoken by majority of people in Zimbabwe).

Consent for publication

Not applicable

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare no conflict of interests.

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Authors' contributions

OT: researcher, concept and study design; AMN : concept design, critical revision and editing; WK: critical revision and editing, GD: PhD co-supervisor, concept design, critical revision and editing; SH:PhD supervisor, concept and study design, critical revision and editing; BSP, critical revision and editing. All authors reviewed and approved this manuscript.

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CHAPTER SIX

Introduction

This chapter follows up from chapter four and five and informed on how health service models are entrenching inequities in access and utilization of cervical cancer treatment and palliative care among women. The chapter further explores how the resources and organization of the health system impacts on cervical cancer service delivery and pathways of care.

6.0 HEALTH SERVICE DELIVERY MODELS ENTRENCHING INEQUITIES TO TREATMENT AND CARE AMONG WOMEN WITH CERVICAL CANCER IN HARARE, ZIMBABWE.

Abstract

Background

Cervical cancer is a major cause of morbidity and mortality among women yet access to treatment and care remains a huge challenge in Zimbabwe. The objective of this study was to investigate how health service delivery approaches are entrenching inequities to treatment and care among women with cervical cancer in Harare, Zimbabwe.

Methods

A sequential explanatory mixed methods design was used for this study. Phase 1 comprised of two surveys named: the patient and the health worker surveys with sample sizes of 134 and 78 participants respectively. Validated structured questionnaires programmed in Android tablet with *SurveytoGo* software were used for data collection during the surveys. Univariate and bivariate analyzes were conducted using *STATA®* version 14 to generate descriptive statistics and independent factors. In Phase 2, 16 in-depth interviews, 20 key informant interviews and 6 focus group interviews were conducted to explain survey results. Participants were purposively selected and sample sizes were informed by saturation principle. English transcripts were manually coded line by line in *Dedoose software* using the

thematic codes that had been established from the survey data. The final codes were used to support and explain the survey data at the interpretation stages.

Results

Health service delivery gaps identified in surveys were: limited or lack of training for health workers, weakness of surveillance system for cervical cancer, limited access to treatment and care, inadequate health workers, reliance of patients on out-of-pocket funding for treatment services, lack of back-up provision for major equipment. Qualitative inquiry revealed the following barriers to treatment and care: high costs of treatment and care, lack of knowledge about cervical cancer, bad attitudes of health workers, few screening and treating centres located mostly in urban areas, lack of clear referral system resulting in bureaucratic processes, and limited screening and treating capacities in health facilities due to lack of resources.

Conclusion

The results of this study show that health services delivery models and their organization present barriers that lead to inequities to cervical cancer treatment and care. Strong political will, mobilization of resources both domestically and from partners and sound policies are imperative to address key health service challenges.

Key words: Cervical cancer, health service delivery, inequity, access, treatment and care, sequential explanatory mixed methods, policies, Harare.

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6.1 Background

Cervical cancer is the fourth most commonly diagnosed neoplasm among women worldwide [1]. The incidence of cervical cancer has been reported to vary by region, with Eastern and Southern parts of Africa carrying the largest burdens [2]. In Zimbabwe, cervical cancer is the most commonly diagnosed cancer among black women and in 2016 it accounted for 33% (1375 new cases) of the women cancers reported [3]. Despite cervical cancer being preventable through early detection and treatment, most sub-Saharan African countries' health systems are weak such that most cases present for health care in very late stages when incurable and only suitable for palliative care. Diagnosis and treatment of cervical cancer requires a health system which is functional, interactive and responsive physically and in terms of human resources to be able to identify, diagnose and treat cases. The infrastructure and organization of health systems in low-to- middle income countries are not sufficiently developed to provide comprehensive care to cancer patients [4]. Cervical cancer is a complex condition which requires continuum of care and comprehensive programmes which are also dependent on the stage of the cancer to improve health outcomes [4]. In low-to-middle income countries the morbidity and mortality rates of cervical cancer are high owing to late presentation of cases and failure to complete treatments due to lack of resources. Challenges of affordability, availability of drugs and accessibility of treating facilities impede engagement of patients into treatment and care [4, 5].

Several years of economic challenges have reduced the capacity of the health system to provide comprehensive care for cervical cancer in Zimbabwe [4-6]. Health policies in the country outline equity in access and distribution of healthcare services but do not mention components of health policies as reported by Navarro [7]. The current National Cervical Cancer policies did not outline key determinants of equity in access; nor provide mechanisms of addressing known barriers to access to treatment and care. Understanding that generally cancer occurs in a complex social, political, cultural, environmental and economic context is critical in investigating the possible barriers and factors which promote access and utilization of treatment and palliation services [8]. Current evidence from a recent study suggests that inequalities in access to and use of cancer care persist up until death [9]. Reports of

palliative care use have concluded that older patients are less likely to receive these services compared to their younger counterparts [8, 10]. In Zimbabwe, inequities to healthcare access and utilization entrenched by age, social class, income, occupation, ethnicity, gender and place of residence are well documented [11]. However, there is no documented evidence of how the functioning of the health system and its organization are contributing to inequities for cervical cancer treatment and care. This study was conducted to address that knowledge gap in the country.

6.2 Methods

This study was a sequential explanatory mixed methods design and it was conducted in Harare, Zimbabwe. The study was in two distinct phases;Pphase 1 which was quantitative consisting of two cross sectional surveys and Phase 2 consisted of of a qualitative inquiry. The qualitative phase was used to explain results from the cross sectional surveys and findings were integrated at interpretation stage.

6.2.1 Data sources and population

Phase 1

Two cross sectional surveys were conducting namely; 1) Patient survey and ;2) Health worker survey. The surveys were conducted in health facilities providing treatment and care for cervical cancer patients in Harare namely; Harare Hospital, Parirenyatwa Hospital, Island Hospice and Cancer Association of Zimbabwe. In both studies, patients and health workers were selected randomly using health facility records as sampling frames. Patients who visited the study sites during January-March 2018, were histologically confirmed as shown by their records or verified by health workers, were at least 25 years of age, were stable to be interviewed as approved by their health workers and gave consent in writing to be enrolled into the survey. The age range was informed by studies and anecdotal evidence from health facilities that have shown the incidence of cancer being higher amongst women who are older than 30 years. The Zimbabwe Cervical Cancer Policy recommends routine screening for sexually active females between 18 and 65 years old [12,13] and for this study we considered women aged at least 25 years as there is no evidence,in

Zimbabwe, of cervical cancer affecting women younger than this age. A total of 134 patients with different cervical cancer disease stages were enrolled in the study. Patients were selected regardless of where they were resident. The reason is the chosen health facilities were quaternary facilities that treat and care for patients from across the country and for this study it was important to reduce bias by selecting patients regardless of where they stayed. For the health worker survey, 78 participants were selected randomly from the health facilities from which cervical cancer participants were drawn. Staff registers were used as the sampling frame from which participants were selected to avoid bias by selecting from those on duty at the time of the survey. We assumed that the characterstics of the health worker participants who were present at work for potential enrolment into this study were the same as those who were away from duty at the time of the study. Validated structured questionnaires were used for data collection for both surveys [14]. Questionnaires were programmed in *SurveytoGo* software in an Android tablet to allow for electronic data collection.

Phase 2

In qualitative inquiry, participants were purposively selected for enrolment in the study. Participants were selected in communities, health facilities and in institutions involved with cervical cancer interventions. Focus group discussions, in-depth and key informant interviews were conducted using discussion and interview guides developed based on the survey findings. For FGDs and in-depth interviews, the participants were healthy men and women, caregivers and patients selected from communities and health facilities. Key informants were selected from health facilities, Ministry of Health and Child Care Family Health directorate, non-governmental organizations (NGOs) involved with cervical cancer programmes, World Health Organization, churches, and traditional healer's associations. A total of 84 participants were selected based on desired characteristics for the study. Six focus groups with an average of 9 participants each, were conducted in the communities and one of the treating health facilities (Parirenyatwa Hospital). For in-depth and key informant interviews 16 and 20 participants were enrolled for participation based on theoretical saturation principle [15]. All interviews and FGDs were audio-recorded after obtaining written consent from the participants.

6.2.3 Data analysis

Phase 1

Data from the two surveys were analyzed separately as the variables were not related. This study focused and reported on the key health service attributes. Variables related to the health service delivery system for cervical cancer were selected from the two datasets and analyzed. Descriptive statistics and bivariate analysis were conducted for both surveys using datasets that had been cleaned prior to analysis. For the patient survey, comparisons were done for each variable between untreated and treated patients to identify significant differences. For the health worker survey, comparisons were made between proportions of health workers based on their responses to the different questions. For both surveys, the Chi-squared *test* at 5% level of significance was used to test for the differences in the proportions. All analyzes were conducted using *STATA* version 14 (StataCorp, Texas).

Phase 2

Transcription and translation of audio-recordings were undertaken by the researcher and his assistants. Uniquely identified transcripts were analyzed using themes that had been established apriori based on the survey findings. Unique identifiers were used to link the guides and the interview or FGD only after the conclusion of transcription. All in-depth interviews, key informant interviews and FGDs were coded manually line by line by the researcher using *Dedoose software* using the established thematic codes. Only five themes were identified as relevant to answer the research question for this study. Findings of phase 1 (surveys) and phase 2 (qualitative inquiry) were integrated at interpretation stage in which case qualitative findings assisted in explaining and interpreting survey results.

6.3 Results

6.3.1 Phase 1: Quantitative Findings

Table 6. 1: Health service attributes and their distribution amongst women with cervical cancer, 2018

Participant type	Cervical cancer patients [N=134]		
Variables	**Untreated [n=42] (%)**	**Treated [n= 92] (%)**	**p-value***
Method of payment for health services Medical aid (insurance) Out-of-pocket	5 (12) 37 (88)	22 (24) 70 (76)	0.557 0.139
Distance from nearest health facility (km)			
≤10	38 (90)	76 (82)	0.264
11-20	4 (10)	8 (9)	0.955
>20	0	8 (9)	-
Mode of transport to nearest health facility			
Walking	28 (67)	49 (53)	0.231
Public transport	13 (31)	33 (36)	0.748
Private car	1 (2)	9 (10)	-
Motorcycle	0	1 (1)	-
Time to travel to nearest health facility (minutes)			
≤30	32 (76)	75 (82)	0.476
31-60	7 (17)	12 (13)	0.811
>60	3 (7)	5 (5)	0.906
Distance from nearest cervical cancer screening health facility (km)			
≤10	5 (12)	30 (33)	0.343
11-50	4 (10)	18 (19)	0.667
>50	1 (2)	7 (8)	-
Don't know	32 (76)	37 (40)	**0.003**
Mode of transport to nearest cervical cancer screening health facility Walking	3 (7)	12 (13)	0.773
Public transport Private car	35 (83) 3 (7)	70 (76) 10 (11)	0.412 0.840
Other	1 (3)	0	-
Time to travel to nearest screening health facility (minutes) ≤30	15 (36)	51 (45)	0.536
31-60	14 (33)	25 (27)	0.692
>60	9 (22)	10 (11)	0.516

Don't know	4 (9)	6 (7)	0.908
Access to Specialists			
Yes	34 (81)	73(79)	0.811
No	8 (19)	19 (21)	0.906
Frequency of being seen by Specialists in previous 6 months			
None	17 (40)	27 (29)	0.451
Once or more	25 (60)	65 (71)	0.316
Access to a regular General Practitioner			
Yes	8 (19)	56 (61)	**0.025**
No	34 (81)	36 (39)	**<0.001**
Visits to health facility or doctor in previous 6 months			
None	10 (24)	4 (4)	0.382
≤10 times	30 (71)	55 (60)	0.313
11-20 times	2 (5)	17 (19)	0.622
>20	0	16 (17)	-
Challenges experienced in seeking treatment.			
Finances	20 (48)	45 (49)	0.941
Transport	22 (52)	39 (42)	0.451
Other	0	8 (9)	-

*Bold shows statistically significant differences.*The p-values are for comparisons between treated and untreated women with cervical cancer.*

Table 6.1 above show that there were few but notable differences between treated and untreated women with cervical cancer with respect to the selected health service attributes. There was no difference in the proportions of untreated and treatment women with cervical cancer who were seen or more time by specialists in the previous six months. Untreated women had less access to regular general practitioners compared to treated women with cervical cancer (p=0.025; p <0.001). Untreated women were less likely to know the estimated distances from their residence to the nearest cervical cancer screening health facilities compared to treated women (p=0.003).

Table 6. 2: Health service attributes of health workers and facilities providing treatment and care for cervical cancer, 2018.

Variable	Number of health workers [N=78] (%)	p-value**
Received on-the-job training for cervical cancer treatment or palliative care No Yes	22 (28) 56 (72)	**<0.001**
Perception of being adequately trained to provide cervical cancer treatment and palliative care No Yes	22 (28) 56 (72)	**<0.001**
Health facilities have clinical guidelines for cervical cancer treatment and palliative care No Yes	59 (76) 19 (24)	**<0.001**
Have knowledge or read National Cancer Prevention and Control Policy (201342018) No Yes	30 (38) 48 (62)	**0.039**
Have knowledge or read Zimbabwe Cervical Cancer Prevention and Control Strategy (2016-2020) No Yes	30 (38) 48 (62)	**0.039**
Perceptions of adequacy of policies and strategies for treatment and care of cervical cancer patients No Yes	44 (56) 34 (44)	0.293
Perceptions of strength of surveillance system for cervical cancer No Yes	60 (77) 18 (23)	**<0.001**
Motivated to provide services No Yes	24 (31) 54 (69)	**0.002**
Working conditions Excellent Good Poor	4 (5) 54 (69) 20 (26)	-
Perceptions of adequacy of health workers No Yes	69 (88) 9 (12)	**<0.001**
Perceptions of histological investigation capacity from suspected cervical cancer patients No Yes	33 (42) 45 (58)	0.163
Perceptions of access to treatment and care by patients No Yes	41 (53) 37 (47)	0.597
Payment methods for services by majority of patients		

Out-of-of pocket	49 (63)	
Medical aid	26 (33)	**-**
Social Welfare	3 (4)	
Challenges faced by most patients in seeking treatment and care		
Transport	29 (37)	**0.026**
Finances	49 (63)	
Proposed solutions to improve access to treatment and care for cervical cancer	46 (59)	
Free treatment	13 (17)	
Built more treating facilities	8 (10)	**-**
Government to assist people to seek treatment abroad	7 (9)	
Increase human resources capacity	4 (5)	
Other		
Perceptions of availability of adequate basic equipment		
No	33 (42)	0.163
Yes	45 (58)	
Perceptions of availability of functional equipment		
No	42 (54)	0.481
Yes	36 (46)	
Perceptions of availability of back-up for major equipment		
No	61 (78)	**<0.001**
Yes	17 (22)	
Perceptions of analgesic stock-outs in previous 3 months		
No	61 (78)	**<0.001**
Yes	17 (22)	
Perceptions of contingency plans for major drugs for cervical cancer		
No	19 (24)	**<0.001**
Yes	59 (76)	

Bold shows statistically significant differences.**The p-values are for comparisons between the proportions of health workers in each variable.

Table 6.2 above shows that health workers had significant differences in perceptions or knowledge of most of the health service attributes related to cervical cancer treatment and care investigated in the study. Twenty-two percent (22%) of health workers reported not having received training and adequately trained for cervical cancer treatment and care respectively. Thirty-eight percent (38%) reported not knowing or having read the National Cancer Prevention and Control Strategy (2014-2018) and the Cervical Cancer Prevention and Control Strategy for Zimbabwe (2016-2020) respectively. The proportion of health workers who perceived that health professionals were not enough to meet the demand of services in health facilities was 88% compared to 12% who believed they were sufficient (p<0.001).About 47% of health workers perceived that most women with cervical cancer had access to treatment and care, which is a good indication in our low-income context. The proportion of participants who believed that the surveillance system for cervical cancer was weak was 77%. However, despite these findings 69% of health workers were motivated to provide their services and only 26% reported poor working conditions in the health facilities. The majority (63%) of participants reported that the main mode of payment for cervical cancer treatment and care was out-of-pocket financing and the same proportion reported that the major barrier to treatment was lack of finances. As high as 59% of the health workers suggested free treatment for

cervical cancer as a solution to improving access in the country. While 58% of participants reported having adequate basic equipment in health facilities, as high as 78% reported non-availability of back-up for major equipment.

6.3.2 Phase 2: Qualitative Findings

Main Theme: Health service delivery system for cervical cancer is challenged

The main theme that emerged from this study was that the functioning and organization of the health service delivery system was compromised to provide comprehensive treatment and care to women with cervical cancer. The salient sub-themes that emerged are reported as quotes below:

Sub-theme: High cost of treatment and care

Most participants reported that the costs of treatment and care for cervical cancer were exorbitant to be afforded by ordinary patients. The costs included staging and monitoring investigations which are provided in private facilities as public health facilities do not have sufficient capacity to offer them. Treating health facilities do not provide chemotherapy drugs and they refer patients to private pharmacies. Since these drugs are imported, the costs of buying them become unaffordable for the patients. Furthermore, lack of price regulatory framework for healthcare commodities in the country subjects patients to the mercy of private health workers. These issues are revealed in the following statements from some participants:

> *"Not everyone can manage because the costs of treatment here are high".*
> Caregiver, Chishawasha, 26 years

> *"From the little knowledge that I have it looks like they are not accessing the treatment because of the economic situation. Medication is expensive and not everyone is on medical aid and for those who are it does not cover most illnesses and one will have to pay for the shortfalls".* Key informant, Pentecostal Pastor

> *"…..cancer medication tends to be more expensive…."* Key informant, Pharmacologist

"In most of our communities people don't earn that much they can't afford and therefore they end up seeking alternative therapies in the form of traditional healers or spiritual healers". Key informant, Senior Gynaecologist

One cervical cancer patient in an FGD reported that:

"I was prescribed a drug at Parirenyatwa and was told to go and buy in pharmacies but I couldn't afford. I didn't buy any of the prescribed drugs as I did not have the money"

Sub-theme: Limited health professional's knowledge and attitudes

Some respondents, especially key informants reported that health workers still lacked adequate knowledge about cervical cancer to educate the communities and also to know what to do when a patient presents with symptoms. Some of the symptoms may not be so obvious and health workers especially in the primary care health facilities may not suspect cervical cancer or refer someone for screening. Some participants reported bad attitudes amongst health workers for which the unintended consequences are poor health seeking behaviours amongst the communities.

"One may just think of the queues that will be there and also it depends with the nurses that are on duty because some of them aren't friendly they are harsh so one may decide to just go back home without being screened for cervical cancer." Healthy woman, Hopely, 31 years

"Some people go to private doctors so as to get quick assistance and in some cases one gets treatment for a different disease so instead of screening for cancer first one maybe diagnosed with fibroids and they start treating fibroids yet the patient has cervical cancer" -Caregiver, Goromonzi, 23 years

"….. if one goes to the doctors and is given wrong diagnosis and treatment the cancer would be spreading therefore contributing to advanced disease presentation. In my case I was discharging some odourless fluids so I went to the doctors and they started treating me for STIs yet the test results were negative for STIs" - Cervical cancer survivor, Mabvuku, 39 years

"You walk into a rural health facility and you ask nurses about cervical cancer or cancer in general but they have no clue of what it is but we are asking people in the communities to go to the clinic where the nurses don't know anything about cancer."- Key informant, Midwife

Sub-theme: Inequitable distribution of screening and treating health facilities

Most participants reported that screening services for cervical cancer were available only in a few health facilities. Also due to lack of resources women tend to fail to attend for services. Treatment for confirmed cervical cancer is only available in Harare and Bulawayo and this presents logistical challenges for women who may be coming from faraway places. A high number of participants reported logistical and accommodation challenges during treatment of cervical cancer which may require a patient to be attending the treating centre for many days consecutively.

One VIAC nurse (key informant) reported that:

"There are a few VIAC clinics and the people that come here come from far so there is an issue when it comes to accessibility and affordability"

Another key informant revealed the challenges of accommodation and had this to say:

".....maybe its accommodation as we treat people that come from afar and where they are staying in Harare they may not be welcome". -Key informant, Radiographer

One caregiver reiterated that:

"Lack of money is also a problem because some people stay far away from hospitals so some may not even have money for transport" -Caregiver, Mabvuku, 41 years

Sub-theme: Unclear pathway of care

Most participants revealed that the referral systems being used for cervical cancer patients were bureaucratic and could result in attrition of patients or incentivizing them to seek alternatives such as traditional medicines and spiritual interventions. Some participants reported that by the time the patients get to be engaged into

treatment and care they would have interfaced with many health facilities or service providers and their disease would have advanced.

A 23 year old female caregiver from Goromonzi said:

"The challenges we faced include the following: we went to different hospitals, consulted different traditional healers, prophets and went to different churches to no avail my mother would get prayed for and feel better for maybe 3 days and it would worsen. That is why we got to a point of believing that there were evil spirits behind my mothers' sickness. At Karanda hospital they did a biopsy and after 2 weeks her results were out and then she was referred to Parirenyatwa hospital. That is when we came in March and the doctors were on strike but it seemed my mother was getting worse by the day after the biopsy was taken".

One cervical cancer patient also reiterated the challenges of the referral system:

*"The fact that when you come here you will have to pay consultation fees, money is needed for every service they will render to you, like scan, blood tests, blood transfusion etc. However; the costs are lower with prophets or traditional healers". -*Cervical cancer patient, Kwekwe, 45 years

A cervical cancer patient reported in a FGD that:

"I was screened at Parirenyatwa in 2013 and I was operated and they took specimen after the operation and told me that I was now okay. From 2013 I considered myself as a cancer free person then last year I started to feel pain and I visited the doctor. I was told that the pain was being caused by ulcers. Around March last year (2017) I started spotting and I visited my nearest clinic and consulted them about my issue and I was referred to a gynecologist who took some specimens and I was told that the cervical cancer had recurred"

Sub-theme: Limited capacities of screening and treating health facilities

Some participants reported challenges in accessing cervical cancer screening services resulting in discouragement from seeking such services in future. Most participants reported that even though treatment was being offered in Harare, some patients could not access it due to being resident in faraway places. Some reported that treating health facilities did not have capacity to conduct all the staging and

monitoring investigations and provide the drugs that were needed by patients mostly chemotherapies and analgesics. Most participants particularly patients and health workers reported that the radiotherapy machine had frequent breakdowns and there is no back-up for this machine as it is a very expensive piece of equipment.

One oncologist reported that:

"I think also the fact that access to treatment was not consistent in the sense that there were times when machines for treating patients were not working that also can be a negative push factor."

A cervical cancer patient also added to the challenge of limited capacities in health facilities by reporting that:

"When I first went the nurses were on strike, I then went back there twice more and they had no equipment that is when I was referred to Gomba where I had my biopsy done and it was taken to Lancet Private Laboratories" Cervical Cancer patient, Beatrice, 42 years

Another patient reported some of the challenges experienced in receiving treatment:

"Every Monday I have my blood examined and then Tuesday I go for chemotherapy but sometimes I don't have the money to buy the medication for that particular session so I would have to look for money and then go later." Cervical cancer patient, Chiredzi, 49 years

6.4 Discussion

This study has revealed a myriad of health service barriers to accessing treatment and care by women with cervical cancer in Zimbabwe. Some of the structural barriers found in our quantitative study were: limited or lack of training for health workers, weakness of surveillance system for cervical cancer, limited access to treatment and care, inadequate health workers, reliance of patients on out-of-pocket funding for treatment services, lack of back-up for major equipment. The barriers to cervical cancer treatment and care reported in the qualitative study included: high costs of treatment and care, lack of knowledge about cervical cancer and bad attitudes of health workers, few screening and treating centres located mostly in

urban areas, lack of clear referral system resulting in bureaucratic processes, and limited screening and treating capacities in health facilities due to lack of resourcesand transport. These barriers were not only in the lack of infrastructure and resources to provide comprehensive services but in the organization of the health system. These findings are supported by a recent review of sub-Saharan Africa which revealed major challenges in cancer care. Researchers reported that diagnosis and treatment of cancer require a health system that is functional, interactive and responsive physically and human resources to identify diagnose and treat cases. The elements of such a health system are: physical infrastructure, qualified staff, supportive policies, and supportive laws [3].

Our findings suggest that the frequency of interface with specialists and access to regular general practitioners may be independent predictors of engagement into treatment and care. Limited access to health professionals may explain the relatively low uptake of treatment and care services among women with cervical cancer resulting in presentation of advanced disease [4, 5]. In Zimbabwe only about 10% of the population is on medical aid [16] and therefore access to regular general practitioners and specialists may be limited as most people rely on local primary care clinics for any health issue. These findings are consistent with those of a Pacific region study which reported limited number of cancer specialists due to lack of resources and migration to "greener pastures". Access to cancer treatment was reported as limited in the Pacific region as treatment centres were far away and patients were unwilling to travel long distances to seek screening and treatment services [17]. Our results are also supported by the reports of recent studies conducted in Zimbabwe which showed health system challenges to provide comprehensive treatment and care for cervical cancer [4, 5].

Lack of knowledge of distances to nearest screening centres by untreated women with cervical cancer may be a proxy for more underlying health service issues. The most plausible assumption in cervical cancer programmes is that all women will be suspected of cervical cancer through screening and later referred for diagnosis and treatment. However, our qualitative study revealed that some patients were never screened as they presented with clinically advanced disease and were straightway referred for histological investigations. Some of these patients were people living with HIV/AIDS who are recommended to be screened yearly due to the high risk of

cervical cancer incidence in this population. Zimbabwe adopted the integration of sexual reproductive health (SRH) services including cervical cancer screening with HIV/AIDS services to improve access to screening by PLWHA. Surprisingly our findings revealed that some of these patients presented with locally advanced disease despite the integration of services in the country. This suggests health service delivery or organization or policy failures. Furthermore, screening centres are still limited and are available mostly in urban centres, yet the majority of women in Zimbabwe live in rural areas [18]. Due to lack of financial resources most women cannot travel to seek health services for screening and later on for treatment. These findings are in tandem with those of Mohammadnezhad et al [17] and Kuguyo et al [5] who reported limited and centralized screening and treatment services in low-income contexts.

Our study revealed suboptimal training and knowledge for the treatment and care of cervical cancer patients amongst health workers in tertiary health facilities. This was supported by the fact that only 62% of the health workers, mostly from the tertiary health facilities, knew or had read the key national cancer policies. In the qualitative inquiry health worker lack of knowledge and bad attitudes towards patients were reported as key barriers to engaging patients into screening and treatment. Lack of knowledge among health workers particularly in the primary health care system was manifested in wrong diagnoses and treatments of patients leading to locally advanced disease presentation. Bad attitude towards patients with chronic diseases by health workers play a significant role in undermining health seeking behaviors [19] and may lead to patients resorting to alternative interventions. Unavailability of adequately trained health workforce reduces the availability of diagnosis and treatment services [17, 20]. Studies in the USA have reported that deficiency of knowledge and lack of training of health workers were barriers to cancer services which results is in line and supportsour findings [20, 21]. Lack of knowledge and inadequate training in cancer amongst health workers in tertiary facilities is real in Zimbabwe and this suggests even bigger gaps in the primary health system.

Findings from this study revealed that cervical cancer surveillance system in the country is weak and cannot account for some cases of cervical cancer and it is probable that the majority of cases are not reported or documented. Considering the limited capacities in screening facilities and the bureaucracy involved in patient

referrals to treatment centres suggested by our qualitative study, it is likely that the burden of cervical cancer in Zimbabwe may be grossly underestimated. In addition, pathways to care are not clear and it takes more than just the patient and their immediate family to navigate through the multitudes of barriers to get into treatment. This could also explain late disease presentations and poor cervical cancer survival or outcomes [4, 5, 22]. The costs associated with transport to health facilities, investigations, purchasing of drugs mostly from private pharmacies and receipt of radiotherapy are so high that the majority of patients cannot afford them. The major barriers reported in our qualitative work were lack of transport and financial resources to pay for transport to health facilities, investigations, drugs and radiotherapy session. One of the other key limitations in the provision of cervical cancer treatment was technical breakdowns of the radiotherapy machine and lack of back-up equipment. This results in disrupted services and may explain loss to follow-up that was reported in our study. Most patients on radiotherapy require 21-23 sessions which translates in days to about a month of visiting the health facility for treatment and because the majority are not from Harare or do not have close relatives in Harare, any breakdown of the machines may discourage them and lead to defaulting. Concomitant with lack of a follow-up system, this will result in high recurrence rates and poor survival [5, 22].

Despite the multi-dimensional health service barriers to cervical cancer treatment and care, health workers were still hopeful and motivated to provide services to patients. However, several health worker strikes have occurred to pressure the government for better remuneration and working conditions, even during the course of this study. These strikes were also reported to have affected the treatment and care of cervical cancer patients. However, some of the participants especially from in-depth interviews and FGDs reported that treatment services were still comparable to other countries and they would prefer being treated locally than going abroad if given a chance.

This study encountered some limitations worthy of mentioning; firstly we relied on bivariate analysis for our surveys and care must be exercised as the results may be confounded. Secondly, this study was conducted in Harare and the results may not be generalizable to other settings, therefore readers are advised to interpret the results with caution. Thirdly, this research involved cross sectional surveys whose

findings cannot be used to infer causal relationships. However, this study had some strengths; the use of mixed methods design allowed for deeper understanding of issues and the involvement of a diverse study population resulted in a diversity of perspectives which is crucial in any research endeavor. Most importantly, to our knowledge, this study was the first primary research to investigate health service delivery with regards to cervical cancer treatment in Zimbabwe.

6.5 Conclusion

The results of this study show that prevailing health services delivery approaches and their organization present barriers that entrench inequities to cervical cancer treatment and care. It is imperative that sustainable and workable strategies are devised and implemented, in the short-term future, in order to reduce the morbidity and mortality of cervical cancer in a low-income setting. Improvement in the organization and distribution of cervical cancer screening and treatment services needs to address the identified barriers. Strong political will and mobilization of resources both domestically and from global partners to built more capacity for screening and treatment of cervical cancer will go a long way in mitigating some of the key health service delivery challenges. Sound and realistic health policies that will create a health system that is functional, interactive and responsive to identify, diagnose and treat cases are recommended in addressing the growing incidence of cervical cancer amongst women in low-income countries. Capacity building of health care workers to improve their knowledge on cervical cancer is an imperative strategy low-income countries should consider.

List of abbreviations

AIDS	Acquired immunodeficiency syndrome
FGD	Focus Group Discussion
HIV	Human immunodeficiency virus
NGO	Non-governmental organization
PLWHA	People living with HIV and AIDS
SRH	Sexual reproductive health

| VIAC | Visual inspection with acetic acid cervicography |
| ZDHS | Zimbabwe demographic and health survey |

Declarations

Ethics approval and consent to participate

This study was carried out in partial fulfillment of the requirements of a PhD degree at the University of Pretoria and was approved by several ethics committees/bodies:

17. University of Pretoria, Faculty of Health Sciences Research Ethics Committee (**REC 487/17**)
18. Harare Hospital Ethics Committee (**HCHEC 271017/77**)
19. Joint Parirenyatwa and University of Zimbabwe Research Ethics committee (**JREC 33A/18**)
20. Medical Research Council of Zimbabwe (**MRCZ/A/ 2271**)

All participants in this study were consented in writing before interviews. Consent forms were administered by the researchers in the language of the participant's preference i.e English or Shona (local language spoken by majority of people in Zimbabwe).

Consent for publication

Not applicable

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare no conflict of interests.

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Authors' contributions

OT: researcher, concept and study design; AMN: concept design, critical revision and editing; WK: critical revision and editing, GD: PhD co-supervisor, concept design, critical revision and editing; SH: PhD supervisor, concept and study design, critical revision and editing; BSP, critical revision and editing. All authors reviewed and approved this manuscript.

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Introduction

This chapter presents some key strategies that could be implemented to address individual, societal and health system barriers to access and usage of cervical cancer treatment and palliative care in Zimbabwe. The chapter explores potential public health strategies that could improve access and uptake of cervical cancer services based on findings from chapters two up to six.

7.0 MODEL STRATEGIES TO ADDRESS BARRIERS TO CERVICAL CANCER TREATMENT AND PALLIATIVE CARE AMONG WOMEN IN ZIMBABWE: A PUBLIC HEALTH APPROACH

Abstract

Background

Cervical cancer treatment and care remains limited in Zimbabwe despite the growing burden of the disease among women. This study was aimed at investigating strategies to address barriers in accessing treatment and care by women with cervical cancer in Harare, Zimbabwe.

Methods

A qualitative inquiry was conducted to generate evidence for this study. Eighty-four (84) participants were purposively selected for interviews and participation in focus group discussions. Discussion and interview guides were used as data collection tools and discussions/interviews were audio-recorded, transcribed and translated into English. Inductive thematic analysis was conducted using *Dedoose* software.

Results

Salient sub-themes that emerged in the study at the individual patient level were: provision of free or subsidized services, provision of transport to treating health facilities and provision of accommodation to patients undergoing treatment. At the societal level, the sub-themes were: strengthening of health education in communities and training of health workers and community engagement. Salient

sub-themes from the national health system level were: establishment of more screening and treatment health facilities, increasing the capacities of existing facilities, decentralization of some services, building of multidisciplinary teams of health workers, development and rolling out of standardized guidelines and reformation of AIDS levy into a fund that would finance priority disease areas.

Conclusion

This study revealed some noteworthy strategies to improve access to cervical cancer treatment and care in low-income settings. Improved domestic investments in health systems and reforming health policies underpinned on strong political are recommended.

Key words: Cervical cancer, Zimbabwe, barriers to access, treatment, palliative care, strategies, qualitative inquiry, thematic analysis, health policies.

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7.1 Background

Cervical cancer is fourth most common cancers worldwide and approximately 85% of new diagnoses occur in less developed regions of the world [1]. Recent reports have indicated that about 87% of the 266,000 global cervical cancer deaths occur in developing countries [2]. In 2016, Zimbabwe National Cancer Registry reported that at least 1375 new cases of cervical cancer and in 2018 GLOBOCAN report revealed that 3,186 new cases were diagnosed [1, 3]. Despite the growing burden of the disease in the country, patients encounter a myriad of multi-dimensional barriers in gaining access to treatment and care [4]. These challenges could be the underlying factors resulting in about 80% of the cases locally being presented in advanced stages [5].

With the global burden of cervical cancer disproportionately affecting women in low-income context, several barriers to treatment and care have been reported by researchers in USA. Inadequate infrastructure, limited access to preventive HPV vaccines, screening, and treatment, as well as limited trained personnel and training opportunities continue to impede efforts to improve access to treatment and care in less developed world [6]. Health systems in low-income countries are overwhelmed with competing priorities and health care providers are often ill-prepared for the growing demand for their services [7]. A recent report from Latin America indicated that high cervical cancer incidence in that region was attributable to limited access to screening services and inadequate providers to perform diagnostic and therapeutic procedures. Geographical distances and cultural barriers were also cited as impediments to access and uptake of recommended diagnostic and treatment services for cervical cancer [8]. In South Africa, a recent study reported limited knowledge of cancer, lack of biomedical treatment and stigma as barriers to linkages to treatment and care by women with cervical cancer [9].

Zimbabwe has been experiencing a plethora of economic challenges that have resulted in weakening of social services including health care system [10, 11]. Several barriers to cancer treatment and care have been reported in the country and these include: resource constraints, centralized diagnostic, treatment and palliative care services, shortages of specialists and high costs associated with treatment [12]. Our recent study demonstrated comprehensive multi-dimensional barriers to

accessing treatment and care and these included: few treatment centers, lack of infrastructure, lack of commodities such as drugs, limited number of radiotherapy machines, frequent breakdowns of radiotherapy machines, high costs of services, few specialists, lack of standardized guidelines, limited health information system linked to cancers, lack of patient follow-up system, limited knowledge or inappropriate attitudes of health workers, frequent health worker strikes and bureaucratic referral system. Societal barriers reported were lack of knowledge, fear, stigma, misconceptions, family influences, attitudes and beliefs, influence of traditional and spiritual healers [4, 13]. Strategies suggested to fight against stigma in recent studies included involvement of traditional healers in interventions due to their community status [9]. Kuguyo and colleagues [14] suggested increased funding for cervical cancer screening and community health education to promote early detection of the disease as some of the urgent interventions in Zimbabwe. To date most studies in low-income settings have focused on screening and secondary prevention of cervical cancer. However, this study was envisaged to unpack some of the key and contextual modelling strategies that could be implemented to improve access and uptake of cervical cancer treatment and palliative care by women.

7.2 Methods

This study was a qualitative inquiry conducted in Harare, Zimbabwe as part of a sequential explanatory mixed methods study. The main purpose of the study was to understand and explain some of the findings from the quantitative studies. The qualitative approach became useful in investigating some of the key strategies that could be implemented to address barriers to cervical cancer treatment and palliative care. A total of 84 participants were enrolled purposively in the study of which 16 were in-depth interviews, 20 were key informants and six focus groups with an average of eight participants each were conducted in different locations (see Figure 7.1 below). All participants gave consent in writing before taking part in the study. The selection of the participants was conducted in the communities, health facilities and key institutions. Participants were selected based on knowledge and experience gained by interacting with women with cervical cancer or similar conditions. In-depth interview and focus group participants were identified during surveys in the communities and health facilities. Key informants were identified predominantly

utilizing snowballing technique in which cases health workers in surveys would suggest names of potential participants to be considered for enrolment [15].
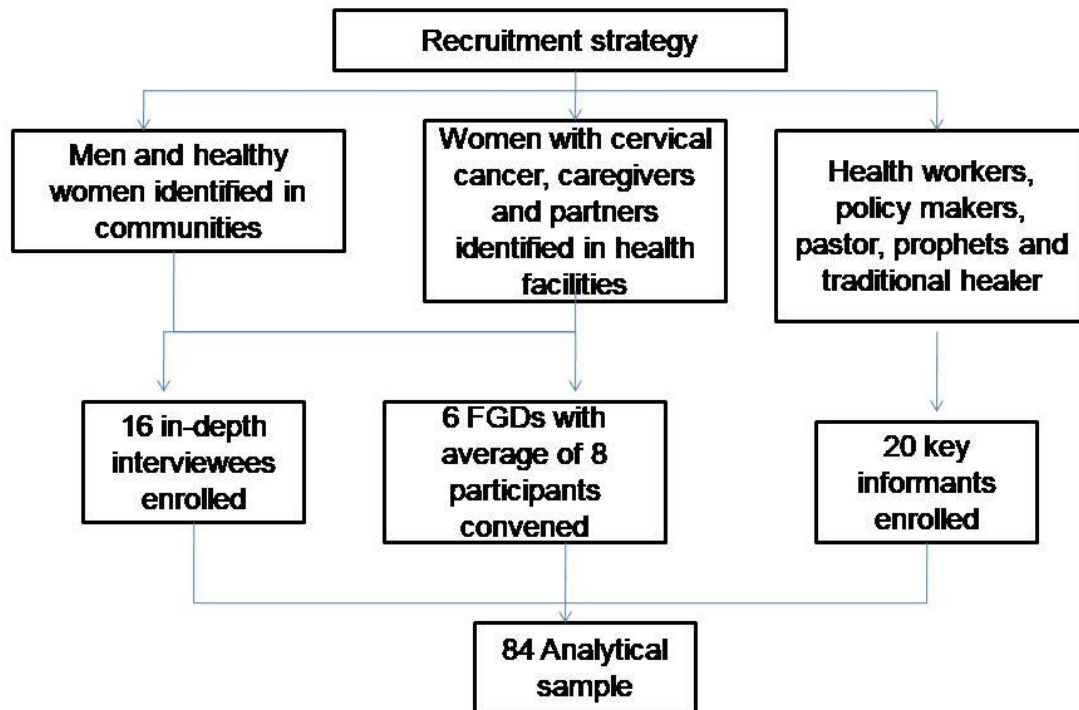
Figure 7. 1: A flow diagram of participant enrolment in qualitative study (phase 2).

The figure above shows the sequence of selection and groups of people recruited in the qualitative study (phase 2) in Harare, Zimbabwe. A total of 84 participants were enrolled and these comprised of 16 in-depth interview participants, 20 key informants and 6 FGDs with an average group size of 8 participants.

7. 2.1 Data collection

All participants provided consent in writing to be interviewed and audio-recorded during the interviews and discussions. Interview and discussion guides designed by the researcher were used as data collection tools in this study. The questions used in the data collection tools had been designed based on the findings from the surveys and the overall research questions. The researcher and his trained research

assistant conducted the interviews and moderated the focus group discussions (FGDs). In-depth interviews and FGDs were conducted in communities were conducted in institutions. In addition to the audio-recordings, notes were also taken during each interview/discussion especially for observation of participants' non-verbal communication. In-depth interview and FGD participants were given refreshments during the interview or discussion sessions in addition to an allowance of USD8 each to compensate for their time and travel [16-18].

7.2.2 Data analysis

Interviews and FGDs were transcribed verbatim and translated into English where applicable. Transcription and translation of audio-recordings were undertaken by the researcher and his assistant after receiving some training. Transcripts were identified by the unique identifier assigned to each participant (and stated by each participant at the beginning of the FGD/interview) rather than by any personal information. Unique identifiers were used to link the guides and the interview only after the conclusion of transcription. All in-depth interviews, key informant interviews and FGDs were coded manually line by line by the researcher using *Dedoose software* after creation of codes based on the research question and literature. Codes were discussed between the researcher and his assistant and only codes that were agreeable were considered. Manually generated thematic codes were processed in the same software to produce final outputs for the study. The final themes were displayed as direct quotes [16-18] and these were based on the research question

7.3 Results

7.3.1 Main Theme: Strategies to address barriers to cervical cancer treatment and care.

Most participants had high hopes that with sufficient investments and sound policies key barriers to accessing cervical cancer treatment and care could be removed. A myriad of sub-themes emerged related to some of the key strategies that could be implemented in the country to improve access and utilization of treatment and palliative care services by women with cervical cancer.

7.3.2 Individual level sub-themes

Sub-theme: Provision of free or subsidized services

Most participants reported that cervical cancer treatment and care was associated with high costs which could not be afforded by most people and hence the government should consider free or subsidized services. Some indicated that HIV and TB were being treated for free hence they felt that cervical cancer should also be considered for free treatment. Some respondents complained that the government and its partners were only providing them with free screening services yet if one is suspected of cervical cancer they would have to rely on out-of-pocket funding. One young caregiver suggested a strategy to assist cervical cancer patients to access treatment and care:

> *"I think if the government could subsidize medication to allow people to get it at a cheaper price because someone from the rural areas who doesn't work cannot afford the medication".*-Caregiver aged 23 years from Goromonzi.

One FGD participant mentioned that uptake for screening services was low because when one is suspected of cervical cancer they would need to pay high bills for treatment which they would not afford hence some women would opt not to be screened at all:

> *"I don't think it's easy to go for screening because if you are suspected of cervical cancer the next stages needed for confirmation are very expensive so I think the government should lower the charges of cervical cancer services so that people can get treatment earlier".*-Healthy woman, FGD participant from Hopely.

Another respondent reported that women with cervical cancer were dying due to lack of resources hence the government should do something to help them:

> *"I think the government could facilitate for free treatment of cervical cancer for all women in Zimbabwe and it would alleviate the problem because many can actually die because of lack of resources to get treatment".*-Cervical cancer survivor aged 60 years from Shurugwi.

Sub-theme: Provision of transport to treating health facilities through coupons or cash

Most participants alluded to the centralization of cancer treatment services causing challenges for women who live in rural areas. The high costs of transport to treating facilities deter some women from seeking early treatment for cervical cancer. One respondent revealed that addressing the transport challenges would improve access and uptake of treatment and care services for cervical cancer.

> *"Transport costs have to be small if people are to come in for treatment and care and if there are huge it has defeated our purpose. So that's a very big policy issue that we need to discuss*".- WHO Expert, key informant from WHO Country Office in Harare.

Sub-theme: Provision of accommodation to women with cervical cancer during their treatment.

With only two cancer treating health facilities in the country most respondents reported accommodation challenges during treatment sessions. Some of the patients have no relatives in major cities where treatment and care is provided hence they are faced with many problems. One respondent explained her challenges in accessing treatment and care:

> *"I do not have relatives in Harare so as a result my challenges will be much more and they include accommodation, food, transport and also medication".-* Women with cervical cancer, FGD participant.

7.3.3 Societal level sub-themes:

Sub-theme: Strengthening of health education in communities and training of health workers.

Some participants reported that health education and cervical cancer awareness that was being given to communities was not adequate hence more is required in order to reach more people. Lack of knowledge about cervical cancer and its treatment was a source of misconceptions which were further impeding access and utilization of treatment services. One respondent revealed the limitations of the current awareness and health education interventions:

> *"….. I don't think we are reaching enough in terms of education because we just give health education to those that would have visited the health centre*

and we don't have outreach programmes that help us reach the communities." -Midwife, key informant from Harare Hospital.

Two other key informants also suggested strengthening of education for health workers:

"…the health worker needs education in order to disseminate all the information, at the moment they are disseminating the message that there is lots of cervical cancer and people should go and be screened and they stop there. Any other question asked they cannot go any further so we need to educate and empower the lowest level of health workers who reaches the highest number of people in the communities". -Senior Pathologist, key informant from Parirenyatwa Hospital.

"…..for health care professionals maybe our curriculum also needs to be adjusted to incorporate more cancer awareness as we go like what we have done with communicable diseases." -Pharmacologist, key informant from Harare.

An apostolic sect prophet proposed improved health education in communities to increase early detection of cervical cancer:

"According to my thinking from the church side or prophecy the cancer care people should educate people in our churches" -Apostolic sect prophet, key informant from Zvimba..

Sub-theme: Community engagement

Most participants reported the need for community engagement in promoting uptake of screening and treating services for cervical cancer. Some of the community leaders that are crucial to engage because of their significant influence on communities include local leaders, traditional healers, pastors and prophets. One key informant had this to say:

"……as Africans we know that you go to present whether to a village health worker or traditional healer or doctor or nurse when you are sick…" -Senior Pathologist, key informant from Parirenyatwa Hospital.

A traditional healer reiterated the influence and importance of traditional healers in cervical cancer screening, treatment and care utilization:

"…we [traditional healers] are seeing 80% of women with cervical cancer or the population in Zimbabwe consults traditional practitioners because they are accessible and their medicines are affordable".-Traditional healer, key informant from Harare.

Another community leader reported on their experience with women affected by cervical cancer:

"…..we have heard about it [cervical cancer] and we have been praying for people coming to church who had that challenge…..but we [pastors] are not well informed about the disease as there is no platform for the Ministry of Health to engage with the Church but we believe such a platform is essential for health related collaborations". -Senior pastor, key informant from Harare.

An apostolic sect prophet reported the importance collaborations with the government in order to improve access to cervical cancer treatment and care:

"…. the best is for people that have the knowledge on to come to centres like churches and ask to address the congregants because the moment you address maybe 1000 people gathered it means you have given information to almost 5000 people because the 1000 people will then spread the word out there…". - Apostolic sect prophet, key informant from Zvimba.

7.3.4 National Health system sub-themes:

Sub-theme: Establishment of more screening and treatment health facilities.

The majority of participants suggested the establishment of more cervical cancer screening and treating health facilities across the country. This is due to the inadequate number of health facilities providing these services. A caregiver suggested the following strategy:

"……..if they could also increase the number of hospitals in different provinces that treat cancer of the cervix because some come from as far as Bulawayo and if you have no relative in Harare what will you do?" -Caregiver aged 23 years old from Goromonzi.

One key informant reiterated the need to increase screening facilities through mobile clinics:

> *"I think it can also go a long way if there are mobile screening services because remember some of our facilities patients need to walk some 5kms to access them."* -Senior Gynaecologist, key informant from Harare Hospital.

Sub-theme: Increasing capacity in screening and treating health facilities

Increasing the capacity of cervical cancer screening and treating health facilities was a salient emerging sub-theme especially among healthy women, women with cervical cancer and health workers. One health worker reported the following:

> *"I think three broad areas: health education, capacity and costs are the major areas that we need to tackle and others may come in as we go."* -WHO Expert, key informant from WHO Country Office

Another key informant reiterated the need to strengthen existing facilities to increase their capacities:

> *"………I think we need to improve the treatment centres that are available. Make them function optimally before we start thinking of establishing new centres."* -Senior Oncologist, key informant from Parirenyatwa Hospital

Another key issue that emerged is the issue of addressing persistent radiotherapy machine breakdowns to ensure uninterrupted services. One key informant reported the following with regards to the radiotherapy machines:

> *"I think also the fact that access to treatment was not consistent in the sense that there were times when machines for treating patients were not working that also can be a negative push factor and needs to be addressed urgently".* -Senior Oncologist, key informant from Parirenyatwa Hospital.

Sub-theme: Decentralization of some services such as follow-ups

The salient strategy reported by most participants was for the government to decentralize treatment and care of cervical cancer to lower levels of the health system across the country. A key informant reported the need to decentralize other services such as follow-ups of patients:

> *"Concerning decentralizing some services such as follow up services I think that is imperative however; in terms of treatment I think we need to improve the treatment centres that are available. Make them function optimally before we start thinking of establishing other centres."* -Senior Oncologist, key informant from Parirenyatwa Hospital

Sub-theme: Building of multidisciplinary teams of health workers in treating health facilities.

Another sub-theme that emerged was the need to build multi-disciplinary teams of health workers to provide the comprehensive treatment services for cervical cancer. Team work cannot be underestimated given the multitude of care levels that cervical cancer patients have to go through as part of their treatment and care. Other registered practitioners such as traditional healers and prophets should also be engaged through their representative bodies in order to promote awareness and address stigma and misconceptions about cervical cancer:

> *"We shouldn't forget that we have other people who claim to know a lot about cancer in the communities and societies be they herbalist, traditionalists and spiritual healers that are saying things and you know somehow psychologically or traditionally black people tend to believe them."* -Senior Oncologist, key informant from Parirenyatwa Hospital

The multi-disciplinary approach to cervical cancer treatment and care sub-theme was reinforced especially by oncology specialists:

> *"What we are also lacking in terms of cancer care is that multi-disciplinary approach because then when you have multi-disciplines all coming together to work together at least for the good of the patient and at the end of the day you find that you will get reinforcement and collaboration of whatever needs to be done for the patient. If I may say even in this department we don't have social workers and psychologists, I mean we have oncology nurses but they*

cannot double up to be everything." -Senior Oncologist, key informant from Parirenyatwa Hospital

Another key informant explained palliative care and how it is provided by multiple health care workers using a team approach:

> *"Palliative care is the treatment that is given to a patient from the point of diagnosis up to his or her death. It is also a multidisciplinary approach that involves the oncologists, physicists, radiographers, nurses, social welfare, family and church".*-Oncology nurse, key informant from Parirenyatwa Hospital.

Sub-theme: Development and rolling out standardized guidelines

Another sub-theme that emerged from the study was the issue of development and rolling out of referral and treatment guidelines to all levels of the health care system. One respondent explained the need for guidelines:

> *"Yes people can say we refer a patient but I think we need guidelines such that if a patient is suspected of having cervical cancer they know that I'm going to go to this place to see either doctor A or doctor B or a cervical cancer clinic that they will just go straight into cervical cancer clinic without having to be booked into a general clinic because that helps".*-Senior Oncologist, key informant from Parirenyatwa Hospital

Another key informant reiterated the need for developing guidelines with input of multi-disciplinary team of health workers:

> *".....we need to have guidelines that are set up by a multi-disciplinary team. It must be the whole team. It must be pathologists, it must be oncologists, it must be gynaecologists, it must be the nurses, epidemiologists coming together looking at the data, looking at the population coming up with guidelines that work for us here in Zimbabwe".*-Senior Pathologist, key informant from Parirenyatwa Hospital.

Sub-theme: Reformation of AIDS levy into a Fund that would fund priority disease areas such as cervical cancer.

The AIDS levy was established to mobilize domestic resources to scale-up treatment and care for HIV/AIDS in Zimbabwe. However, HIV/AIDS is a known risk factor for cervical cancer yet the same fund does not cater for cervical cancer treatment services. Some respondents reported that the AIDS levy needed to be reformed so that it funds priority disease areas of which cervical cancer is one of them:

> *"I think at the moment there is so much to talk about cancer. The need is there people may feel overwhelmed if they are going to have another levy in addition to the AIDS levy but what I would recommend is that the AIDS levy can be slashed and then they share the AIDS levy and the Cancer levy but not to call it AIDS levy hoping that they will then share with cancer. There should be a separate budget for cancer"*. - Senior Oncologist, key informant from Parirenyatwa Hospital

7.4 Discussion

As the burden of cervical cancer is increasing particularly in low-income countries [1, 6], there are windows of opportunities for improving the existing health systems to increase access to treatment and care. This study revealed some of the strategies that could be implemented in Zimbabwe in the short to long term. At the individual patient level, this study suggests the following strategies: removal of user fees or subsidizing services, provision of transport to treating health facilities through coupons or cash and provision of accommodation to women with cervical cancer during their treatment. At the societal level the following interventions were suggested by our findings: strengthening of health education in communities and training of health workers and community engagement. Finally, at the national health system level our findings suggests the following interventions: establishment of more screening and treatment health facilities , increasing capacity in the existing screening and treatment facilities, decentralization of some services such as follow-ups, building of multidisciplinary teams of health workers in screening and treating health facilities, development and rolling out of standardized guidelines and reformation of AIDS levy into a fund that would finance priority disease areas including cervical cancer. While these strategies may not be exhaustive they are a good starting point to drive cervical cancer treatment and care to priority in low-income contexts.

This study showed that removal of user fees or subsidizing treatment was imperative to remove the burden of high costs that impede linkages to treatment and care by women with cervical cancer. This finding is consistent with what was reported in the USA, where Clinton Health Access Initiative and American Cancer Society found that cost was a major barrier to timely and quality care worldwide and they established a partnership in 2015 to optimize cancer drug market to improve access to affordable treatment [1]. Nyakabau [5] recommended the availability of free or affordable and accessible chemotherapy in public health institutions to improve access and usage of treatment services. In a recent systematic review, researchers noted that fee exemption policies were one of the key strategies in improving access and utilization of maternal and neonatal care in sub-Saharan Africa [19]. Another study in Malawi revealed that user fees were a significant barrier to health care access and reduced detection of serious infectious diseases [20]. These findings confirm our results which have demonstrated suboptimal access to cervical cancer treatment and care due to high costs.

Our study reported that challenges of transport to treating health facilities could be mitigated by interventions to provide transport assistance in the form cash or coupons to women with cervical cancer. However, this may be a short-to-medium term intervention in low-income settings. A USA study reported that patient transport or treatment centre accessibility could be improved through national commitment to infrastructural development such as road and rail networks, enhanced geographical distribution of treatment facilities and infrastructural support from non-governmental organization (NGOs) and industry [6]. This finding is long-term and more sustainable for settings with high incidences of cervical cancer however; such investments will take time and demand strong political will due to limited resources and competing priorities in low-income settings [5, 6].

Cervical cancer treatment modalities usually involve women spending many days visiting treatment facilities for treatment whether radiation therapy or chemotherapy or a combinations of different modalities. Unfortunately at least 80% of cervical cancer patients in low-income contexts present late and they have to spend many days receiving treatment and care in tertiary health facilities [5]. In most cases accommodation challenges pose as a barrier to accessing and utilization of treatment and care services for patients who live outside major cities. One strategy

to mitigate against these challenges is for the government and its partners to provide accommodation to cervical cancer patients during their treatment phases. Anecdotally, Tariro hostel at Harare Hospital used to accommodate cancer patients who were being treated at Parirenyatwa hospital until 2007 when it closed down due to lack of resources. Re-capacitating the home to accommodate cancer patients from outside Harare would go a long way to ameliorate the challenges of accommodation and transport which were key emerging barriers to engagement into treatment and its adherence in this study.

This study revealed that strengthening of health education and training of health workers at all levels of the health system were imperative interventions to improve cervical cancer treatment access and usage. Lack of awareness has been reported as a barrier to cervical cancer screening uptake in low-income settings [21]. A South African study reported the importance of community outreach cancer education interventions involving traditional healers, churches and the youths to address stigma and other social ills associated with cervical cancer [9]. Researchers in the USA reported that collaboration of nations, international organizations and industry to develop and roll out workshops, courses and exchange programmes were key to improving health care knowledge and skills about cancer [6]. In Zimbabwe, researchers reported the importance of prioritizing training of primary care health workers in order to support the decentralization of some services to improve linkages to preventive and curative services [5]. Our work supports the findings and recommendations from the cited studies [5, 6, 9] and further reinforces the need for comprehensive community health education and health worker training interventions. However, collaborative work involving government, academic institutions, international organizations and industry cannot be underestimated.

Findings of this study revealed the importance of community engagement through community leaders such as traditional or local leaders, pastors, prophets and traditional healers. These have significant influence in communities that could be used to promote uptake of preventive and curative services for cervical cancer. Given the complexities associated with cervical cancer as a disease and its treatment modalities community involvement is imperative [12]. Involvement of community leaders such as local chiefs, traditional healers, pastors and prophets is important to promote early detection and treatment of cervical cancer. Researchers

in South Africa reported that anti-stigma interventions for cervical cancer could partner traditional healers as they have a critical role in society [9]. Our study supports this suggested intervention and further extends it to include other community leaders who command respect in African communities.

Increasing the number and optimally distribute cervical cancer screening and treatment facilities was a major salient sub-theme in our study. Another key sub-theme that emerged was the strengthening of capacities of the existing cervical cancer screening and treatment facilities to improve linkages into screening and treatment services. Recent studies have shown inequitable distribution of cervical cancer services and weak systems to provide comprehensive preventive and curative care services in low-income countries [5-7, 9, 12,14]. Capacity building for cervical cancer treatment and care would entail a list of different things from human resources, equipment, physical infrastructure, commodities, information systems, financial resources and leadership. A Kenyan study reported that reliance on one radiotherapy machine by the whole country was a cause for poor health outcomes and higher cancer mortality rates [23]. This finding supported the results of our present study. However, despite the limitations and competing priorities, most low-income countries have strong political will and sub-regional, regional and international collaborations are potential mechanisms to build sustainable capacities [6].

Decentralization of some cervical cancer services was another key strategy reported in our study. Recently, researchers in Tanzania suggested that decentralization of service delivery for cervical cancer services was one of the key facilitators in initiating and expanding screening and treatment [22]. In Kenya in 2015, the government and its global partners established three more cancer treating centres in order to decentralize the diagnosis, treatment and care services to reach more people [23]. Nyakabau [5] in Zimbabwe also proffered decentralization of some services as a policy priority in the nation to address barriers in the cancer continuum of care.

Findings indicate that building of multidisciplinary teams of health workers is strategic to improving access to high quality care and usage of treatment services. Taplin and colleagues [24] reported the effectiveness of multidisciplinary care teams (MDTs) in

the cancer care continuum from screening to end-of-life. Multidisciplinary care team work improved follow-ups and adherence to prescribed procedure and reduced the time from diagnosis to treatment [24]. In Zimbabwe, this concept is still not in place due to a number of factors chief of which is limited number of specialists [5], however; there is need for the government and its partners to embrace some of these effective approaches.

Another key finding was that the development and roll out of guidelines for treatment and care of cervical cancer was an urgent priority across the country. The availability of guides and training resources for a complex condition such as cervical cancer cannot be underestimated on the background of poor health worker welfare which results in staff attrition in the country's public health facilities which serves the majority of the populace [10, 11]. Alignment of the existing health infrastructure with cancer management is underpinned on the implementation of effective guidelines [5]. It is within a sound policy framework that the government is able to effectively coordinate all activities to provide comprehensive cancer treatment and care.

A noteworthy finding from our research was the need for reforming the AIDS levy into a fund that would finance interventions for other priority conditions like cervical cancer. The AIDS levy was introduced in 1999 in order to mobilize resources to fight against HIV/AIDS in Zimbabwe [25]. The fund has performed well in terms of raising resources for HIV/AIDS intervention in addition to demonstrating commitment to fighting the disease which has also seen several global partners coming in to assist with more resources [26]. However, such a funding mechanism requires review in light of other emerging diseases like cervical cancer. Treatment of cervical cancer is multimodal and complex hence it warrants the government to prioritize it given its high morbidity and mortality rates among women. Furthermore, donor funding for non-communicable disease has remained low over the past several years [26] signaling the need for low-income countries to come up with innovative strategies to raise domestic resources to finance non-communicable disease interventions. However; in low-to-middle income countries domestic funding for non-communicable diseases has been dominated by impoverishing out-of-pocket financing [25]. While introducing another levy on top of the existing one in Zimbabwe would be disastrous on the already overtaxed workforce, reviewing the AIDS levy to re-prioritize its beneficiary conditions may be a plausible starting point to raise domestic resources

for priority conditions. Other innovative funding mechanisms such "sin" taxes levied on products like tobacco and alcohol may be introduced to complement the reformed AIDS levy. Collaborations between the government, international organizations and industry could also realize more innovative strategies to mobilize resources to improve cervical cancer treatment and care linkages in low-income settings.

Few studies, to our knowledge have investigated strategies that could be implemented to address broader barriers to cervical cancer treatment and care linkages in low-income settings. Future directions for cervical cancer control policy in low-income settings should consider: 1) sound and realistic policies underpinned by strong political will; 2) wider health system strengthening or diagonal approaches; 3) community engagement & involvement in decision making; and 4) collaborations with international organizations and industry to mobilize sufficient resources to finance interventions. Our study should be reviewed in light of some limitations. Firstly, data was collected in Harare and therefore findings cannot be generalized to other contexts. Secondly, the study collected limited demographic information from participants in order to ensure confidentiality which the researcher had guaranteed during consenting process. Lastly, but not least some key policy makers in the Ministry of Health were not available for interviews hence the researcher had to work with those that were available. Despite encountering some limitations, this study had its fair share of strengths. The sample for this study comprised of diverse participants and these included: men, healthy women, women with cervical cancer, caregivers, managers from NGOs involved in cancer interventions, some policy makers from Ministry of Health, health workers, traditional healers, pastors and prophets. This culminated in a wider diversity of perspectives that enriched our outcomes. This study being qualitative and a second phase of a sequential explanatory mixed methods design meant that issues were investigated very deeply to understand them better than would have been achieved in a quantitative design alone. Our study was further enriched by the use of observations for non-verbal communication of participants which was crucial for understanding the subject under investigation. To the best our knowledge, this study was the first primary research in Zimbabwe to investigate the strategies that could be implemented to mitigate against barriers to accessing and utilizing cervical cancer treatment and care. Future policy directions could start from this work and other literature from similar contexts.

7.5 Conclusion

In conclusion, our study advanced scientific body of knowledge by demonstrating some of the key policy interventions that could be implemented to improve linkages to treatment and care by women with cervical cancer in a low-income setting. While the policy interventions identified are certainly not exhaustive, they are a good starting point to addressing challenges being faced by women in the country. Improved domestic investments in health systems and reforming health policies underpinned by strong political will are broader strategies that should be prioritized to sustainably reduce high cervical cancer morbidity and mortality in a low-income context.

What is known about this topic:

- Cervical cancer is one of the leading causes of morbidity and mortality among women in Zimbabwe.
- Cervical cancer treatment and palliative care services are largely centralized and access is low due to lack of resources in low-to-middle income countries
- There are limited contextual studies in Africa on strategies to improve linkages to cervical cancer treatment and care as most studies have focused on primary and secondary prevention.

What this study contributes:

- An in-depth and broader understanding of key policy interventions that could be implemented to improve linkages to cervical treatment and palliative care in Zimbabwe.
- Sound and realistic policies underpinned by strong political will are a key framework through which other interventions could be driven.
- Wider health system strengthening or diagonal approaches should be considered to leverage on already successful programmes such HIV/AIDS, malaria and TB.
- Community engagement is a key public health intervention for complex conditions like cervical cancer to reduce social ills such as stigma, misconceptions and resistance to utilize preventive and curative services.

- Collaborations with international organizations and industry to mobilize sufficient resources to finance interventions are imperative to sustainably deliver good cervical cancer outcomes in low-income settings.

Competing interests

Authors' contributions

OT: researcher, concept and study design; AMN : concept design, critical revision and editing; WK: critical revision and editing, GD: PhD co-supervisor, concept design, critical revision and editing; SH: PhD supervisor, concept and study design, critical revision and editing; BSP, critical revision and editing. All authors reviewed and approved this manuscript.

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CHAPTER EIGHT

8.0 GENERAL DISCUSSION AND CONCLUSION

The growing burden of cervical cancer in low-income settings is now common knowledge with 85% of the new diagnoses globally being reported in these contexts[1]. However; limited access and utilization of cervical cancer screening, treatment and palliative care among women in the less developed world due to a myriad of multidimensional factors is well known.[1-3] Health systems in low-to-middle income countries are too fragile to provide comprehensive cervical cancer preventive, treatment and care services to women who need them. Limited resources, poor infrastructure, limited number of specialist health professionals, centralized treatment health facilities, poor policies and limited funding of non-communicable disease programmes are some of the major challenges impacting on cervical cancer services.[2-5] This study was aimed at understanding equity in access and utilization of cervical cancer treatment and palliative care and their determinants in Harare as a first step to improving services to one of the fastest growing public health challenge in the country. In addition, this research was envisaged to contribute new scientific knowledge to inform future studies and policy that could be used in other similar contexts. This final chapter presents the overall discussion and conclusions of the findings of each objective investigated in this research study from chapter two to seven. This chapter also draws recommendations and discusses some of the proposed areas that would require further investigations in future studies.

Evidence-based policies are crucial in public health and health systems across the globe should ideally be underpinned by a sound and robust policy framework[2]. In Zimbabwe, the first National Cancer Prevention and Control strategy (2013-2017) was developed in 2013 and by 2017 it had not been fully implemented due to limited resources and competing priorities in the country. Since, its expiry in 2017; there has been no indication by government of a review of this policy and later on the development of a new updated strategy to guide cancer programmes. Furthermore, the Zimbabwe Cervical Cancer Prevention and Control strategy was developed in 2016 and it has not been fully implemented due to the same limitations noted in the

latter strategy. Zimbabwe like many of its neighbouring countries, is popular for the development of detailed and sound policies on paper but lacks the implementation capacity especially in the public health sector. On the background of these facts, it is not unsurprising why the country is faced with a huge unmet need for cervical cancer preventive and treatment services across the nation.

Chapter two outlines the critical first step of developing structured questionnaires to investigate the complex issues of access and utilization of cervical cancer treatment and palliative care among women. These tools were developed based on literature, the Andersen-Newman model of health service utilization[6], tools from other population level surveys and the tools were validated for scientific fitness of purpose before use. Further, the Chapter also revealed that the developed tools were scientifically valid and reliable to be used in the study. The tools contained valid constructs upon which the investigation of access and usage of cervical cancer treatment and palliative care could be based. For the community and patient survey questionnaire, 15 meaningful constructs were identified while for the health worker survey questionnaire 13 meaningful constructs were extracted from factor and principle component analyses. All the identified constructs had acceptable Cronbach's internal consistency coefficient ≥0.70[7]. These findings provided a confident footing from which this study could be carried out to understand complex issues with significance in the public health discourse of Zimbabwe and other similar contexts.

Chapter three presents the first investigation into the socio-demographic variations in access and uptake of cervical cancer screening, treatment and palliative care in Harare. This investigation was based on community and patient based surveys. The findings from this study revealed low usage of cervical cancer screening services (29%) in Harare. The Ministry of Health and Child Care and its partners in Zimbabwe have been engaging in nationwide awareness and cervical cancer screening campaigns in the last few years. However, despite these efforts there has not been significant changes in the uptake of cervical cancer screening services given that in 2015 only 24% of women in Harare had reported ever screening in their lifetimes in a national demographic and health survey.[8] This study also showed that few socio-demographic characteristics were associated with uptake of cervical cancer

screening services in Harare and these factors were religious affiliations and usage of health facilities. Furthermore, only affiliations to protestant churches were associated with access and usage of cervical cancer treatment and care services in Harare. This study suggested that variations in access and utilization of cervical cancer screening, treatment and palliative care could be better explained by societal and health system factors other than socio-demographic characteristics.

Chapter four presents a follow-up study from Chapter three that was aimed at investigating the determinants of access and usage of cervical cancer treatment and palliative care in Harare. The study suggested that societal and health system factors like reported above, were more important in influencing uptake of treatment and care services among women with cervical cancer than individual level factors. These findings reinforce the findings from chapter three that inequities to cervical cancer services may be entrenched mostly by societal and health system factors. These findings are also supported by other recent studies in Zimbabwe which have broadly described limited resources and physical infrastructure at the national level as among the major impediments to engagement into treatment and care among cancer patients.[3, 4] Unlike communicable diseases such as HIV/AIDS, TB and malaria, cervical cancer treatment and care services are predominantly financed from out-of-pocket funds as there are not subsidized by the government or supported by global partners. Out-of-pocket financing is well known for its devastating impoverishing effects on households at a time Zimbabwe is going through severe macroeconomic challenges. [9, 10]

Chapter five presents an investigation of knowledge, attitudes, beliefs and practices of women towards cervical cancer, its treatment and care in Harare. The study also explored knowledge of causes, risk factors, prevention and treatment and the associated determinants among women affected by the disease. Despite relatively high levels of knowledge of cervical cancer risk factors, prevention, screening and treatment, specific knowledge of causes, access to primary care and utilization of screening services remains suboptimal. This study also showed that the majority of women with cervical cancer had positive attitude and, beliefs towards their condition. The qualitative phase of the study further revealed some drivers of limited specific knowledge of cervical cancer and low uptake of screening services. The study

further reported that despite the increased cervical cancer awareness campaigns across the country in the last few years, detailed or specific knowledge of the disease has not improved and this may suggest limitations in the packaging of the messaging.

Chapter six presents an investigation into how health system barriers are impacting on access and treatment among women with cervical cancer. This study used data from health worker survey and qualitative inquiry to understand how health delivery models and their organization were impacting on access and utilization of treatment and care among women with cervical cancer. This study builds up from chapters three to five, which suggested the importance of societal and health system factors as major causes of inequities to cervical cancer treatment and care. The findings of this study further revealed the health system barriers in Zimbabwe, in terms of resources and organization to provide comprehensive treatment and care for a complex condition like cervical cancer. Several worker strikes by doctors and nurses during the course of this study, protesting poor conditions of service such as poor remuneration and lack of health care commodities in public health facilities was a sign of deep systemic health system challenges in the country.[11] Qualitative findings of this study showed that in order to engage in treatment and care, women with cervical cancer needed more than just physical resources to navigate and cope with the bureaucratic pathways of care in Zimbabwe's health facilities. The study further revealed that health service level barriers in treating centres were also further impeding early screening and treatment of cervical cancer. This is because these barriers reinforces stigma, fear of the unknown, beliefs that cervical cancer is not treatable among other misconceptions about the disease and its treatment modalities. This may partly explain the reasons why at least 80% of cervical cancer cases present late in the less developed world. [3, 4]

Chapter seven presents an investigation of the model strategies that could be implemented to address the individual, societal and health system barriers to cervical cancer treatment and palliative care identified in Zimbabwe. This study was a qualitative inquiry with a diverse group of participants. The findings of this study show some of the key model strategies that could be implemented in Zimbabwe to improve cervical cancer treatment and palliative care. Such strides would not only

ultimately result in improved morbidity and mortality outcomes but would also strengthen the wider health system and promote early screening and treatment. Our findings also support Zimbabwe's proposal of integrating oncology and palliative care in order to improve quality of life for patients and their families, improve efficiency in the use of resources and improve outcomes in line with international recommendations.[12] However, this integration project is funded by donors and is coordinated by an NGO run Hospice and furthermore the National Cancer Strategy has not been updated since its expiry in 2017. In addition, Zimbabwe's major cancer programmes in the Ministry of Health and Child Care are shared among Directorates of Family Health, Non-communicable diseases and Pathology and with such a set up ownership and stewardship of programmes and policies could be challenging. With the country's health programmes predominantly funded by global partners, non-communicable disease programmes which are currently not a priority to major donors tend to suffer resulting in limited capacities. These challenges may drive high incidence, morbidity and mortality rates from cervical cancer in low-income settings.

This study contributes towards improvement of cervical cancer preventive and curative interventions in Zimbabwe through programme and policy recommendations. It is important that all cancer programmes are well structured and managed/coordinated through a sound, robust and evidence-based policy framework. This research proffers a good starting point for updating the National Cancer Prevention and Control and the Cervical Cancer Prevention and Control policies as it provides a plethora of evidence. Through a wide dissemination of the research; health workers, programme managers and policy makers may be compelled to work together to implement some of the recommendations with the common goal of reducing cervical cancer incidence, morbidity and mortality in Zimbabwe.

8.1 Recommendations

The primary responsibility of improving cervical cancer treatment and palliative care interventions including policies in Zimbabwe lies with the Ministry of Health and Child Care as the ultimate beneficiaries of this research. Several recommendations have been drawn from this study and they are detailed below:

- There is need for the strengthening of the National Cancer Control Programme (NCCP) to manage and coordinate all cancer programmes and taking ownership and stewardship of policies and strategies in Zimbabwe. This department should be the lead institution in the formulation of policies and strategic documents drawing from evidence from research. The NCCP should advocate for a policy framework to ensure that all research relevant to its functions inform its programmes and policies.

- The government should prioritize reviewing and development of sound, evidence-based and realistic national strategies for cancer. There is an urgent need to review and update the National Cancer Prevention and Control stratetgy initiated in 2013. There is also need to fully implement and conduct a mid-term review of the subsisting Zimbabwe Cervical Cancer Prevention and Control Strategy (2016-2020). Commitment to these strategies will motivate the donor community and industry to support the government in its initiatives.

- There is need for the government to invest more in cancer programmes from prevention, treatment and palliative care to ensure that services are accessible and affordable to the people who need them. Such investments would require strong political will and the engagement of global partners for support. These investments should capacitate the existing cancer treatment centres i.e Parirenyatwa and Mpilo Hospitals before establishing more treatment centres. Once the two existing treatment centres have been capacitated fully in terms of human resources, functional radiotherapy machines, health information systems, training of health workers, healthcare commodities and robust follow-up systems then more centres could be established starting with provincial hospitals to provide easily accessible services across the nation.

- There is need for the decentralization of some cervical cancer services to the lower levels of the health system to achieve universal coverage. Services such as cervical cancer screening using the VIAC approach, HPV vaccinations, treatment of pre-cancerous lesions and follow-up reviews of cervical cancer patients after treatments could be decentralized to district and

provincial levels. The use of mobile clinics offering HPV vaccinations, screening and treatment of pre-cancerous lesions using the "See and Treat" approach should be scaled up across the country with the support of industry and global partners.

- There is need for more investments in the broader health systems in the country to ensure availability of basic services and establishment of standardized care pathways for cervical cancer to treatment health facilities. Fiscal allocations to the Ministry of Health and Child Care should be improved based on needs and complemented by global partners. However, for sustainability of health system financing the government should consider, in consultations with other stakeholders, introducing "sin taxes" on alcohol, sugar and tobacco products and channel the funds to finance non-communicable disease interventions.

- There is also need to review the AIDS levy and consider reforming it into a national health fund that would finance the wider health system or critical conditions based on national needs and evidence that would be reviewed periodically.

- There is need to invest in in-service health worker education about cancers in general at all levels of the health system to capacitate them to provide correct information and advise patients appropriately with regards to cancers. Curricula for nurses and doctors, both at undergraduate and postgraduate levels should be reviewed and updated in line with international standards to strenghthen cancer education.This education will also prepare the health workers for community health education campaigns to improve uptake of preventive services, promote early treatment seeking behaviors and dispel myths and misconceptions about cancers and their treatment modalities.

- There is need to improve health education campaigns about cervical cancer in communities across the country. These campaigns should be properly organized and consistently conducted by trained health workers including community health workers (also known as village health workers) who have a

greater presence in communities in Zimbabwe.

- There is also urgent need to develop and roll-out standardized cancer screening, treatment and palliative care guidelines including clear pathways of care to all the levels of the health system. In order to improve engagement into treatment and care in the national health system, it is crucial that guidelines are developed based on international best practices and contextual evidence. This will also instill confidence among health workers and will ultimately improve service provision, referral systems and health outcomes.

- The involvement of key opinion leaders in cervical cancer programmes such as traditional healers, prophets, pastors, community leaders including traditional leaders such as headmen and chiefs is important because of the influence and respect they command in African societies. These leaders could be educated about cervical cancer, its prevention, treatment and palliation care to ensure that they encourage people to seek these services early.

- There is urgent need to integrate oncology with palliative care based on best practices from the global community but within an affordable framework. This will require training or workshops of key health workers and other professionals such as psychologists, social workers and spiritual counselors to form multidisciplinary care teams across the nation. This process would also require the involvement of Universities, medical schools and nursing training schools to reform their curricula to include palliative care as a module that is examinable. Palliative care specialty or sub-specialty should be considered in medical and nursing schools at the postgraduate level.

- There is need to improve cervical cancer awareness programmes that have been going on across the country. These campaigns need to be reviewed periodically in light of new evidence, and adjusted accordingly from time to time. The packaging of messages in the existing awareness campaigns needs to be reviewed and targeted messages that are informed by evidence are thus recommended.

- The surveillance system for cervical cancer needs to be strengthened across

the country to ensure that all cases are accounted for; to enable proper planning and efficient allocation of resources. There is need to invest in mHealth solutions such as DHIS2 system to document, follow-up and analyze data from suspected and confirmed cases of cervical cancer in health facilities regularly to inform decisions. Until the government knows the correct magnitude of the cervical cancer burden that a good surveillance system could offer it will be difficult to mobilize support and more resources for the disease interventions.

- Significant investments to increase the capacities of public health pathology laboratories are imperative in the country to ensure efficient and timely diagnoses of cervical cancer. This would also reduce reliance on private laboratories whose charges are unsustainably high for the majority of the women who need these services.

- There is urgent need for the government to collaborate with industry, international organizations and academic institutions to ensure availability of affordable drugs (chemotherapies and analgesics), diagnostic and therapeutic machines (including backup services) used in the treatment of cervical cancer.

8.2 Limitations of the study

This study could have encountered information bias during community-based surveys from participants who had firsthand experience with cervical cancer or had the disease or a history of the condition, however; random selection of participants, stratification of participants according to their area of residence and use of multivariate analyses were used to reduce the threats of such biases on outcomes. This research was conducted during a tough period in Zimbabwe, when health workers were engaged in sequential strikes and several delays and disruptions in data collection were experienced. This could also have resulted in selection bias as certain groups of participants perhaps with resilience and better copying mechanisms to the circumstances could have visited our study sites (Harare and Parirenyatwa Hospitals) and subsequently enrolled for the study. This study was conducted in Harare, therefore the findings may not be generalizable to other

contexts and further research is recommended to include the rest of the country. No rural setting investigated in this study hence the findings need to be interpreted in light of that context. Furthermore, cross sectional surveys cannot be used to infer causal relationships; hence findings from this study may not be used to establish causality. The achievement of small sample sizes for some variables during surveys compromised on the precision of estimates and hence future research studies with bigger sample sizes are suggested. Qualitative inquiry findings from phase 2 of this study are not generalizable and are associated with bias hence care should be exercised in interpreting this study outcomes.

8.3 Areas of future research

This study was a first step towards the comprehensive understanding of systematic barriers of access and utilization of cervical cancer treatment and palliative care in Zimbabwe. Therefore; this work could also be strengthened further through potential future research which could benefit cervical cancer programmes and policy. The identified future areas of potential research are as follows:

- A nationwide research to better understand access and usage of cervical cancer prevention, treatment and palliative care services in Zimbabwe would be imperative as a follow-up to this present study.

- An investigation of the factors associated with cervical cancer disease stage at presentation, which influences treatment modalities, would be beneficial to better our understanding.

- On the background of integrated cervical screening services in HIV treatment facilities, it would be crucial to understand the uptake of these services and associated barriers among women living with HIV/AIDS.

- Given that the majority of women with cervical cancer are living with HIV/AIDS it would be important to understand how cervical cancer disease stages are associated with HIV immunological and virological parameters. This study would help our understanding of the impact of HIV on cervical cancer disease trajectory.

- Further investigation of the time to treatment from the time of being suspected and diagnosed of cervical cancer and the associated factors would be imperative in strengthening evidence for programme and policy improvements in Zimbabwe.

- The development of a cervical cancer policy framework from research evidence and how it can be implemented in Zimbabwe to guide programmes is another area of future study.

In conclusion, this study revealed a plethora of evidence relevant to cervical cancer programme and policy development in low-income settings affected by the growing burden of cervical cancer. The consideration and implementation of the model strategies reported in this study might go a long way in addressing the majority of the impediments to access and utilization of cervical cancer treatment and care in Zimbabwe and other similar contexts. However, the success of future cervical cancer programmes is hinged on the strengthening of the National Cancer Control Programme and key strategies in the Ministry of Health and Child Care. It is proposed that this lead institution take ownership and stewardship of policies and interventions including coordinating different partners. Furthermore, wider dissemination of relevant research, wider stakeholder engagements and collaborations and strong political will of the government is required to invest and mobilize resources to strengthen non-communicable disease interventions.

8.4 References

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APPENDICES

Appendix 1: Table 2.3: Full results from 15 factor solution of the final *Patient and Community* questionnaire from factor analysis and internal consistency testing for each factor.

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
5. Knowledge of cervical cancer	0.7607	<0.001	0.75															
e. Knowledge about cervical cancer causes and treatment			0.80															
What are the causes of cervical cancer that you know or have heard about?				0.64														
How is cervical cancer prevented?																		
How do you think cervical cancer may be treated?				0.63														

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
					0.51													
f. Sources of information			0.70															
Where did you hear/see about messages on cervical cancer?					0.63													
Where did you hear about palliative care?					0.57													
Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
g. Knowledge of palliative care			0.80															
Have you ever heard about palliative care that is given to cancer patients including those suffering from cervical					0.71													

197

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
cancer? **Where did you hear about palliative care?** **Where are palliative care servicesgiven in Harare?**						0.79 0.70												
h. Knowledge of cervical cancer treatment					0.70													
Do you think that cervical cancer can be treated? ***How do you think it may be treated?**							0.55 0.54											

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
6. Access to cervical cancer treatment and palliative care	**0.7150**	**<0.001**	**0.79**															

d. Access to treatment and palliative care	0.94
If you were to be diagnosed of cervical cancer today do you think you would have access to treatment and palliative care services in Harare?	0.91
Where would you go to seek treatment?	0.57
Where would you go to seek for palliative care services?	0.85
Are you currently accessing cervical cancer treatment or palliative care?	0.97
What made you go for cervical cancer screening just before your diagnosis?	0.96
Where you were first screened and suspected of cervical cancer?	0.85
Do you have access to treatment for your	0.98

Items		KMO	Bartlett's test (p	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
condition?																			
How much have you paid or are you paying on average for your treatment in one month?										0.69									
e. Health facilities that provide treatment and palliative care										0.70									
Generally, where would you go or refer someone for cervical cancer palliative care services?										0.54									
Where do you think people can be treated of cervical cancer in Harare?										0.50									
Where would you go to seek treatment?										0.50									
Where would you go to seek for palliative care services?										0.66									

	value)	
f. Health facilities that treat cervical cancer in Harare	0.73	

Where do you think people can be treated of cervical cancer in Harare?	0.64	
Where would you go to seek treatment?	0.49	
Where were you referred for further investigations (histological tests) to confirm your diagnosis?	0.47	
Where were you commenced on treatment?	0.45	

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
7. Utilization of cervical cancer treatment and palliative care	**0.9016**	**<0.001**	**0.84**															
d. Utilization of cervical cancer treatment and palliative care			0.89															

Do you have a regular doctor whom you see when you require health services	0.92
If you are not feeling well where would you go first?	0.64
If you were to be given some medication or treatment for a disease would adhere to it	0.98
Have you ever been screened for cervical cancer?	0.91
Who do you believe can manage cervical cancer better?	0.85
What challenges do you usually face in using health services?	
How many times have you visited your health facility or doctor for treatment/check up in the last 6 months?	0.65
Do you have a regular doctor whom you see	0.51

when you require health services?	
What treatment are you on or have you received for your condition?	0.98
Are (Were) these fees affordable to you or your household?	
Who do you believe can manage cervical cancer better?	0.93
What challenges do you usually face in using	0.98
	0.93
	0.72
e. Challenges faced in accessing health services	0.75

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
*What challenges do you usually face in using health services?														0.72				
f. Access to cervical cancer screening			0.89															
Where were you screened? **Were the charges [for screening] affordable to you or your household?**														0.78 0.79				
8. Perceptions, attitudes and beliefs about cervical cancer treatment and palliative care	**0.8132**	**<0.001**	**0.78**															

f. Attitudes	0.88	
I can discuss experiences of cervical cancer with my family members.		0.59
I can discuss experiences of cervical cancer with my friends.		0.51
Awareness of cervical cancer is done in my community		0.52
The local hospital offers cervical cancer screening to women.		0.54
The local hospital offers cervical cancer vaccination to young girls.		0.50
My partner/husband [would] supports me to go for cervical		
My partner/husband [would] support me to go for cervical cancer		0.64

treatment.

My friends support me to go for cervical cancer treatment.	0.58
My family supports me to go for cervical cancer treatment.	0.57
I encourage others to be screened and treated for cervical cancer	0.59
I am too busy to go for cervical cancer treatment [R]	0.67
I do not have time to go for cervical cancer treatment [R].	0.60
Cervical cancer treatment procedure is embarrassing [R].	
Screening is important for early treatment of cervical cancer.	0.57
Cervical cancer treatment saves lives	0.51
Cervical cancer treatment gives a woman and their family	

peace of mind.	0.60
Cervical cancer treatment gives a woman control over her health.	0.64
HIV testing is optional when being screened for cervical cancer.	0.56
Cervical cancer treatment is for all women regardless of background	0.52
I am responsible for my health.	0.50
Test results for cervical cancer screening are immediate	0.56
Cervical cancer screening does not take too long.	0.51

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
															0.53			
															0.52			
g. Availability of treatment and palliative care services			0.82															
The local hospital offers treatment to women with cervical cancer.																0.62			
The local hospital offers laboratory investigations for women suspected of cervical cancer.																0.68			
The local hospital has adequate trained staff to provide cervical cancer																0.60			

treatment.

The local hospital offers treatment to ALL cervical cancer patients in this community.   0.57

Hospitals/clinics in my community offer cervical cancer treatment services for free

Hospitals/clinics in my community offer free treatment services for cervical cancer patients who cannot afford to pay.   0.56

                                                                                                                                    0.64

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
h. Quality of care			0.70															
The hospital/clinic in my community offers timely services for people with cervical cancer.																0.49		
The local hospital offers																		

Items		KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
counselling to cervical cancer patients and their partners/families.																	0.47		
Cervical cancer patients do not survive long even when treated [R].																	0.49		
Health care workers who perform cervical cancer treatment are well trained.																	0.49		
Health care workers who perform cervical cancer treatment are very helpful.																	0.48		
i.	Perceptions about treatment services abroad			0.86															

I get better value for money for cervical cancer treatment abroad than in my local hospital/clinic.	0.41
Cervical cancer treatment is best done abroad.	0.47
Health professionals abroad provide better care for cervical cancer patients.	0.57
Cervical cancer patients treated abroad have better survival chances	0.53
j. Beliefs 0.70	
Cervical cancer patients should not be stigmatized.	0.42
I encourage others to be screened and treated for cervical cancer.	0.45
I am afraid of cervical cancer treatment [R].	
Getting results of cervical cancer	0.47

screening is scary [R].

Women should go for cervical cancer screening only when they experience serious health problems [R].

0.46

Cervical cancer treatment is for people with money [R].

0.45

Cervical cancer screening is for promiscuous people [R].

0.47

I am too busy to go for cervical cancer treatment [R].

0.46

I do not have time to go for cervical cancer treatment [R].

0.48

Cervical cancer treatment procedure is embarrassing [R].

0.49

0.43

Appendix 2: Table 2.4: Full results from 13 factor solution of the final *Health Worker* questionnaire from factor analysis and internal consistency testing for each factor.

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
				Factor loadings												
5. Health worker characteristics	**0.532**	**<0.001**	**0.72**													
d. Professional development			0.72													

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
Have you ever received any on-the job training on cervical cancer treatment and palliative care?				0.74												
Do you feel that you have received adequate training to provide cervical cancer treatment and palliative care services?				0.55												
Does your employer support your continuous professional development (CPD) in cervical cancer treatment and palliative care?				0.51												
Have you read or heard about the Zimbabwe Cervical Cancer Prevention and Control Strategy (2016-2020)?				0.54												
What are the general perceptions of cervical cancer patients and their families on the services you provide in this facility?				0.65												
Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
e. Profession training			0.71													
What is your profession?					0.49											
Where did you receive your basic professional training?					0.66											

Where did you receive your specialist training?	0.40
f. Quality of care	0.70
Do most of your cervical cancer patients adhere to prescribed treatments?	0.53
Are you motivated to provide your services to cervical cancer patients in this facility?	0.47
d. Working conditions	0.78
How many hours do you work in a week?	0.46
Do you think the benefits (salaries and allowances) you are receiving are commensurate with the services you provide to cervical cancer patients?	0.49

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
e. Perception of cervical cancer strategies and policies			0.71													
Does your facility have clinical guidelines for the treatment and palliation of cervical cancer patients?								0.44								
Have you read or heard about The National Cancer Prevention and Control Strategy for Zimbabwe (2013-2017)?								0.49								
Have you read or heard about the Zimbabwe Cervical Cancer Prevention and Control Strategy (2016-2020)?								0.51								
Do you think Zimbabwe has adequate policies and strategies for the treatment and management of cervical cancer?								0.46								
Do you think that the cervical cancer surveillance system is adequate in the Zimbabwe to account for every case?								0.46								
6. Health facility characteristics	**0.639**	**<0.001**	**0.79**													

a. Characteristics of cervical cancer service providers	0.87
Who owns this facility	0.92
Who mainly pays the salaries of staff at this facility?	0.96
Who mainly pays for running costs for this facility?	0.66
What is the type of the health facility?	0.90
b. Perceptions about provider quality of services	0.71
Besides health services where else are cervical cancer patients seeking help for their conditions?	0.60
Do you think cervical cancer patients are better off seeking treatment abroad than in Zimbabwe if they have the resources?	0.81
Would you recommend your cervical cancer patients to seek treatment	0.80

abroad if they have the resources?

Are the available health professionals adequate to serve all the patients (all disease areas) you receive?

0.47

Do you have a specific number of beds reserved for cervical cancer patients in this health facility?

0.56

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
7. Service characteristics	**0.5**	**<0.001**	**0.70**													
c. Cervical cancer services			0.70													

Does this facility offer cervical cancer screening?	0.87
Does this facility offer treatment of pre-cervical cancer lesions?	0.67
What treatment options for pre-cervical cancer lesions are available in this facility?	0.71
What cervical cancer treatment services are available in your facility?	0.84
d. Cervical cancer service referrals	0.70
Where do you refer patients for histological investigations?	0.61
Where do you usually transfer/refer cervical cancer patients for other services?	0.46
What services do you usually transfer/refer cervical cancer patients for?	0.78

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
8. Infrastructure, equipment and drugs capacity	**0.538**	**<0.001**	**0.79**													
a. Availability of basic services, equipment and drugs.			0.84													
What is the main source of water for this facility?													0.89			
Over the last 3 months have you experienced water supply interruptions of this source of more than 2 hour?													0.54			
Are there functional (soap and water) hand washing facilities for patients or													0.55			

in the toilets?

Does the facility have access to ambulance facility for emergency transport? — 0.87

If the facility owns an ambulance is fuel available for use in cases of emergency? — 0.75

Does the health facility have adequate basic equipment? — 0.72

Is most equipment in this facility in functional order? — 0.66

Does the facility have adequate analgesics and other medication for palliative care patients today? — 0.50

Items	KMO	Bartlett's test (p value)	Alpha (α)	1	2	3	4	5	6	7	8	9	10	11	12	13
b. Hygiene, sanitation and waste management capacity			0.70													
What back-up water supply does this health facility has?														0.55		
Are there functional (soap and water)																

222

hand washing facilities for patients or in the toilets?	0.50
What method does this facility use in the final disposal of sharps?	
Is the incinerator functional today?	0.58
Is the power source for the incinerator available today?	0.65
Have you or any staff member received training in health care waste management practices in the past 2 years?	0.67
	0.72
c. Supply of basic services, equipment and drugs.	0.70
Over the past 3 months have you experienced any power interruptions of this source of more than 2 hours?	0.50
Has the facility faced challenges in transporting patients in emergency situations in the last 3 months?	0.43
Does the facility have modern equipment for treating cervical cancer	
Did the facility experience stock of outs	0.41

of analgesics and other medication for palliative care patients in the last 3 months? **Does the facility have adequate analgesics and other medication for palliative care patients today?**	0.70 0.55
d. Availability drugs for treatment of cervical cancer.	0.91
Does the facility have adequate stocks of drugs such as cisplastin for treatment of cervical cancer today? **Did the facility experience stock-outs of cisplastin in the last 3 months?**	0.70 0.64

Appendix 3: Table 3.1: Distribution of healthy women and cervical cancer patient participants by socio-demographic characteristics

Participant type	Healthy women, N=143			Cervical cancer patients N=134		
Socio-demographic variables	[N=143] (%)	Ever screened [n= 42] (%)	p-value	[N=134] (%)	Treated [n= 92] (%)	p-value
Province of residence Manicaland	-	-	-	17(12)	14 (15)	0.193
Masvingo	-	-	-	9(7)	8 (9)	0.176
Midlands	-	-	-	7(5)	5 (6)	0.871
Matebeleland North	-	-	-	1(1)	1 (1)	0.498
Mashonaland Central	-	-	-	5(4)	4 (4)	0.671
Mashonaland East	-	-	-	24(18)	16 (17)	0.871
Mashonaland West	-	-	-	5(4)	3 (3)	0.671
Harare	143 (100)	42 (100)	0.120	66(49)	41 (45)	0.217
Residence Urban	93 (65)	36 (86)	**0.001**	74 (55)	47 (51)	0.154
Urban_Low density	31(21.7)	20 (48)	**<0.001**	3(2)	3 (3)	0.237
Urban_High density	31 (21.7)	4 (9)	**0.023**	67(50)	40 (44)	**0.025**
Urban_Medium density	31 (21.7)	12 (29)	0.197	4(3)	4 (4)	0.170
Peri-urban	50 (35)	6 (14)	**0.001**	60(45)	45 (49)	0.154

Age (years)	Mean (35)	Mean (37)		Mean (52)	Mean (53)	
25-34	78 (55)	21 (50)	0.481	6(4)	4 (4)	0.914
35-44	40 (28)	8 (19)	0.981	31(23)	19 (21)	0.313
45-54	22 (15)	12 (29)	0.434	41(31)	26 (28)	0.642
55 or more	3 (2)	1 (2)	0.879	56(42)	43 (47)	0.180
Ethnicity						
Shona	133 (93)	39 (92.8)	0.964	130(97)	88 (96)	0.170
Ndebele	6 (4)	1 (2.4)	0.485	2(1)	2 (2)	0.336
Other	4 (3)	2 (4.8)	0.358	2(2)	2 (2)	-
Marital status						
Married/co-habiting	98 (69)	31 (74)	0.381	52(39)	30 (33)	0.029
Never married	17 (12)	3 (7)	0.258	1(1)	1 (1)	0.498
Widowed	13 (9)	2 (5)	0.246	59(44)	44 (48)	0.190
Divorced or separated	15 (10)	6 (14)	0.339	22(16)	17 (18)	0.341
Religion						
Roman Catholic	24 (17)	7 (17)	0.981	34(25)	24 (26)	0.779
Protestant	22 (16)	11 (26)	**0.021**	24(18)	21 (23)	**0.028**
Pentecostal	56 (39)	11 (26)	**0.040**	34(25)	21 (23)	0.316
Apostolic sect	27 (19)	5 (12)	0.169	34(25)	24 (26)	0.779
Other	14(9)	8 (19)	**0.016**	8(7)	2 (2)	**0.006**
Education						
Primary	19 (13)	2 (5)	0.053	43(32)	30 (33)	0.849
Secondary	100 (70)	30 (71)	0.801	75(56)	50 (54)	0.576
Higher	24 (17)	10 (24)	0.147	6(5)	5 (5)	0.428
None	0	0	-	10(7)	7 (8)	0.924
Household head education						
Primary	5 (3)	1 (2)	0.640	16(12)	12 (13)	0.560

Secondary	74 (52)	16 (38)	**0.035**	50(37)	30 (33)	0.096
Higher	54 (38)	23 (55)	**0.007**	14(10)	12 (13)	0.146
Not Applicable	10 (7)	2 (5)	0.500	5(4)	37 (40)	0.194
None	-	-	-	49(37)	1 (1)	**0.017**
Occupation Unemployed	59 (41)	14 (33)	0.214	90(67)	60 (65)	0.478
Student	7 (5)	4 (10)	0.098	3(2)	2 (2)	0.336
Professional	14 (10)	7 (17)	0.074	3(2)	3 (3)	0.620
Police/Military/Security	5 (4)	3 (7)	0.126	12(9)	9 (10)	0.137
Trucker/transport business	1 (1)	1 (2)	0.120	1(1)	2 (2)	-
General worker	6(4)	2 (5)	0.828	1(1)	4 (5)	0.318
Self employed	26 (18)	7 (17)	0.762	5(4)	10 (11)	0.572
Vendor	25 (17)	4 (9)	0.106	16(12)	2 (2)	0.940
Occupation of household head	9 (6)					
Unemployed	1 (1)	2 (5)	0.627	25(19)	15 (16)	0.301
Farm worker	52 (37)	0	0.518	2(1)	2 (2)	0.336
Professional	11 (8)	23 (55)	**0.003**	23(17)	20 (22)	**0.038**
Police/Military/Security	15 (10)	3 (7)	0.874	5(4)	5 (5)	0.124
Trucker/transport business	5 (4)	5 (12)	0.722	1(1)	0	0.137
General worker	31 (22)	1 (2)	0.640	0	0	0.246
Self employed	7 (5)	5 (12)	0.067	30(22)	18 (20)	0.498
Vendor	1 (1)	0	0.080	1(1)	1 (1)	0.621
Other	8 (6)	0	0.518	47(35)	0	-
Not applicable		3(7)	0.874	0	31 (34)	-
Personal income (US$)						

No income	52 (36)	20 (48)	0.071	77(57)	52 (57)	0.744
<200	51 (35)	7 (17)	**0.002**	32(24)	23 (25)	0.653
200-400	24 (17)	6 (14)	0.606	19(14)	13 (14)	0.981
430 or more	16 (12)	9(21)	**0.012**	6(4)	4 (4)	0.914
Household income (US$) No income	52 (36)	21 (50)	**0.029**	71(53)	50 (55)	0.640
<600	55 (39)	8 (19)	**0.002**	53(40)	35 (38)	0.597
600-1000	16 (11)	4 (9)	0.684	6(4)	4 (4)	0.914
1200 or more	20 (14)	9 (23)	0.098	4(3)	3 (3)	0.718
Medical insurance/aid Yes	50 (35)	25 (60)	**<0.001**	27(20)	22 (24)	0.108
No	93 (65)	17 (40)	-	107(80)	70 (76)	-
Wealth quintiles Poorest	50 (35)	28 (67)	**<0.001**	7(5)	6 (7)	0.318
Poorer	22 (15)	6 (14)	0.814	32(24)	23 (25)	0.653
Middle	19 (13)	2 (5)	0.053	36(27)	23 (25)	0.471
Richer	30 (21)	3 (7)	**0.009**	26(19)	15 (16)	0.179
Richest	22 (16)	3 (7)	0.078	33(25)	25 (27)	0.311
Sources of cervical cancer information Radio	94 (70)	30 (73)	0.753	31 (25)	23 (27)	0.868
TV	20 (15)	8 (20)	0.747	27 (21)	19 (22)	0.935
Health workers	8 (6)	0	-	57 (45)	36 (42)	0.776
Other	13 (9)	3 (7)	0.911	11 (9)	8 (9)	-

Knowledge that cervical cancer is treatable						
Yes	106 (74)	38 (90)	**0.040**	113 (84)	81 (88)	0.433
No	19 (13)	3 (7)	0.768	7 (5)	2 (2)	0.854
Don't	18 (13)	1 (3)	0.768	14 (11)	9 (10)	0.934
Number of visits to health facilities or doctors in previous 6 months						
None	46 (32)	4 (10)	0.358			
Once	30 (21)	6 (14)	0.695	_	_	-
Twice	34 (24)	13 (31)	0.624			
Thrice or more	33 (23)	19 (45)	0.099			
Have regular general practitioner (doctor)						
Yes	44 (31)	20 (48)	0.190	_	_	-
No	99 (69)	22 (52)	0.128			

Bold shows p value<=0.05 indicating statistical significance.

Appendix 4: Table 3.2: Multivariate logistic regression analysis showing socio-demographic factors associated with cervical cancer screening of healthy women and treatment of women with cervical cancer.

Service type	Screening, n=42			*Treatment, n=92		
Socio-demographic variables	OR (adjusted for household head education and occupation)	95% CI	p-value	OR (adjusted for household head education, occupation and stage of presentation)	95% CI	p-value
Province of residence Manicaland	-	-	-	0.57	0.07 to 4.53	0.596
Masvingo	-	-	-	1.86	0.08 to 44.63	0.701
Midlands	-	-	-	0.21	0.01 to 3.97	0.299
Mashonaland Central	-	-	-	0.09	0.00 to 2.35	0.148
Mashonaland East	-	-	-	0.45	0.06 to 3.32	0.439
Mashonaland West	-	-	-	0.22	0.01 to 4.18	0.310
Harare	-	-	-	Ref	-	
Age (years) 25-44	0.21	0.02 to 1.90	0.166	0.46	0.02 to 13.66	0.653
45 or more	0.29	0.02 to 3.50	0.327	0.95	0.2 to 4.77	0.952
Education Primary	0.22	0.0 to 895	0.718	0.18	0.00 to 7.54	0.371
Secondary	2.14	0.23 to 19.82	0.500	0.37	0.0 to 12.91	0.583
Higher	-	-	-	Ref	-	-
None	Ref	-	-	0.08	0.00 to 4.31	0.212

Ethnicity Shona	0.20	0.0 to 11.86	0.444	-	-	-
Other	Ref	-		-	-	-
Occupation Unemployed	0.10	0.01 to 1.60	0.103	0.22	0.01 to 5.03	0.347
Professional	0.84	0.05 to 13.11	0.901	0.08	0.00 to 2.19	0.248
Self employed	Ref	-	-	Ref	-	0.681
Other	0.67	0.02 to 22.98	0.826	0.35	0.01 to 21.97	0.507
Marital status Married/co-habiting	0.39	0.04 to 4.26	0.438	0.14	0.01 to 1.24	0.415
Never married	2.24	0.08 to 63.36	0.637	-	-	-
Widowed	0.09	0.00 to 3.35	0.189	0.46	0.06 to 3.26	0.645
Divorced or separated	Ref	-	-	Ref	-	-
Religion Roman Catholic	0.006	0.00 to 0.25	**0.007**	10.60	0.29 to 377	0.195
Protestant	0.01	0.00 to 0.49	**0.020**	68.32	1.22 to 381	**0.040**
Pentecostal	0.003	0.00 to 0.10	**0.002**	16.00	0.46 to 553	0.125
Apostolic sect	0.02	0.00 to 0.93	**0.045**	22.00	0.57 to 846	0.097
Other	Ref	-	-	Ref	-	-
Personal income (US$) No income	5.14	0.17 to 151	0.343	0.17	0.00 to 38.26	0.517
<200	4.47	0.14 to 148	0.401	0.54	0.00 to 80.20	0.808
200-400	1.51	0.07 to 33	0.794	0.57	0.01 to 25.37	0.771
430 or more	Ref	-	-	-	-	-
Household income (US$) No income	0.52	0.04 to 6.63	0.618	32.74	0.15 to 7017	0.699
<600	0.13	0.0 to 6.23	0.300	5.18	0.06 to 436	0.214
600-1000	0.50	0.02 to 12.41	0.672	0.23	0.01 to 38.23	0.972
1200 or more	Ref	-	-	Ref	-	-

231

Medical insurance/aid						
Yes	7.24	0.67 to 78.68	0.104	0.84	0.11 to 6.52	0.874
No	Ref			Ref		
Wealth quintiles						
Poor	2.10	0.25 to 17.59	0.492	4.00	0.07 to 227	0.501
Middle	0.04	0.0 to 2.05	0.107	0.46	0.07 to 2.95	0.414
Rich	0.23	0.00 to 203	0.799	0.69	0.05 to 9.43	0.781
Sources of cervical cancer information						
Radio	1.18	0.02 to 58.95	0.934	0.16	0.01 to 2.83	0.210
TV	5.48	0.08 to 396	0.436	0.16	0.01 to 3.39	0.236
Health workers	-	-	-	0.26	0.02 to 2.72	0.260
Other	Ref	-	-	Ref	-	-
Knowledge that cervical cancer is treatable						
Yes	4.95	0.21 to 119.27	0.324	1.60	0.21 to 12.10	0.648
No	5.33	0.05 to 492.77	0.468	0.02	0.0 to 2.18	0.099
Don't	Ref	-	-	Ref	-	-
Number of visits to health facilities or doctors in previous 6 months						
None	0.02	0.0 to 0.59	**0.024**			
Once	0.08	0.0 to 0.93	**0.044**	-	-	-
Twice	0.57	0.09 to 3.33	0.537			
Thrice or more	Ref	-	-			
Have regular general practitioner (doctor)						
Yes	0.10	0.01 to 1.82	0.121	-	-	-
No	Ref	-				

*Bold shows p value<=0.05 indicating statistical significance, * Treatment included surgery, chemotherapy and radiotherapy as well as palliative chemotherapy or radiation therapy.*

Appendix 5: Table 4.1: Characteristics of 143 healthy women and 134 women with cervical cancer

Participant type	Healthy women N=143	Cervical Cancer patients N=134	
Variables	[N=143] (%)	[N=134] (%)	Treated [n= 92] (%)
Province of residence Manicaland	-	17(12)	14 (15)
Masvingo	-	9(7)	8 (9)
Midlands	-	7(5)	5 (6)
Matebeleland North	-	1(1)	1 (1)
Mashonaland Central	-	5(4)	4 (4)
Mashonaland East	-	24(18)	16 (17)
Mashonaland West	-	5(4)	3 (3)
Harare	143 (100)	66(49)	41 (45)
Residence Urban	93 (65)	74 (55)	47 (51)
Urban_Low density	31(21.7)	3(2)	3 (3)
Urban_High density	31 (21.7)	67(50)	40 (44)
Urban_Medium density	31 (21.7)	4(3)	4 (4)
Peri-urban	50 (35)	60(45)	45 (49)
Age (years) 25-34	**Mean (35)** 78 (55)	**Mean (52)** 6(4)	**Mean (53)** 4 (4)
35-44	40 (28)	31(23)	19 (21)
45-54	22 (15)	41(31)	26 (28)
55 or more	3 (2)	56(42)	43 (47)

Participant type	Healthy women N=143	Cervical Cancer patients N=134	
Variables	[N=143] (%)	[N=134] (%)	Treated [n= 92] (%)
Ethnicity Shona	133 (93)	130(97)	88 (96)
Ndebele	6 (4)	2(1)	2 (2)
Other	4 (3)	2(2)	2 (2)
Marital status Married/co-habiting	98 (69)	52(39)	30 (33)
Never married	17 (12)	1(1)	1 (1)
Widowed	13 (9)	59(44)	44 (48)
Divorced or separated	15 (10)	22(16)	17 (18)
Religion Roman Catholic	24 (17)	34(25)	24 (26)
Protestant	22 (16)	24(18)	21 (23)
Pentecostal	56 (39)	34(25)	21 (23)
Apostolic sect	27 (19)	34(25)	24 (26)
Other	14(9)	8(7)	2 (2)
Education Primary	19 (13)	43(32)	30 (33)
Secondary	100 (70)	75(56)	50 (54)
Higher	24 (17)	6(5)	5 (5)
None	0	10(7)	7 (8)

Participant type	Healthy women N=143	Cervical Cancer patients N=134	
Variables	[N=143] (%)	[N=134] (%)	Treated [n= 92] (%)
Household head education			
Primary	5 (3)	16(12)	12 (13)
Secondary	74 (52)	50(37)	30 (33)
Higher	54 (38)	14(10)	12 (13)
Not Applicable	10 (7)	5(4)	37 (40)
None	-	49(37)	1 (1)
Occupation	59 (41)		
Unemployed		90(67)	60 (65)
Student	7 (5)	3(2)	2 (2)
Professional	14 (10)	3(2)	3 (3)
Police/Military/Security	5 (4)	12(9)	9 (10)
Trucker/transport business	1 (1)	1(1)	2 (2)
General worker	6(4)	1(1)	4 (5)
Self employed	26 (18)	5(4)	10 (11)
Vendor	25 (17)	16(12)	2 (2)
Occupation of household head			
Unemployed	9 (6)	25(19)	15 (16)
Farm worker	1 (1)	2(1)	2 (2)
Professional	52 (36)	23(17)	20 (22)
Police/Military/Security	11 (8)	5(4)	5 (5)
Trucker/transport business	15(10)	1(1)	0
General worker	5 (3)	0	0
Self employed	31 (22)	30(22)	18 (20)
Vendor	7 (5)	1(1)	1 (1)
Other	1 (1)	47(35)	0
Not applicable	11 (8)	0	31 (34)

Participant type	Healthy women N=143	Cervical Cancer patients N=134	
Variables	[N=143] (%)	[N=134] (%)	Treated [n= 92] (%)
Personal income (US$) No income	52 (36)	77(57)	52 (57)
<200	51 (35)	32(24)	23 (25)
200-400	24 (17)	19(14)	13 (14)
430 or more	16 (12)	6(4)	4 (4)
Household income (US$) No income	52 (36)	71(53)	50 (55)
<600	55 (39)	53(40)	35 (38)
600-1000	16 (11)	6(4)	4 (4)
1200 or more	20 (14)	4(3)	3 (3)
Medical insurance/aid Yes	50 (35)	27(20)	22 (24)
No	93 (65)	107(80)	70 (76)
Wealth quintiles Poorest	50 (35)	7(5)	6 (7)
Poorer	22 (15)	32(24)	23 (25)
Middle	19 (13)	36(27)	23 (25)
Richer	30 (21)	26(19)	15 (16)
Richest	22 (16)	33(25)	25 (27)
Access/perception of access to treatment			
Yes	114 (80)	92 (69)	-
No	29 (20)	42 (31)	-

Appendix 6: Table 4.3: Description of health system attributes and factors associated with perceived access to cervical cancer treatment and care from health worker surveys.

Participant type	Health worker [N=80]		
Variables	**n (%)**	**Bivariate analysis p-value**	**Logistic regression analysis p-value**
Mean age of health workers	37 (SD=10)		
23 - 30	15 (19)	0.947	
31 – 40	42 (54)	0.162	
41 – 49	15(19)	0.947	-
54+	6 (8)	**0.015**	
Mean number of years of experience of health workers			
1 – 5	12 (SD=10)		
6 – 10	22 (28)	0.469	
11 – 20	27 (34)	**0.046**	
23+	20 (26)	0.432	
	9 (12)	**0.002**	-
Health facilities in the survey			
Parirenyatwa Hospital	42 (54)		
Harare Hospital	26 (33)		
Island Hospice	9 (12)	-	-
Cancer Association	1 (1)		
Continuous Professional Development support			
Yes	62 (80)	0.306	
No	8 (10)		
Not applicable	8 (10)		-
Institutions of basic training			
University of Zimbabwe	17 (22)		**0.046**
National University of Science and Technology	3 (4)	0.214	0.959
Ministry of Health and Child Welfare	58 (74)		Ref
Specialization			
Yes	41 (53)	0.645	
No	37 (47)		-
Adequacy of health professionals			
Yes	9 (11)		
No	67 (86)	0.360	
Do not know	2 (3)		
			-

Participant type	Health worker [N=80]		
Variables	**n (%)**	**Bivariate analysis p-value**	**Logistic regression analysis p-value**
Motivation Yes No Not applicable	54 (69) 18 (23) 6 (8)	0.161	-
Remuneration satisfaction Yes No Not applicable	5 (6) 67 (86) 6 (8)	0.497	-
Relationship with patients Excellent Good Poor Refused to comment	31 (40) 44 (56) 2 (3) 1 (1)	0.592	-
Knowledge of national cancer policy Yes No	30 (38) 48 (62)	0.132	0.422 Ref
Knowledge of cervical cancer policy Yes No	30 (38) 48 (62)	**0.049**	0.456 Ref
Adequacy of policies for treatment of cervical cancer Yes No	44 (56) 34 (44)	**0.026**	0.693 Ref
Support treatment seeking abroad Yes No	58 (74) 20 (26)	0.432	-
Disease presentation Early Late	3 (4) 75 (96)	0.496	-

Participant type	Health worker [N=80]		
Variables	**n (%)**	**Bivariate analysis p-value**	**Logistic regression analysis p-value**
Service quality perceptions			
Excellent	22 (28)		
Good	46 (59)	0.613	**0.035**
Poor	8 (10)		
Do not know	2 (3)		
Screening services at health facility			
Yes	9 (12)	**0.002**	
No	69 (88)		-
Strength of surveillance system for cervical cancer			
Yes	18 (23)		
No	57 (73)	**0.008**	
Do not know	3 (3)		-
Adequacy of basic equipment*			
Yes	45 (58)		
No	27 (34)	0.984	
Do not know	6 (8)		-
Modern equipment adequacy*			
Yes	40 (51)	**<0.001**	0.591
No	27 (35)		
Do not know	11 (14)		
Functional equipment*			
Yes	36 (46)	0.633	
No	34 (44)		-
Do not know	8 (10)		
Electricity challenges*			
Yes	7 (9)	**0.001**	**0.036**
No	52 (67)		
Do not know	19 (24)		
Water challenges*			
Yes	38 (49)	**0.009**	0.674
No	24 (31)		
Do not know	16 (20)		

Participant type	Health worker [N=80]		
Variables	n (%)	Bivariate analysis p-value	Logistic regression analysis p-value
Cancer drug stock-outs*		**0.001**	0.143
Yes	7 (9)		
No	28 (36)		
Do not know	43 (55)		
Analgesic adequacy*		0.773	-
Yes	39 (50)		
No	13 (17)		
Do not know	26 (33)		
Analgesic stock-outs*		0.203	0.639
Yes	17 (22)		
No	34 (43)		
Do not know	27 (35)		
Challenges faced in seeking treatment			**0.066**
Finances	29 (37)		
Transport	49 (67)	**0.078**	
Knowledge of clinical guidelines for cervical cancer			
Yes	59 (75)		
No	13 (17)		
Do not know	6 (8)	0.757	-

Outputs from model 2, bold show significance or close (p<0.05). Outcome variable was perception of access to treatment and care by health workers.

Appendix 7: Table 5.3: Factors associated with correct knowledge of causes and prevention of cervical cancer among 134 women with the disease in Harare.

	Women with cervical cancer [N=134]			
	Correct knowledge of causes		Correct knowledge of prevention	
Variables	OR, (95% CI)	p value	OR, (95% CI)	p value
Residence Urban	25.12 (0.82 to 767)	0.065	0.38 (0.01 to 19.1)	0.625
Peri-urban	Ref	-	Ref	-
Age (years) 25-44	1.09 (0.04 to 300)	0.976	189 (0.01 to 2890)	0.133
45 or more	0.02 (0.00 to 0.15)	**0.004**	0.17 (0.01 to 5.63)	0.328
Marital status Married/co-habiting	6.00 (0.08 to 473)	0.599	0.08 (0.00 to 72.0)	0.716
Never married	-	-	-	-
Widowed	0.99 (0.07 to 14.10)	0.994	0.04 (0.00 to 1.54)	0.085
Divorced or separated	Ref	-	Ref	-
Religion Roman Catholic	1.80 (0.03 to 120)	0.787	0.35 (0.00 to 42.0)	0.665
Protestant	2.27 (0.04 to 143)	0.697	58.64 (0.32 to 1069)	0.125
Pentecostal	0.56 (0.00 to 39)	0.786	0.07 (0.00 to 5.56)	0.238
Apostolic sect	5.85 (0.05 to 709)	0.470	169 (0.36 to 7965)	0.102
Other	Ref	-	Ref	-

Occupation Unemployed	2.87 (0.13 to 65)	0.508	1.19 (0.05 to 26.6)	0.912
Professional	0.00 (0.00 to 6.84)	0.116	284 (0.00 to 7340)	0.567
Other	Ref	-	-	**-**
Household income (US$) No income	0.02 (0.00 to 0.07)	**0.007**	0.13 (0.00 to 74.0)	0.843
<600	0.02 (0.00 to 0.13)	**0.015**	0.03 (0.00 to 1.02)	0.717
600-1000	0.52(0.00 to 107)	0.897	4.12 (0.00 to 708)	0.200
1200 or more	Ref	-	Ref	**-**
Wealth quintiles Poor	1.84 (0.00 to 24.3)	0.987	-	-
Middle	0.01 (0.00 to 0.66)	**0.032**	-	-
Rich	0.33 (0.00 to 3.73)	0.157	-	-
Watching TV per week				
Daily	0.01 (0.00 to 0.14)	**0.007**	0.18 (0.00 to 36.1)	0.525
1-6 times	0.02 (0.00 to 0.92)	**0.045**	1.67 (0.04 to 62.9)	0.782
Never	Ref	-	-	**-**
Listening to radio per week				
Daily	394 (11.02 to 1406)	**0.001**	77 (1.89 to 3114)	**0.022**
1-6 times	100 (2.95 to 3364)	**0.010**	174 (2.42 to 1255)	**0.018**
Never	Ref	-	Ref	-

Reading newspaper per week				
Daily	14.5 (0.64 to 3263)	0.333	188 (0.36 to 9840)	0.076
1-6 times	1.60 (0.10 to 243)	0.857	0.04 (0.00 to 2.68)	0.097
Never	Ref	-	10.1 (0.01 to 7837)	0.418

*Model controlled for sources of cervical cancer information and head of household's occupation, education, radio listenership, watching TV, reading newspapers and accessing internet for general information. Bold shows factors that were significant.

Appendix 8: Community and Patient Survey Questionnaire

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

SPEAK TO THE HEAD OF THE HOUSEHOLD: Hello. My name is Oscar Tapera and I am a PhD student at the University of Pretoria, South Africa. We are interviewing women aged at least 25 years old here in [name of PLACE] in order to obtain your views,opinions and experience on Cervical Cancer treatment and palliative (also known as supportive, hospice or terminal)care services in Harare. You or your household has been randomly selected to participate in this study. This interview will take not more than 45 minutes and you are free to ask me any questions after the interview or if you need any clarity you may stop me during the interview so that I may assist you.

Makadii.Zita rangu ndinonzi Oscar Tapera uye ndirikuita zvidzidzo zve PhD ku yunivhesiti yePretoria ku South Africa. Tiri kuita hurukuro nevanhukadzi vane makore makumi maviri nemashanu vanogara muzvimbo ino --------------- kuitira kuti tiwane maonero mapfungiro uye zvamakasangana nazvo pamusoro pe kurapwa kwe gomarara remuromo wechibereko pamwe nekuchengetwa kunoitwa vanhu vanegomarara iri mu Harare.Imi ne mhuri yenyu masarudzwa pachishandiswa nzira yemabhiza kuti mupinde mutsvakurudzo ino.Atitarisire kuti hurukuro yatichaita nemi itore maminetsi anopfura makumi mana nemashanu.Shure kwehurukuro iyi makasununguka kubvunza chero mibunzo yamuinayo kana kuti kunezvamunenge musina kunzwisisa makasununguka kundimisa mobvunza henyu kuitira kuti ndikubatsirei.

For household interviews speak to household head: I would like your permission to identify a respondent and begin the interview. *Ndinokumbira mvumo yenyu kuti ndisarudze munhu mumwe chete wandingaite hurukuro naye.*

[**Note**: Ensure formal consent process is done prior to interviewing the selected respondent].

ID01	**IDENTIFICATION** Questionnaire No. [ ]
ID02	Province of residence : _____

ID03	District of residence : _____
ID04	Ward of residence : _____
ID05	Area of residence : _____
ID06	Health facility Name: _____
ID07	For health facility **Private ----------------------------1** **Public------------------------------2**
ID08	Type of respondent **Healthy woman -----------------1** **Cervical cancer survivor----2**

ID09	**INTERVIEWER VISITS**
	
	        A B C
	
	       Visit 1 Visit 2 Visit 3
	
	DATE _____ _____ _____

ID10	**HOUSEHOLD SELECTION STATUS** Originally selected household --------------------------------------1 (SKIP TO ID11) Replacement --2 (If a replacement) REASON FOR REPLACEMENT Not at home after repeated visits----------------------------------1

ID11	No eligible respondent---2
	Refused --3
	Other (Specify)--4
ID12	INTERVIEW STATUS Completed interview--1
	Partially completed interview----------------------------------2

				Skip instructions
SECTION 1. POPULATION CHARACTERISTICS				
Q101	How old were you at your last birthday? *Ma/Waive nemakore mangani pabhavhadhe renyu/rako rekupedzisira?*	_____	Age in completed years	
Q102a	What is your ethnicity? *Urimurudzii*	Shona Ndebele Other African White Asian Other (specify)_____	1 2 3 4 5	

Q102b	What is your current marital status? *Makamira sei panhau dzewanano?*	Married/Co-habiting Never married Widowed Divorced Separated	1 2 3 4 5	
Q103a	What is the highest level of school you attended: primary, secondary or higher? *Ndechipi chinhanho chepamusoro mukudzidza chamaka pedza?*	Primary Secondary Higher None	1 2 3 4	
Q103b	What is the highest level of school attended by head of your household? *Ndechipi chinhanho chapamusoro mukudzidza chakasvikwa ne anotungamira musha?*	Primary Secondary Higher None Not applicable	1 2 3 4 5	
Q104a	Do you have any child(ren)? *Mune mwana/vana here?*	Yes No	1 2	If No skip to Q105
Q104b	If **Yes**, how many children do you have? *Kana ati hongu, Mune vana vangani?*	[ ]	Number of children	
Q105	What is your religion? *Munotevedzera chinamato chipi?*	Traditional Roman Catholic Protestant Pentecostal	1 2 3 4	

		Apostolic Sect	5	
		Muslim	6	
		None	7	
		Other (specify)_____		
Q106a(i)	What is your current occupation? *Parizvino basa ramunoita nderipi?*	Unemployed	1	
		Student	2	
		Miner/Mining industry	3	
		Farm worker	4	
		Professional	5	
		Police/Military/Security	6	
		Domestic worker	7	
		Trucker/Transport business	8	
		General worker	9	
		Self employed	10	
		Vendor	11	
		Other (specify)_____		
Q106a(ii)	What is the current occupation of the head of your household? *Munhu anotungamira musha uno anoita basa reyi?*	Unemployed	1	
		Student	2	
		Miner/Mining industry	3	
		Farm worker	4	
		Professional	5	
		Police/Military/Security	6	
		Domestic worker	7	
		Trucker/Transport business	8	
		General worker	9	

		Self employed	10	
		Vendor	11	
		Not applicable	12	
		Other (specify)_____		
Q106b	How much is your personal income in a month in US$? *Unotambira marii pamwedzi?* **Note**: If no income put "00", unsure put "99"	[ ]	US$	
Q106c	How much is your household income in a month in US$? *Semhuri ino marii yamunowana pamwedzi imarii?* **Note:** If no income put "00", don't know/unsure put "99"	[ ]	US$	
Q106d	Do you or any member of your household have a bank account? *Imi pachezvenyu kana mumwe munhu wemhuri ino mune accountye bhanga?*	Yes No	1 2	
Q106e	Are you on medical aid? *Mune "medical aid' here?*	Yes No	1 2	If No, skip to Q107a
Q106f	If **Yes**, which medical aid are you on? *Kana ati hongu, ndeipi "medical aid" yaari?*	CIMAS PSMAS FML FLIMAS	1 2 3 4	

		CELL MED	5	
		HMMAS	6	
		ALTFIN	7	
		GMB	8	
		Generation Health	9	
		RailMed	10	
		Alliance Health	11	
		Corporate 24	12	
		Other (specify)_____		
Q107	What kind of toilet facility does your household usually use? *Chimbuzi chinoshandiswa nevagari vepano chakamira sei?* **For community survey ask to observe.**	**Flush or pour flush toilet**		
		Flush to piped sewer system	1	
		Flush with septic tank	2	
		Flush to pit latrine	3	
		Flush to somewhere else	4	
		Flush, don't know where	5	
		Pit latrine		
		Ventilated improved pit latrine	6	
		Pit latrine with slab	7	
		Pit latrine without slap/open pit	8	
		Bucket toilet	9	
		No facility/bush/field	10	
		Other (specify)_____		

Q108	What type of fuel does your household mainly use for cooking? *Nguva zhinji nderipi samba ramuno shandisa kubika mumba muno?*	Electricity	1	
		LP gas	2	
		Natural gas	3	
		Biogas	4	
		Paraffin/kerosene	5	
		Coal,lignite	6	
		Charcoal	7	
		Wood	8	
		Straw/shrubs/grass	9	
		Animal dung	10	
		No food cooked in household		
		Other (specify)_____		

Q109	Does your household have: *Munotevedzera chinamato chipi?* **Read list to respondent**		No	Yes	
		Electricity	0	1	
		Radio	0	1	
		Television	0	1	
		Non-mobile telephone	0	1	
		Computer	0	1	
		Refrigerator	0	1	
		Battery/generator	0	1	
		Solar panel	0	1	
		Dish/decoder	0	1	
		Washing machine	0	1	
		Borehole	0	1	
		Watch	0	1	
		Mobile phone	0	1	
		Motorcycle/scooter	0	1	
		Car/truck	0	1	
		Boat with motor	0	1	

Q110	What is the main material of the **floor** of the main house of your household?
	
	Zvii zvakashandiswa mukugadzira pasi remba ino?
	
	Community survey: Observe the main materials
		Natural floor
		
		  Earth/sand
		
		  Dung
		
		Rudimentary floor
		
		  Wood planks
		
		Finished floor
		
		  Parquet or polished wood
		
		  Vinyl or asphalt strips
		
		  Ceramic tiles
		
		  Cement
		
		  Carpet
		
		Other (specify)_____
			
			1
			
			2
			
			3
			
			4
			
			5
			
			6
			
			7
			
			8	

Q111	How often do you watch TV *Munowona chivhitivhiti kangani?*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never	1 2 3 4 5 6	
Q112	For women in marriage or co-habiting: How often does your husband or partner watch TV*?* *Murume wenyu kana kuti wamunogarisana naye anowona chivhitivhiti kangani?*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never Don't know	1 2 3 4 5 6 7	

Q113	How often do you read newspapers? *Munoverenga bepanhau kangani?*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never	1 2 3 4 5 6	
Q114	**For women in marriage or co-habiting:** How often does your husband or partner read the newspapers? *Murume wenyu kana kuti wamunogarisana naye anoverenga bepanhau kangani?*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never Don't know	1 2 3 4 5 6 7	
Q115	How often do you listen to the radio? *Munoteerera nhepfenyuro(redhiyo) kangani*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never	1 2 3 4 5 6	
Q116	**For women in marriage or co-habiting:** How often does your husband or partner listen to the radio? *Murume wenyu kana kuti wamunogarisana naye anonoteerera nhepfenyuro(redhiyo) kangani*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never Don't know	1 2 3 4 5 6 7	

Q117	Do you have access to the internet on computer or phone? *Munokwanisa kuwana foni kana kuti kombuyuta?*	Yes No	1 2	If No skip to Q201
Q118	**For women in marriage or co-habiting:** Does your husband or partner have access to internet on computer or phones? *Murume wenyu kana kuti wamunogarisana naye anoenda pa "internet" kangani*	Yes No Don't know	1 2 3	
Q119	If **Yes**, how often do you access the internet? *Kana ati hongu, Unoenda kangani pa "internet"?*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never	1 2 3 4 5	
Q120	**For women in marriage or co-habiting:** If Yes how often does your husband or partner access the internet? *Murume wenyu kana kuti wamunogarisana naye anoshandisa kangani "internet" ?*	Every day 4 to 6 days a week 2 to 3 days a week Once a week Never Don't know	1 2 3 4 5 6	

SECTION 2: GENERAL KNOWLEDGE ON CERVICAL CANCER

In this section I am going to ask you some questions about what you know concerning cervical cancer and please free to let me if you do not know or you are not sure about anything.

Q201	Have you ever heard/seen about messages on cervical cancer? *Makambonzwa kana kuwona mashoko pamusoro pe gomarara remuromo we chibereko?*	Yes No	1 2	If No skip to Q203
Q202	Where did you hear/see about messages on cervical cancer? *Makanzwa kupi kana kuwona kupi mashoko pamusoro pe gomarara remuromo wechibereko* **Multiple selection possible**	Radio Television Workplace Newspaper/magazine Poster Billboard Health/community worker/Counselor Friends/relatives Other(Specify) _____	1 2 3 4 5 6 7 8	
Q203	What are the causes of cervical cancer that you know or have heard about? *Ndezvipi zvamunoziva kana zvamakambonzwa kuti zvino konzera gomarara remuromo wechibereko?* **Multiple selection possible**	Human papilloma virus (HPV) HIV/AIDS Don't know Other (specify)_____	1 2 3	

Q204	How is cervical cancer prevented? *Gomarara remuromo wechibereko rino dzivirirwa sei?* **Multiple selection possible**	Early screening and treatment	1	
		Male circumcision	2	
		HPV Vaccination	3	
		Stop smoking	4	
		Stop drinking alcohol	5	
		Eating healthy	6	
		Regular exercises	7	
		Don't know	8	
		Other (specify)_____		
Q205a	Do you think that cervical cancer can be treated? *Mukufunga kwenyu gomarara remuromo wechibereko rino rapika here?*	Yes	1	
		No	2	
		Don't know	3	
Q205b	If **Yes**, how do you think it may be treated? *Kana, Hongu, Munofunga kuti rino rapika sei?* **Multiple selection possible**	Drugs (Medication)	1	
		Surgery	2	
		Radiotherapy	3	
		Herbs/Traditional medicine	4	
		Spiritual means	5	
		Don't know	6	
		Other (specify)_____		
Q206	Have you ever heard about palliative care that is given to cancer patients including those suffering from cervical cancer? *Makambonzwa maererano ne kuchengetwa kana rutsigirwo runopiwha vanorwara ne gomarara rechibereko?*	Yes	1	If No skip to Q208
		No	2	

Q207a	If Yes, where did you hear about it?	Radio	1	
	Kana ati hongu, makanzwa kupi mashoko aya?	Television	2	
		Workplace	3	
		Newspaper/magazine	4	
		Poster	5	
		Billboard	6	
	Multiple selection possible	Health/community worker/Counselor		
			7	
		Friends/relatives		
			8	
		Internet		
			9	
		Other(Specify) _____		
Q207b	Where are palliative care services given in Harare?	Island Hospice	1	
	Ndekupi kuno chengetwa kana kutsigirwa vanhu vane gomarara remuromo wechibereko?	Hospice and Palliative care association of Zimbabwe	2	
		Nursing homes		
			3	
		Don't know		
			4	
	Multiple selection possible	Other (specify)_____		
Q208	Do you think that cervical cancer is somehow associated with HIV/AIDS*?*	Yes	1	
		No	2	
	Mukufunga kwenyu mungati gomarara remuromo wechibereko rino kuwadzana ne HIV/AIDS	Don't know	3	

Q209	In your opinion do you think cervical cancer is a problem in Zimbabwe? *Mukuwona kwenyu munofunga kuti gomarara remuromo wechubereko rave dambudziko munyika ye Zimbabwe*	Yes	1	
		No	2	
		Don't know	3	

SECTION 3: ACCESS AND USE OF CERVICAL CANCER TREATMENT AND PALLIATIVE CARE

In the next section I am going to ask you questions regarding access and use of cervical cancer treatment and palliative care.

Muchikamu chirikutevera ndichakubvubnzai pamuroro pekuwanikwa kwekurapwa nekuchengetwa kwecanhu vane gomara remuromo wechibereko

MEASURE OF ACCESS TO CERVICAL CANCER TREATMENT				
HEALTHY WOMEN				
Q301	Do you know where to get or to refer someoneto get cervical cancer treatment and palliation services? *Munoziva kwekuwana kana kwekureva kuti mhunu ano ongororwa kuti ane kana hana gomarara remuromo wechibereko uye nzvimbo dzinobatsira avo vane gomarara?*	Yes No	1 2	If No skip to Q303

Q302a	Generally, where would you go or refer someone for cervical cancer treatment services? *Munga ende kupi kana kureva kuti mumwe anowana rubatsiro rune chekuita nezve gomarara remuromo wechibereko* **Multiple responses possible**	Clinic Hospital Private Practitioner New Start Centre Traditional healer Prophet or pastor Other (specify)_____	1 2 3 4 5 6	
Q302b	Generally, where would you go or refer someone for cervical cancer palliative care services? *Munga ende kupi kana kureva kuti mumwe anowana rubatsiro rune chekuita nekuchengetwa kwe vane gomarara remuromo wechibereko* **Multiple responses possible**	Island Hospice Hospice and Palliative care association of Zimbabwe Nursing homes Don't know Other (specify)_____	1 2 3 4	
Q303	How far is your nearest health facility from your home? *Kiriniki kana chipatara chamungati chiripaduze nemusha wenyu chiri kure zvakadii?* **Probe for an estimate in km**	[ ]	Km	

Q304	How do you usually get to your nearest health facility? *Munoenda sei kukirinki/chipatara?*	Walking Public transport (e.g commuter omnibus or bus) Private car Motor cycle Other (specify)_____	1 2 3 4	
Q305a	How long does it take you to get there? *Zvinokutorerai nguva yaka reba sei kuti musvike ikoko?*	[ ]	Minutes	
Q305b	Do you afford the fees charged by your local health facility? *Munokwanisa kubhadara mari dzinoda kukokwa kukiriniki/chipatara?*	Yes No	1 2	

Q305c	How much does your health facility charge for a single visit? *Panguva yoga yamunoshanyira kiriniki yenyu munobhadara marii ?*	[ ]	US$	
Q306a	In your opinion do you think that your local health facility has the capacity to treat cervical cancer? *Mukuwona kwenyu mungati kirniki yenyu inogona kurapa gomarara remuromo wechibereko*	Yes No Don't know		
Q306b	If No or DNK, where do you think people can be treated of cervical cancer in Harare? *Kana ati kwete kana kuti hazive-* *Munofunga kuti vanhu vanga ende kupi ku Harare kuno rapwa gomarara remuromo wechibereko?* **Multiple responses possible**	Harare Hospital Parirenyatwa Hospital Private hospitals Private doctors Traditional healers Prophets and pastors Other (specify)_____	1 2 3 4 5 6	If Yes to Q306a skip to Q306c
Q306c	If you were to be diagnosed of cervical cancer today do you think you would have access to treatment and palliative care services in Harare? *Kurikunzi nhasi mabatwa kuti munegomarara remuromo wechibereko munofunga kuti mungawane kupirubatsiro kana kurapwa mu Harare?*	Yes No	1 2	

Q306d	Where would you goto seek treatment? *Munga ende kupi kuno rapwa?* **Multiple response possible**	Harare Hospital Parirenyatwa Hospital Local health facility Private hospitals Private doctors Traditional healers Prophets and pastors Other (specify)_____	1 2 3 4 5 6 7	
Q306e	Where would you go to seek for palliative care services? *Munga ende kupi kuno wana rubatsiro kune avo vanochengeta vane gomarara?* **Multiple responses possible**	Island Hospice Hospice and Palliative care association of Zimbabwe Nursing homes Don't know Other (specify)_____	1 2 3 4	

Q307a	Do you think people with cervical cancer are able to access treatment and palliative care services in Harare? *Munofunga kuti vanhu vanga ende kupi ku Harare kuno rapwa gomarara remuromo wechibereko kana kuno wana rubatsiro kune vanochengeta vano rwara negomarara?*	Yes No Don't know	1 2 3	
Q307b	Do you think that Harare has adequate specialists to treat and manage cervical cancer patients? *Munofunga kuti mu Harare mune anamazvikokota kavakwana uye vachikwanisa kurapa vese avo vane gomarara remuromo wechibereko?*	Yes No	1 2	

Q308	What challenges do you think cervical cancer patients potentially face in trying to access treatment and palliative care services in Harare? *Munofunga kuti ndeapi matambudziko angasangane neavo vanegomarara remuromo wechibereko kana vachida kuno rapwa kana kuti kunowana rubatsiro kune avo vano chengeta vanegomarara?* **Read out list to respondent** **Multiple selection possible**	Lack of transport to go the health centres.	1	
		Lack of finances to pay for the services.	2	
		Few centres offer the specialized services.	3	
		Bad attitude of health professionals	4	
		Stigma from the society		
		Stock-outs of drugs (medication) at health facilities.	5	
		Bureaucratic processes in accessing treatment services		
		Lack or dysfunctional equipment at health centres.	6	
		Other (specify)_____	7	
			8	

CERVICAL CANCER SURVIVORS				
Q309	What made you go for cervical cancer screening just before your diagnosis? *Chii chakaita kuti muno ongororwa imi musati mabatwa kuti munegomarara remuromo wechibereko?* **Multiple selection possible**	Routine screening Friend/relative advice Health problem Health professional's advice Other (specify)_____	1 2 3 4	
Q310	Wherewere you first screened and suspected of cervical cancer? *Ndekupi kwamakatanga kuongororwa neku fungidzirwa kuti mune gomarara remuromo wechibereko?*	Clinic Hospital Private Practitioner New Start Centre Other (specify)_____	1 2 3 4	
Q311a	What is the exact name of the health facility or practitioner? *Zita chairochairo rechipatara/kiriniki kanadokota akaku udzai kuti mune gomarara remuromo wechibereko rinotii?*	[ ]		If not sure put "Not sure"
Q311b	Where were you referred for further investigations (histological tests) to confirm your diagnosis? *Makanzi muende kupi kuno tarisiswa kusimbisisa kuti mune gomarara remuromo wechibereko?*	Harare Hospital Parirenyatwa Hospital Private laboratories Private hospital/ Dr's surgery Other (specify)_____	1 2 3 4	

Q312	How far is your home from the health facility you were screened and suspected of cervical cancer? *Kure sei ku kuriniki/chipatara chamakano udzwa pekutanga kana kufungidzirwa kuti mune gomarara remuromo wechibereko?* **Probe for an estimate in km**	[ ]	km	
Q313	How did you go to the health facility where you were first screened and suspected of cervical cancer? *Makaenda neyi kuriniki/chipatara pamaka udzwa pekutanga kana kufungidzirwa kuti mune gomarara remuromo wechibereko?*	Walking Public transport (e.g commuter omnibus or bus) Private car Motor cycle Other (specify)_____	1 2 3 4 5	
Q314	How long did it take you to get to the health facility? *Zvakatora nguva yakareba sei kuti musvike kukiriniki/chipatara?*	[ ]	Minutes	
Q315	How much money were you asked to pay for screening services? *Makanzi mubhadare marii kuti muongororwe?*	[ ]	US$	Put 0000 if no charge, if on medical aid covered put 9999

Q316	**If charged:** Was the amount affordable to you? *Makakwanisa kubhadara mari dzai diwa?*	Yes No	1 2	Skip if answer to Q315 is 0000 or 9999
Q317	How many times were you screened for cervical cancer in your life? *Muhupenyu wenyu wese makano ongororwa kangani gomarara remuromo wechibereko?*	[ ]	Put 9999 if cannot remember	
Q318a	Do you have access to treatment for your condition? *Munokwanisa kurapwa zvamurikurwara nazvo izvezvi?*	Yes No	1 2	
Q318b	Do you have access to specialist services for your condition? *Munokwanisa kunowna anamazvikokota mukurapa gomorara remuromo wechibereko?*	Yes No	1 2	
Q318c	How many times have you been seen by a specialist in the last 3 months *Mumwedzi mitatu yapfuura makawonekwa kangani nana mazvikokota?*	[ ]		Put 00 if not seen.

Q319	How long did it take for you to be put on treatment from the time of diagnosis? *Zvakatora nguva yareba sei kuti muzoiswa pamishonga shure kwekunge maudzwa kut mune gomarara remuromo wechibereko?*	Months Days [ ] [ ]	Put 9999 if not yet on treatment	
Q320	Where were you commenced on treatment? *Matanga kurapwa murikupi?*	Harare Hospital Parirenyatwa Hospital Private nursing home Private hospital/ Dr's surgery Not yet on treatment Other (specify)_____	1 2 3 4 5	
Q321a	What kind of treatment were you put on? *Makarapwa nenzira ipi?* **Multiple selection possible**	Drugs (Medication) Surgery Radiotherapy Other (specify)_____	1 2 3 4	
Q321b	Are you receiving palliative care services? *Murikwana rubatsiro runopiwa neavo vanochengeta vano rwara ne gomarara*	Yes No	1 2	If No skip to Q322a

Q321c	If **Yes,** where are you getting the services? *Murikuri wana kurpi rubatsiro uru?*	Island Hospice Hospice and Palliative care association of Zimbabwe Nursing homes Home Other (specify)_____	1 2 3 4	
Q321d	What other medication or services have you received for your condition apart from those provided at health facility? *Ndeipi mishonga kana rubatsiro rwamawana rusiri rwe kuchipatara?* **Multiple selection possible** **Probe for more**.	Herbs/traditional medicine Spiritual materials (water, oil, or stones) Prayers Other (specify)_____	1 2 3	
Q322a	How much have you paid or are you paying on average for your treatment in one month? *Mumwedzi mumwe chete mabhadara marii kana kuti mri kubhadara narii kuti murapwe?* **Probe for estimates**	[ ]	US$/per month	If no payment put 0000 and skip to Q323

	How much have you paid or are you paying on average for your palliative care services in one month? *Mabhadara marii kana kuti muri kubhadara marii pamwedzi kuti muane rubatsiro rokuchengetwa kweavo vane gomarara?* **Probe for estimates**	[ ]	US$/per month	If no payment put 0000 and skip to Q323
Q322b				
Q322c	Are (Were) these costs affordable to you or your family? *Mari dzinodiwa kuti murapwe munodzikwanisa kana kuti mhuri yenyu inodzikwanisa here?*	Yes No	1 2	

Q323a	What challenges did you or do you face to access treatment services? *Ndeapi matambudziko amunosangana nawo kana muchino rapwa kukiriniki/chipatara?* **Read out list to respondent** **Multiple selection possible**	Lack of transport to go the health centres. Lack of finances to pay for the services. Few centres offer the specialized services. Bad attitude of health professionals Stigma from the society Stock-outs of drugs (medication) at health facilities. Bureaucratic processes in accessing treatment services Lack or dysfunctional equipment at health centres. Other (specify)_____	1 2 3 4 5 6 7 8	
Q323b	Have you been satisfied with the services that you have received in this health facility? *Murikufara nekurapwa kwamuri kuitwa kukiriniki/chipatara ichi?*	Yes No	1 2	

	Would you continue to come back for treatment services in this facility even if you were given other choices? *Mungadzoke here kuzorawa kurikiniki iyi kana mukapiwa mukana wekusarudza kwekuno rapwa?*	Yes No	1 2	
Q323c				
Q323d	Given your experiences so far would you recommend a friend or relative to receive treatment or palliative care in this health facility? *Muchitarisa zvamasangana nazvo munga kurudzire shamwari kana hama yenyu kuti inorapwa kana kunwa rubastiro runopiwa vane gomarara kukiriniki kana chipatara ichi?*	Yes No	1 2	
UTILIZATION OF CERVICAL CANCER TREATMENT				
HEALTHY WOMEN				
Q324a	How many times did you visit your health facility or doctor in the last 6 months? *Mumwedzi nhanhatu yapfuura waenda kangani kukiriniki kana kunowonekwa na chiremba?*	[ ]		If none put 0000
Q324b	Do you have a regular doctor whom you see when you require health services? *Munachiremba wamunno wanzo enda kuno wona kana marwara?*	Yes No	1 2	

Q325	If you are not feeling well where would you go **first**? *Kana musiri kunza zvakanaka ndekupi kwamuno tanga kuyenda kuno rapwa?*	Clinic Hospital Private Practitioner (Doctor) New Start Centre Traditional healer Prophet or pastor Other (specify)_____	1 2 3 4 5 6	
Q326	If you were to be given some medication or treatment for a disease would adhere to it? *Kurikunzi mapihwa mishonga kana kuraphwa chero chirhwere munogona kuteedzera zvinenge zvichidiwa?*	Yes No	1 2	
Q327	Have you ever been screened for cervical cancer? *Makambo ongororwa pachitariswa huvepo hwegomara romuromo wechibereko?*	Yes No	1 2 3	If No skip to Q332a
Q328	When you were last screened? *Makapedzesera rini kuongororwa?*	Month Year [ ] [ ]		If not known put 9999
Q329	Where were you screened? *Makawongororwa kupi?*	Harare Hospital Parirenyatwa Hospital New Start Centre Private hospital/Dr's surgery Cancer Association Other (specify)_____	1 2 3 4 5	

Q330	How much where you asked to pay for the screening services? *Makanzi mubhadare mariikuti muongororwe?*	[ ]	US$	If nothing put 0000 and if medical aid covered put 9999
Q331	Were the charges affordable to you or your household? *Mari dzinodiwa kuti murapwe munodzikwanisa kana kuti mhuri yenyu inodzikwanisa here?*	Yes No	1 2	
Q332a	Who do you believe can manage cervical cancer better? *Ndiyani wamunofunga kuti anogona kurapa gomarara remuromo wechibereko zviri nani?*	Health professionals Traditional healers Prophets and pastors Other (specify)_____	1 2 3	

Q332b	What challenges do you usually face in using health services? *Ndeapi matambudziko amunosangana nawo kana muchino rapwa kukiriniki/chipatara?* **Read out list to respondent** **Multiple selection possible** '	Lack of transport to go the health centres. Lack of finances to pay for the services. Bad attitude of health professionals Stigma from the society Stock-outs of drugs (medication) at health facilities. Bureaucratic processes in accessing treatment services Lack or dysfunctional equipment at health centres. Poor quality of care Side effect of medication or treatments Other (specify)_____	1 2 3 4 5 6 7 8 9	
CERVICAL CANCER SURVIVORS			
Q333a	How many times have you visited your health facility or doctor for treatment/check up in the last 6 months? *Mumwedzi nhanhatu yapfuura maenda kangani kukiriniki kana kunachiremba kunorapwa kana kutariswa?*	[ ]		

Q333b	Do you have a regular doctor whom you see when you require health services? *Munachiremba wamunowona kana muchida kurapwa?*	Yes No		
Q334a	What treatment are you on or have you received for your condition? *Makarapwa nenzira ipi kana kuti murikurapwa nenzira yipi?* **Multiple selection possible**	Drugs (Medication) Surgery Radiotherapy Herbs/Traditional medicine Spiritual means Other (specify)_____	1 2 3 4 5	
Q334b	Where do you or did you get treatment for your condition? *Munoenda kupi kuno rapwa chirwere chamunacho?* **Multiple selection possible**	Harare Hospital Parirenyatwa Hospital Local Clinic Private hospital/Dr's surgery Private nursing home Other (specify)_____	1 2 3 4 5	
Q335	How much are you paying or were you asked to pay for your treatment? *Muri kubhadara kana kuti makabhadara marii kuti murapwe?*	[ ]	US$	If nothing put 0000 and if medical aid covers put 9999

Q336	Are (Were) these fees affordable to you or your household? *Mari dzinodiwa kuti murapwe munodzikwanisa kana kuti mhuri yenyu inodzikwanisa here*?	Yes No	1 2	Skip if answer to Q335 is 0000 or 9999
Q337	Who do you believe can manage cervical cancer better? *Ndiyani wamunofunga kuti anogona kurapa gomarara remuromo wechibereko zviri nani?*	Health professionals Traditional healers Prophets and pastors No one Other (specify)_____	1 2 3 4	

Q338	What challenges do you usually face in using health services? *Ndeapi matambudziko amunosangana nawo kana muchino rapwa kukiriniki/chipatara?*	Lack of transport to go the health centres.	1	
		Lack of finances to pay for the services.	2	
		Few centres offer the specialized services.	3	
		Bad attitude of health professionals	4	
		Stigma from the society		
		Stock-outs of drugs (medication) at health facilities.	5	
		Bureaucratic processes in accessing treatment services	6	
		Lack or dysfunctional equipment at health centres.	7	
		Side-effects from drugs or treatment		
		Other (specify)_____	8	
			9	
	Read out list to respondent **Multiple selection possible**			

I am now going to ask you questions regarding your perceptions on cervical cancer treatment and palliation services. Please tell me if you 'agree' or disagree. Note: Probe if they "agree strongly" or "agree somewhat", and if they "disagree strongly" or "disagree somewhat".

Ikozvino ndave kuda kukubvunzai mibvunzo maererano nemaonero enyu erubatsiro rapwa kwegomarara remurmo wechibereko nekuchengetwa kwavanoitwa. Ndinokumbira kuti mundiudze kana muchibvuma kana kuramba

	SELFEFFICACY	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
Q339	I can discuss experiences of cervical cancer with other women. *Ndino kwanisa kutaura nevamwe vanhukadzi pamusoro pezvandaka sangana nazvo zvakanangana negomarara remuromo wechibereko*	5	4	3	2	1
Q340	I can discuss experiences of cervical cancer with my family members. *Ndino kwanisa kutaura neve mumhuri mangu pamusoro pezvandaka sangana nazvo zvakanangana negomarara remuromo wechibereko*	5	4	3	2	1
Q341	I can discuss experiences of cervical cancer with my friends. *Ndino kwanisa kutaura neshamwari dzangu pamusoro pezvandaka sangana nazvo zvakanangana negomarara remuromo wechibereko*	5	4	3	2	1
Q342	I am afraid to discuss experiences of cervical cancer with anyone [R]. *Ndinotya kutaura nevamwe pamusoro pezvandaka sangana*	5	4	3	2	1

		5	4	3	2	1
	nazvo zvakanangana negomarara remuromo wechibereko					
	AVAILABILITY	5	4	3	2	1
Q343	Health workers at the hospital/clinic are sensitive to cervical cancer patients. *Vashandi vemuchipatara/kiriniki vanonzwisisa vanu vano rwara regomarara romuromo wechibereko*	5	4	3	2	1
Q344	The hospital/clinic in my community offers timely services for people with cervical cancer. *Chipatara/kiriniki chinopa rubatsiro nekuchimbidza kune avo vano rwara regomarara romuromo wechibereko*	5	4	3	2	1
Q345	The hospital staff can handle cervical cancer cases with confidentiality. *Vashandi vemuchipatara/kiriniki vanochengetedza kurwara kwe avo vano rwara negomarara romuromo wechibereko zvakavanzika*	5	4	3	2	1
Q346	Awareness of cervical cancer is done in my community. *Kuzivisa vanhu pamusoro pegomarara remuromo wechibereko kunoitwa munharaunda yangu*	5	4	3	2	1
Q347	The local hospital offers cervical cancer screening to women *Chipatara chemnharudna ino chino ongorora vanhukadzi gomarara remuromo wechibereko mahara*	5	4	3	2	1
Q347	The local hospital offers cervical cancer vaccination to young girls *Chipatara chemu nharaunda ino*	5	4	3	2	1

	chinopa vasikana vechidiki mushonga wekudzivirira gomarara remuromo wechibereko				
Q348	The local hospital offers treatment to women with cervical cancer. *Chipatara chemu nharaunda ino chinorapa vanhukadzi gomarara remuromo wechibereko*	5	4	3	2	1
Q349	The local hospital offers palliative care to cervical cancer patients. *Chipatara chemu nharaunda ino chinopa rubastiro rwekuchengeta avo vane gomarara remuromo wechibereko*	5	4	3	2	1
Q350	The local hospital offers health education about cervical cancer to women. *Chipatara chemunharaunda ino chinopa dzidziso pamusoro pegomarara remuromo wechibereko*	5	4	3	2	1
Q351	The local hospital offers laboratory investigations for women suspected of cervical cancer. *Chipatara chemunharaunda ino chinopa rubatsiro rweku ongorora mumalebhu kunevanhukadzi vvarikufungidzirwa kuti vanenegomarara remuromo wechibereko*	5	4	3	2	1
Q352	The local hospital has adequate equipment for treatment of cervical cancer. *Chipatara chemunharaunda ino chine mishina yekurapa vese vano rwara negomarara remuromo wechibereko*	5	4	3	2	1

Q353	The local hospital has adequate trained staff to provide cervical cancer treatment. *Chipatara chirimunharaunda ino chine vashandi vakadzidziswa kurapa avo vane gomarara remuromo wechibereko*	5	4	3	2	1
Q354	The local hospital offers counselling to cervical cancer patients and their partners/families. *Chipatara chemunharaunda ino chinopa mazanno ukurarama kune vanegomarara remuromo wechibereko*	5	4	3	2	1
Q355	The local hospital offers treatment to **all** cervical cancer patients in this community. *Chipatara chemunharaunda ino chinorapa vese vano rwara negomarara remuromo wechibereko*	5	4	3	2	1
Q356	Churches in my community provide support to people/families with cervical cancer. *Machechi emunharaunda ino anopa rubatsiro kunavhu/nemhuri dzine gomarara remuromo wechibereko*	5	4	3	2	1
Q357	Traditional healers provide cervical cancer treatment in this community *N'anga dzemunharaunda ino dzino rapa gomarara remuromo wechibereko*					

Q358	Medical services for survivors of cervical cancer are not available in my community[R] *Hapana zvirongwa zvekurapwa kwevanhu vararama shure kwekuva negomarara remuromo wechibereko*	5	4	3	2	1
	AFFORDABILITY					
Q359	Cervical cancer treatment services are affordable in my community *Kurapwa gomarara remuromo wechibereko akudhuri.*	5	4	3	2	1
Q360	Most people in my community are able to pay the local clinic/hospital fees for health services. *Vanhu vazhinji vemunharaunda yangu vanokwanisa kubhadara mari dzino diwa kukiriniki /chipatara kuti varapwe.*	5	4	3	2	1
Q361	Hospitals/clinics in my community offer screening for cervical cancer for free. *Zvipatara/ makiriniki emunharaunda yangu zvinovheneka mahara.*	5	4	3	2	1
Q362	Hospitals/clinics in my community offer for cervical cancer treatment services for free. *Zvipatara/ makiriniki emunharaunda yangu zvinorapa mahara.*	5	4	3	2	1

Q363	Hospitals/clinics in my community offer free treatment services for cervical cancer patients who cannot afford to pay. *Zvipatara/ makiriniki emunharaunda yangu zvinorapa mahara avo vasinga kwanise kubhadara.*	5	4	3	2	1
Q364	Cervical cancer treatment is cheaper abroad than in my local hospital/clinic. *Kurapwa gomarara remuromo wechibereko kwakachipha kunze kwenyika tichienzanisa nekurapwa muno*	5	4	3	2	1
Q365	I get better value for money for cervical cancer treatment abroad than in my local hospital/clinic. *Ndiwana rubatsiro rwakakwana kunze kwenyika kupfura muzvipatara zvenumuno, kuburikidza nemari yandinenge ndabhadara*	5	4	3	2	1
	SOCIAL SUPPORT					
Q366	My partner/husband [would] supports me to go for cervical cancer screening. *Murume/mumwe wangu anondikurudzira kuti ndiyende kuno ongororwa gomarara remuromo* wechibereko	5	4	3	2	1
Q367	My partner/husband [would] supports me to go for cervical cancer treatment *Murume/mumwe wangu anondikurudzira kuti ndiyende kuno rapwa gomarara remuromo wechibereko*	5	4	3	2	1

Q368	My friends supports me to go for cervical cancer treatment. *Shamwari dzangu dzinondikurudzira kuti ndiyende kuno rapwa gomarara remuromo wechibereko*	5	4	3	2	1
Q369	My family supports me to go for cervical cancer treatment *Mhuri yangu inondikurudzira kuti ndiyende kuno rapwa gomarara remuromo wechibereko*	5	4	3	2	1
Q370	Cervical cancer treatment is acceptable in my community *Kurapwa gomarara remuromo wechibereko chinhu chakanguchirika munharaunda yangu*	5	4	3	2	1
Q371	Leaders in my community encourage women to be screened and treated for cervical cancer. *Vatungamiri venharaunda inovano kurudzira kut vakadzi vaende kuno ongororwa nekurapwa gomarara remuromo wechibereko*	5	4	3	2	1
Q372	My community believes that cervical cancer can be treated. *Vanhu vemunharaunda yangu vanotenda kuti gomarara remuromo wechibereko rino rapika*	5	4	3	2	1
Q373	My community does not stigmatize women with cervical cancer. *Vanhu vemu nharaunda yangu* *Havasarudze vanhukadzi vane gomarara remuromo wechibereko*	5	4	3	2	1
	ATTITUDES	5	4	3	2	1
Q374	Cervical cancer patients should not	5	4	3	2	1

	be stigmatized *Vano rwara negomarara remuromo wechibereko havafanirwe kusarudzwa*					
Q375	I encourage others to be screened and treated for cervical cancer *Ndinokurudzira vamwe kuti vaende kuno ongororwa nekurapwa gomarara remuromo wechibereko.*	5	4	3	2	1
Q376	I am afraid of cervical cancer treatment [R] *Ndotya kuenda kunorapwa gomarara remuromo wechibereko*	5	4	3	2	1
Q377	Getting results of cervical cancer screening is scary [R] *Kuwana zvabuda mukuongororwa huvepo wegomarara remuromo wechibereko kunotyisa*	5	4	3	2	1
Q378	Women should go for cervical cancer screening only when they experience serious health problems [R] *Vanhukadzi vanofanira kuyenda kuno ongororwa chete kana hutano wavo usisina kumira **zvakanaka.***	5	4	3	2	1
Q379	Cervical cancer treatment is for people with money [R] *Kunorapwa gomarara remuromo wechibereko ndekwe vanhu vane mari*	5	4	3	2	1
Q380	Cervical cancer screening is for promiscuous people [R] *Kuongororwa huvepo hwegomarara remuromo wechibereko kunoitwa nevanhu vasina kuzvibata*	5	4	3	2	1
Q381	I am too busy to go for cervical cancer treatment [R] *Ndine zvakawanda zvakanyanya kuti*	5	4	3	2	1

	ndiyende kuno rapwa gomarara remuromo wechibereko					
Q382	I do not have time to go for cervical cancer treatment [R] *Andina nguva yekuyenda kuno rapwa gomarara remuromo wechibereko*	5	4	3	2	1
Q383	Cervical cancer treatment procedure is embarrassing [R] *Zvinonyadzisa kunorapwa gomarara remuromo wechibereko*	5	4	3	2	1
	BELIEFS					
Q384	Screening is important for early treatment of cervical cancer *Zvakakosha kuyenda pachinenguva kuno ongororwa huvepo we gomarara remuromo wechibereko.*	5	4	3	2	1
Q385	Cervical cancer treatment saves lives. *Kurapwa gomarara remuromo wechibereko zvino chengetedza hupenyu*	5	4	3	2	1
Q386	Cervical cancer treatment gives a woman and their family peace of mind. *Kurapwa gomarara remuromo wechibereko zvinopa munhukadzi nemhuri yake zororo mupfugwa*	5	4	3	2	1
Q387	Cervical cancer treatment gives a woman control over her health. *Kurapwa gomarara remuromo wechibereko zvinopa munhukadzi samba pamusoro pehutanho hwake.*	5	4	3	2	1

Q388	HIV testing is optional when being screened for cervical cancer *Kuongororwa HIV hakumanikidzwe kana uchiongororwa huvepo hwe gomarara remuromo wechibereko*	5	4	3	2	1
Q389	Cervical cancer treatment is not painful *Kurapwa gomarara remuromo wechibereko kunorwadza*	5	4	3	2	1
Q390	Cervical cancer treatment has no side-effects *Kurapwa gomarara remuromo wechibereko hakuna zvakuno kanganisa*	5	4	3	2	1
Q391	Cervical cancer treatment is for all women regardless of background *Kurapwa gomarara remuromo wechibereko ndekwe munhu wese zvisineyi kwaanobva*	5	4	3	2	1
Q392	Cervical cancer cannot be treated [R] *Gomarara remuromo wechibereko harirapike*	5	4	3	2	1
Q393	Cervical cancer patients do not survive long even when treated [R] *Vane gomarara remuromo wechibereko havararame kunyagwe varapwa.*	5	4	3	2	1
Q394	Cervical cancer is best treated with herbs/traditional medicines. *Gomarara remuromo wechibereko rino rapika zvakanaka ne mishonga yechi vanhu*	5	4	3	2	1
Q395	Cervical cancer is best treated using spiritual means performed by prophets and pastors.	5	4	3	2	1

	Gomarara remuromo wechibereko rino rapwa zvirinani nevezve Mweya-Maporofita namafundisi				
Q396	Cervical cancer treatment is best done abroad. *Zvakanaka zvikuru kurapwa gomarara remuromo wechibereko kunze kwenyika*	5	4	3	2	1
Q397	Health professionals abroad provide better care for cervical cancer patients. *Madokota arikunze kwenyika vano rapa zviri nani avo vane gomarara remuromo wechibereko*	5	4	3	2	1
Q398	Cervical cancer patients treated abroad have better survival chances. *Vane gomarara remuromo wechibereko vane mukana urinani wekuti vararame*	5	4	3	2	1
	LOCUS OF CONTROL					
Q399	I am responsible for my health *Ndini ndino fanira kuchengetedza hutano wangu*	5	4	3	2	1
Q400	No one needs to know if I am going for cervical cancer treatment *Hapana anofanira kuziva kuti ndiri kuenda kuno ongororwa huvepo we gomarara remuromo wechibereko*	5	4	3	2	1
Q401	I should not be ignorant of my status relating to cervical cancer *Andifanirwe kusaziva chimiro changu*	5	4	3	2	1

	zvakanangana ne gomarara remuromo wechibereko					
	THREAT					
Q402	Cervical cancer is painful [R] *Gomarara remuromo wechibereko inorwadza*	5	4	3	2	1
Q403	Cervical cancer is smelly [R] *Gomarara remuromo wechibereko inonhuhwa*	5	4	3	2	1
Q404	Cervical cancer can cause death [R] *Gomarara remuromo wechibereko inowuraya*	5	4	3	2	1
	QUALITY OF CARE					
Q405	Test results for cervical cancer screening are immediate *Zvinenge zvabuda mukutariswa pachitsvagwa huvepo hwe gomarara remuromo wechibereko zvinobuda ipapo ipapo*	5	4	3	2	1
Q406	Cervical cancer screening does not take too long *Hazvitori nguva yakarebaka Kuongororwa pachitsvagwa huvepo hwegomarara remuromo wechibereko*	5	4	3	2	1
Q407	Health care workers who perform cervical cancer treatment are well trained *Vashandi vanorapa gomarara remuromo wechibereko vakadzidziswa*	5	4	3	2	1

	zvemhandoyepamusoro					
Q408	Health care workers who perform cervical cancer treatment are very helpful	5	4	3	2	1
	Vashandi vanorapa gomarara remuromo wechibereko vanobatsira zvikuru					

Interviewer's observations

_____
_____
_____

Comments on specific questions

_____
_____
_____

Any other comments

_____
_____
_____

Remarks: Thank the participant for their time and proceed to the next respondent.

---THE END---

Appendix 9: Health Worker Survey Questionnaire

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

SPEAK TO THE HEALTHCARE WORKER: Hello. My name is Oscar Tapera and I am a PhDstudent at the University of Pretoria, South Africa. We areinterviewing health workers at [name of health facility] in order to obtain your views, opinions and experiences on cervical cancer treatment and palliative(also known as supportive, hospice or terminal)care services in Harare. You have been selected to participate in this study because you are involved with cervical cancer patients. This interview will take not more than 30 minutes and you are free to ask me any questions after the interview or if you need any clarity you may stop me during the interview so that I may assist you.

ForHW interviews seek permission from management: I would like your permission to identify a respondent and begin the interview.

[**Note**: Ensure formal consent process is done prior to interviewing the selected respondent].

	IDENTIFICATION Questionnaire No. [ ]
ID01	
	Province : _____
ID02	
	District :_____
ID03	
	Ward : _____
ID04	
	Type of health facility : **Public -----------------------1**
ID05	**Private-----------------------2**
	Health facility Name: _____

ID06	

| ID07 | **INTERVIEWER VISITS**

            A   B   C

       Visit 1   Visit 2   Visit 3

DATE   _____   _____   _____ |

	Skip instructions
SECTION 1. GENERAL INFORMATION	

HEALTH WORKER INFORMATION				
Q101	How old were you at your last birthday?	_____	Age in completed years	
Q102a	**Indicate** The Gender Of The Participant.	Female	1	

		Male	2	
Q102b	What race are you?	Black African	1	
		Coloured	2	
		White	3	
		Asian	4	
		Other (specify) _____		
Q103	What is your profession?	General practitioner	1	
		General nurse	2	
		Oncology nurse	3	
		Nurse aid	4	
		Gynaecologist	5	
		Radiologist	6	
		Oncologist	7	
		Pathologist	8	
		Physician	9	
		Surgeon	10	
		Pharmacist	11	
		Laboratory Scientist	12	
		Medical Physicist	13	
		Radiographer	14	
		Clinical psychologist	15	
		Social worker	16	
		Other (specify)_____		
Q104a	How many years have you been practicing in your profession?	[ ]	Years	

Q104b	Where did you receive your basic professional training?	University of Zimbabwe	1	For nurses put MoHCC.
		NUST	2	
		Midlands State University	3	
		Africa University	4	
		MoHCC	5	
		Foreign institutions	6	
		Other (specify)_____		
Q104c	Where did you receive your specialist training? **Multiple responses possible**	University of Zimbabwe	1	
		NUST	2	
		Midlands State University	3	
		Africa University	4	
		MoHCC	5	
		Foreign institutions	6	
		Other (specify)_____		
Q105a	Have you ever received any on-the job training on cervical cancer treatment and palliative care?	Yes No	1 2	
Q105b	When was the latest training conducted?	Month Year [ ] [ ]		
Q105c	Which institution conducted the training?	[ ]		
Q105d	How long was the training?	[ ]	Days	
Q106a	Do you feel that you have received adequate training to provide cervical cancer treatment and palliative care services?	Yes No	1 2	
Q106b	If No, provide reasons	[ ]		

Q106c	Does your employer support your continuous professional development (CPD) in cervical cancer treatment and palliative care?	Yes No Not applicable	1 2 3	
Q107a	Does your facility have clinical guidelines for the treatment and palliation of cervical cancer patients?	Yes No Don't know	1 2 3	
Q107b	Have you read or heard about **The National Cancer Prevention and Control Strategy for Zimbabwe (2013-2017)**?	Yes No	1 2	
Q107c	Have you read or heard about the **Zimbabwe Cervical Cancer Prevention and Control Strategy for Zimbabwe (2016-2020)**?	Yes No	1 2	
Q107d	Do you think Zimbabwe has adequate policies and strategies for the treatment and management of cervical cancer?	Yes No	1 2	
Q107e	Do you think that the cervical cancer surveillance system is adequate in the Zimbabwe to account for every case?	Yes No Don't know	1 2 3	
Q108a	How many hours do you work in a week?	[ ]	Hours	
Q108b	How many patients do you attend to daily on average?	[ ]		
Q108c	On average what is your relationship with your patients?	Excellent Good Poor	1 2 3	

		Don't want to comment	4	
Q108d	Do most of your cervical cancer patients adhere to prescribed treatments?	Yes No Don't know	1 2 3	
Q108e	Do some of your cervical cancer patients miss treatments or other prescribed procedures?	Yes No Don't know	1 2 3	
Q108f	What is the general perception of cervical cancer patients and their families on the services you provide in this facility?	Excellent Good Poor Don't know	1 2 3 4	
Q109a	How are the working conditions in this facility?	Excellent Good Poor Don't want to comment	1 2 3 4	
Q109b	Are you motivated to provide your services to cervical cancer patients in this facility?	Yes No Don't want to comment	1 2 3	
Q109c	Do you think the benefits (salaries and allowances) you are receiving are commensurate with the services you provide to cervical cancer patients?	Yes No Don't want to comment	1 2 3	

HEALTH FACILITY INFORMATION				
Q110	Who owns this facility?	Government	1	
		NGO	2	
		Church based organization	3	
		Community	4	
		Private for profit	5	
		Other (specify) _____		
Q111	How many health professionals are employed (full or part-time) in this facility?	[ ]		
Q112	Who mainly pays the salaries of staff at this facility?	Government	1	
		NGOs	2	
		Church	3	
		Own income	4	
		Private companies/individuals	5	
		Don't know		
		Other (specify)_____	6	
Q113	Who mainly pays for medical supplies for facility?	Government	1	
		NGOs	2	
		Church	3	
		Own income	4	
		Private companies/individuals	5	
		Don't know		
		Other	6	

		(specify)_____		
Q114	Who mainly pays for running costs for this facility?	Government	1	
		NGOs	2	
		Church	3	
		Own income	4	
		Private companies/individuals	5	
			6	
		Don't know		
		Other (specify)_____		
Q115a	What is the type of the health facility?	Public hospital	1	
		Private Hospital/clinic	2	
		Nursing home	3	
		Palliative care facility	4	
		Other (specify) _____		
Q115b	Where are do most cervical cancer patients attending this facility come from? [Province]	Manicaland	1	
		Bulawayo	2	
		Harare	3	
		Mashonaland East	4	
		Mashonaland Central	5	
		Mashonaland West	6	
		Midlands	7	
		Matebeleland North	8	
		Matebeleland South	9	
		Masvingo	10	

Q116a	How many professionals serve cervical cancer at your health facility?	General practitioner	[ ]	Put "00" if the professional is not there.
		General nurse	[ ]	
		Oncology nurse	[ ]	
		Nurse aid	[ ]	
		Gynaecologist	[ ]	
		Radiologist	[ ]	
		Oncologist	[ ]	
		Pathologist	[ ]	
		Physician	[ ]	
		Surgeon	[ ]	
		Pharmacist	[ ]	
		Laboratory Scientist	[ ]	
		Medical Physicist	[ ]	
		Radiographer	[ ]	
		Clinical psychologist	[ ]	
		Social worker	[ ]	
Q116b	Are the health professionals adequate to serve the number of patients you receive?	Yes No	1 2	
Q116c	How many staff members in your speciality should this health facility have to effectively manage your workload?	[ ]		

Q116d	What specialists are in short supplies in this facility? **Multiple selection possible**	Oncology nurse	1	
		Gynaecologist	2	
		Radiologist	3	
		Oncologist	4	
		Pathologist	5	
		Physician	6	
		Surgeon	7	
		Pharmacist	8	
		Laboratory Scientist	9	
		Medical Physicist	10	
		Radiographer	11	
		Clinical psychologist	12	
		Social worker	13	
		Other (specify)_____		
Q117a	How many days per week is this facility open? **Number 1-7**	[ ]	Days	
Q117b	How many hours per day (on average) does this facility offer patient consultation/services?	[ ]	Hours	If not applicable put 9999
Q118	How many patient visits have you had at this facility in the past 3 months?	[ ]		
Q119	Does this facility hospitalize cervical cancer patients?	Yes No	1 2	

Q120	How many cervical cancer inpatients have you had in the last 3 months in this facility?	[ ]		
Q121	How many inpatient bed days have you had during the past 3 months?	[ ]		
Q122	How many beds are available for hospitalization of cervical cancer patients?	[ ]		
Q123	How many beds in TOTAL are available for patients at your facility?	[ ]		
Q124a	Does this facility offer cervical cancer screening?	Yes No	1 2	If No skip to Q125a
Q124b	Does this facility offer treatment of pre-cervical cancer lesions?	Yes No	1 2	
Q124b	What treatment options are available in this facility?	Cryotherapy LEEP Surgery Other (specify)_____	1 2 3	
Q125a	Does this facility offer histology investigations for patients with suspected cervical cancer?	Yes No	1 2	If Yes skip to Q126
Q125b	If No, where do you refer patients for histological investigations?	Parirenyatwa Hospital Harare Hospital Private laboratories Other (specify) _____	1 2 3	
Q126	How long does it take on average for a patient to receive histology results for cervical cancer?	[ ]	Days	

Q127	What cervical cancer treatment services are available in your facility? **Multiple selection possible**	Radiotherapy	1	
		Chemotherapy	2	
		Radio-chemotherapy	3	
		Surgical treatment	4	
		Not applicable	5	
		Other (specify)_____		
Q128	How long does it take on average for a patient to be started on treatment?	[ ]	Days	
Q129	How many cervical cancer patients are registered in this facility?	[ ]		
Q130a	Of these patients how many are on treatment?	[ ]		
Q130b	How many cervical cancer patients were put on treatment in the last 3 months?	[ ]		
Q131a	How many patients are on palliative care in this facility?	[ ]		
Q131b	How many patients were put on palliative care in the last 3 months?	[ ]		
Q132	How many patients were put on treatment in the last 3 months? :	Radiotherapy	[ ]	
		Chemotherapy	[ ]	
		Radio-chemotherapy	[ ]	
		Surgical treatment	[ ]	
		Other (specify)_____		
Q133	Does this facility transfer/refer patients to other facilities?	Yes	1	If No skip to Q136a
		No	2	
Q134	Where do you usually transfer/refer patients for other services?	Parirenyatwa Hospital	1	
		Harare Hospital Private hospitals/clinics	2	
			3	

	Multiple selection possible	Private laboratories	4	
		Other(specify)_____ _____		
Q135	What services do you usually transfer/refer patients for?

Multiple selection possible | Laboratory services | 1 | |
		Treatment	2	
		Palliative care	3	
		Radiology	4	
		Other (specify)_____		
Q136a	Do you think most patients diagnosed of cervical cancer have access to treatment and palliative care?	Yes	1	
		No	2	
Q136b	How are most patients paying for cervical cancer treatment or palliative care in this facility?	Own funds	1	
		Medical aid	2	
		NGOs	3	
		Private donors	4	
		Other(specify)_____		
Q136c	Are medical aid schemes fully covering cervical cancer treatment and palliative care in Zimbabwe?	Yes	1	
		No	2	
		Don't know	3	
Q137	What challenges do you think most patients experience in accessing and utilizing treatment and palliative care services?

Multiple selection possible

Probe for more challenges | Lack of transport to go the health centres. | 1 | |
		Lack of finances to pay for the services.	2	
		Few centres offer the specialized services.	3	
		Bad attitude of health professionals	4	
		Stigma from the society	5	
		Stock-outs of drugs (medication) at health facilities.	6	

		Bureaucratic processes in accessing treatment services	7	
		Lack or dysfunctional equipment at health centres.	8	
		Other (specify)_____		
Q138	How do you think these challenges could be overcome to improve access and utilization of cervical cancer treatment and palliative care services? **Multiple responses possible**	Provide free services	1	
		Government to build more health facilities.	2	
		Government to help patients get treatment abroad.	3	
		Government to train and hire more health workers.	4	
		NGOs to establish treating and palliative care centres.	5	
		Government to increase capacity in existing health facilities.	6	
		More funding to health facilities.		
		Other (specify_____	7	

INFRASTRUCTURE					
Electricity and Power					
Q201	What is the main source of electricity for the facility	Mains	1	
		Generator	2	
		Solar panel	3	
		No power supply	4	
		Other (specify)_____		

Q202	Over the past 3 months have you experienced any power interruptions of this source of more than 2 hours?	Yes No	1 2	If no skip to Q205
Q203	How long was the longest interruption?	[ ] hours		
Q204	In the last 2 weeks how many days was electricity from this source interrupted for more than 2 hours at a time?	[ ] days		
Q205	Does this facility have a back-up source of electricity? **Multiple selection possible**	Mains Generator Solar panels Inverter None Other (specify) _____	1 2 3 4 5	
Water and sanitation				

Q206	What is the main source of water for this facility?	Piped from mains	1	
		Borehole	2	
		Tanker	3	
		Bottled water	4	
		Other (specify)_____		
Q207	Over the last 3 months have you experienced water supply interruptions of this source of more than 2 hour?	Yes	1	If no skip to Q210
		No	2	
Q208	How long was the longest interruption?	[ ] hours		
Q209	Over the past 2 weeks, how many days was water from this source interrupted for more than 2 hours at a time?	[ ] Days		
Q210	Does this facility have a back-up water supply **Multiple selection possible**	Piped from mains	1	
		Borehole	2	
		Tanker	3	
		Bottled water	4	
		Other (specify)_____		

Q211a	What type of toilet is available for patients?	**Flush or pour flush toilet**		
		Flush to piped sewer system	1	
		Flush with septic tank	2	
		Flush to pit latrine	3	
		Flush to somewhere else	4	
		Flush, don't know where	5	
		Pit latrine	6	
		Ventilated improved pit latrine		
		Pit latrine with slab	7	
		Pit latrine without slap/open pit		
		Bucket toilet	8	
		No facility/bush/field	9	
		Other (specify)_____		
			10	
			11	
Q211b	How many toilets are available in the facility?	[ ]		
Q211c	How many of the mentioned toilets are currently functioning?	[ ]		
Q212	What is the overall hygiene condition of patient toilets?	Extremely clean and well maintained	1	
		Reasonable clean and maintained		
		Not very clean or maintained	2	
	Observe if possible		3	

Q213	Are there separate toilets for male and female patients?	Yes	1	
		No	2	
Q214	Are there functional (soap and water) hand washing facilities for patients or in the toilets?	Yes	1	
		No	2	
Q215	What method does this facility use in the final disposal of sharps?	**Open burning with the facility**		
		Flat ground-no protection	1	
		Pit or protected ground	2	
		Dump without burning (within facility)		
		Flat ground-no protection		
		Covered pit or pit latrine	3	
		Open pit-no protection	4	
		Protected ground or pit	5	
		Remove off site	6	
		Stored in covered container		
		Stored in other protected environment		
		Stored unprotected	7	
		Burn incinerator		
		Other (specify)_____	8	
			9	
			10	
	Multiple selection possible			

Q216	Is the incinerator functional today?	Yes	1	
		No	2	
Q217	Is the power source for the incinerator available today?	Yes	1	
		No	2	
Q218	Does the facility have guidelines for health care waste management?	Yes	1	
		No	2	

Q219	Have you or any staff member received training in health care waste management practices in the past 2 years?	Yes	1	
		No	2	
Communication				

Q220a	Does the health facility have:		No	Yes	
		Fixed telephone	0	1	
		Mobile phone for facility	0	1	
	Observe if possible	Mobile phone for staff useable by facility	0	1	
		Computer for facility	0	1	
		Short wave radio	0	1	
		Internet access	0	1	
		Health information systems	0	1	
		.			
Q220b	Does your facility have a system to document and monitor the treatment of cervical patients on a regular basis?	Yes	1		
		No	2		
		Don't know	3		
Emergency Transportation and Ambulance services					
Q221	Does the facility have access to ambulance facility for emergency transport?	Yes	1		
		No	2		

Q222	If the facility owns an ambulance is fuel available for use in cases of emergency?	Yes	1	
		No	2	
		Not applicable	3	
Q223	Who pays for ambulance services in emergency situations?	Health facility	1	
		Patients/ Medical aid	2	
		Other (specify) _____		
Q224	Has the facility faced challenges in transporting patients in emergency situations in the last 3 months?	Yes	1	
		No	2	
EQUIPMENT, MATERIALS AND SUPPLIES				
Q225	Does the health facility have adequate basic equipment?	Yes	1	
		No	2	
Q226	Is most equipment in this facility in functional order?	Yes	1	
		No	2	
Q227a	In the last 3 months how many major equipment breakdowns has the facility experienced?	[ ]		
Q227b	How long did it take for the equipment to repaired or replaced?	[ ]	Days	
Q228a	Does the facility have back up equipment for use in casesof major equipment breakdowns?	Yes	1	
		No	2	
Q228b	Does the facility have modern equipment for treating cervical cancer?	Yes	1	
		No	2	
DRUGS AND CONSUMABLES				
Q229	Does the facility have adequate stocks of drugs such as cisplastin for treatment of cervical cancer today?	Yes	1	
		No	2	

Q230	Did the facility experience stock-outs of cisplastin in the last 3 months?	Yes	1	
		No	2	
Q231	How long did the stock-out last?	[ ]	Days	
Q232	Does the facility have adequate analgesics and other medication for palliative care patients today?	Yes	1	
		No	2	
Q233	Did the facility experience stock of outs of analgesics and other medication for palliative care patients in the last 3 months?	Yes	1	
		No	2	
Q234	What contingency plans does the health facility have for major drugs supplies for cervical cancer treatment and management of palliative care patients?	None	1	
		Patient have to buy	2	
		Borrow from other facilities	3	
		Never experience stock-outs	4	
		Other (specify)_____	5	

Interviewer's observations

_____
_____
_____

Comments on specific questions

_____
_____

Any other comments

_____
_____
_____

Remarks: Thank the participant for their time and proceed to the next respondent.

---THE END---

Appendix 10: In-depth interview guide

DISCUSSION QUESTIONS
Note that the subsequent questions are a guide to the qualitative interview: they do not all have to be asked and the interviewer may modify the order and ask additional probing questions. Questions with "[C]'' are applicable to cervical cancer patients/survivors or their partners while those marked "[H]" will be applicable to healthy women and men.
General information • Can you tell me about yourself? Probe for: whether they are cervical cancer survivor, healthy woman or a man, race, place of residence, age, marital status and religion. *Ndinokumbirakutimundiudzenezvenyu.* *Bvunzakutimunhuakararamashurekwekuva ne gomarararemuromowechibereko, munhukadzi, munhurume, rudzi, nzvimboyaanogara, makoreekuberekwa, mamiriroakeekuroorwa/kuroora, ne chitenderochake?*
Knowledge of cervical cancer • Tell me what you have heard about cervical cancer? [H] *Mukandiudzezvamakambonzwanezvegomarararemuromo we chibereko* • Before you were diagnosed of your condition, can you please tell me what you heard about it? [C] *Musatimarwara manga mambonzwanezvegomararairi?* • Why do people not know much about cervical cancer? *Seiko vanhuvasinganyatsozivanezvegomomararaemuromowechibereko?* • Why do some people think that cervical cancer is treatable yet others think it's not treatable? *Seiko vamwevanhuvachifungakutigomorararaemuromowechiberekorinorapikavamwevac hitiharirapikipe?*
Experiences of cervical cancer • Can you tell me about your experiences with cervical cancer in your

household/community? [H]. Probe for dates, age and relationship to participant. *Mungandiudzekutizviizvamakasangananazvomumhuriyenyu /nharaundayenyuzvakanganannegomarararemuromowechibereko?Bvunzapamu soropemazuva, makoreekuberekwa ne hukama*

- Can you tell me more about your diagnosis history for your conditions? [C] *Mungandiudzezvizerepamusoropekuongororwakwenyukutimuzonzimunegomarar aremuromowechibereko?*

- Can you please tell me what treatment and palliative care for cervical cancer would mean to you? If you are/were or your partner or relative is/were on treatment or palliative care what would be your expectation? *Mungandiudzawozvinorevakurwapwa kana kuchengetedzwakweavo vane gomarararemuromowechiberekokwamuri? Imi kana mudiwawenyu kana hamayenyu kana muchirwapwa kana kuchengetwandezvipizvamunotarisirakuwana?*

- Tell me what you know about 1) treatment and 2) palliative (also known as supportive, hospice or terminal) care services for cervical cancer? Probe for sources of information? *Mungandiudzezvamunozivanezve1)kurapwa2) nerutsigirworunopiwanevanochengetavanegomarararemuromowechibereko? Bvunzakutiruzivouruakaruwanakupi?*

- Tell me any experiences you will never forget about cervical cancer?*Ndiudzeiwozvamakasanganganananazvozvamusingafemakakanganwapa musoropegomarararemuromowechibereko?*

Access to cervical cancer treatment and palliative care

- Tell me about access tocervical cancer diagnosis (VIAC, histology and colposcopy), treatment and palliative care services in your community? Probe for reasons? *Munofungakutivanhuvemunharaundayenyuvanokwanisakuwanarubatsironekuon gororwauyenerutsigirokunevanochengetavanorwaranegomarara?*

- Can you explain what you think causes women not to go for regular cervical cancer screening in your community? *Mungatsanangure here zvamunofungaseikomadzimaiasinganyanyoendakunoongororwamuromowechibe rekopachitsvagwauwepohwengomararanguvairipokuzvipatara*?

- Who (classes of people) are most likely to get access to treatment and palliative care for cervical cancer in your community? *Ndezvipizvikwatazvevanhuzvinokwanisakuwanarubatsirorwekurapwa kana kuchengetwa?*

- Describe some of the challenges that you/partner or other member of your family or community have experienced or experience in seeking cervical cancer treatment or palliative care? *Mungatsanangurekutindeapimatambudzikoamunosangananawo /kana anosangananemumwewenyu kana kutivanhuvemunharaundayenyu kana vachidakunorapwa kana kutikunowanarubatsirokuneavovanochengetavanegomarara mu munharaudnayenyu?*

- What causes people to resort to traditional healers, herbalists, prophets and pastors for alternative treatments for cervical cancer? *Ndezvipizvinoitakutivanhuvaendekun'anga, maporofita and mafundisikunotsvagarubatsirorwekurapwagomarararemuromowechibereko?*

- What are some of the reasons why women present at advanced stages of cervical cancer despite health facilities conducting free cervical cancer screening*? Ndezvipizvikonzerozvinoitakutimadzimaiaendekuzvipatararagomarararavorakurai kokuinezvirongwazvekuongorororwamiromoyezviberekokuzvipatarapachena?*

- Why do our people take their very sick relatives (advanced cancer patients) to rural areas where health facilities and doctors are few? *Seiko kana munhuachingearwarisapachivanhupeduachiendeswakumushakubvakumadhorob haikokumishakusinazvipatara kana anachirembavangarapechirwerechakafananananegomorrarararemuromowechibereko ?*

Utilization of cervical cancer treatment and palliative care

- Generally, under what circumstances would you visit a health facility or health professional for consultation?
  Ndezvipizvamungasanganenazvozvingaitekutimuendekuchipatara/kiriniki kana kuonamushandiwezveutano?

- If you or your partner or relative were diagnosed of cervical cancer what would you do? [H] Probe for reasons of response and where you would go for treatment?
  Imi kana kutimumwewenyu kana hamayenyuikabatwagomararaaremuromowechiberekomungaitesei? Bvunzapamusoropezvikonzerozvaitakuti ape mhinduroiyoyouyekutimungaendekupikunorapwa?

- Tell me more about your experiences with cervical cancer treatment from the time of diagnosis (histologically confirmed)? [patient/partner/caregiver] Probe for health facility, traditional healer or prophet and frequency of health facility visits?

  Mungandiudzezvizerepamusoropezavamakasangananazvomukurapwagomararaa remuromowechibereko, kubvapaguvayekuongororwa (mumalebhu)? Bvunzapamusoropekiriniki/chipatara, na'nga, kana muporofitanekutivaendakukiriniki/chipatarakangani?

- Can you tell me if there are instances you have missed appointments or medication for your treatment and if so what were your reasons? [C]
  Mungandiudze kana Mmakamboregedzakuendakwachiremba kana kutoramishongayenyuuyezvikonzerozvakaitakutizvidaro.

- How do you tell your treatment is working or worked? Probe for reasons response? [C]
  Munoona Seiko kutikurapwakwenyukurikushanda kana kutikwakashanda? Bvunzapamusoropezvikonzerozvaitaitakuti ape mhinduroiyoyo.

- Tell me your opinions about the quality of treatment services for cervical cancer patients at health facilities? Probe for reasons?
  Munofungakutinekurapwakurukitwaavo vane gomararaaremuromowechiberekokuzvipatara? Bvunzapamusoropezvikonzero?

- What are some of the issues around treatment of cervical cancer using surgery

(removal of womb) and radiotherapy in your community? *Ndezvipizvimwezvinhuzvinhuzvinotaurikamunharaundayenyupamusoropekurapwakwegomararaemuromowechiberekonenziradzekubviswachibereko kana kutikupiswa?*

- What challenges have you/your partner/relative faced in using treatment or palliative services for your condition? [C]
Ndeapimatambudzikoamakasanganawo kana akasangananemumwewenyumukushandisamushonga kana kuwanarubatsir o runopiwa vane gomararaemuromowechibereko

- What do you think are some of the challenges that cervical cancer patients and their families are facing in using treatment and palliative care services in Harare? [H]*Munofungakutindeapimatambudzikoanosangana ne avovanegomararaemuromowechibereko kana vachidakunorapwa kana kutikunowanarubatsirokunevanochengetavanegomarara mu Harare?*

Health services

- What information have you received from your health facility or community with regards to cervical cancer?
Ndeapimashokoakanangananezvegomararaemuromowechiberekoamakawanakubvakukirinik /kana chipatara kana nharaundayenyu?

- If you or a member of your household were to have signs and symptoms of cervical cancer, what would you do and why?
Kana imi kana mumwemunhuwemunharaundainoakavanezvinoratidza kana kunzwazvinonzwikwanevanegomararaemuromo we chibereko, angaitesei? Seimadaro?

- What are your opinions about people in your community with you regards to seeking treatment early when they suspect cervical cancer?
Munofungakutivanhuvemunharaundayenyuvanotsvagarubatsironguvaichiripo kana vachifungidzirakuti vane gomararaemuromowechibereko?

- Why do you think there are few cervical cancer treatment centres in Zimbabwe despite the high burden of the disease?*Munofunganemhakayeizvipatarazvinorapagomararaemuromowechiber ekozvirizvishomamuZimbabwe?*

- What do you think about getting treatment for cervical cancer abroad compared to being treated locally? *Ndezvipizvamunofungapamusoropekurapwagomararaaremuromomowechiberekokunzekwenyikatichienzanisanemunomunyika?*

- What do you think should be done at this health facility or generally in Zimbabwe to improve cervical cancer treatment and palliative care services? Probe for reasons?
  Ndezvipizvamunofungakutizvinofanirwakuitwamuzvipatara kana makirinikikuvandudzakurapwakwegomararaaremuromomowechibereko ne kuchengetwa /kubatsirwakwe vane gomararairi mu Zimbabwe?

Remarks: Thank the participant for their time and proceed to the next participant.

--**The End**---

Appendix 11: Key informant interview guide

DISCUSSION QUESTIONS

Demographics of respondent

• Can you please tell me more about yourself : Probe for: Age, ethnicity, education, occupation, place of residence, interaction with communities and how long they have been interacting with communities?

Ndinokumbirakutimundiudzezvizerenezvenyu. Bvunza makore ekuberekwa ,rudzi, dzidzoyaakaita,Basaraanoita, nzvimboyaanogara, , kushandakwaanoitanevanhuvemunharaunda?Anemakoremanganiachishandanemnhar aundaiyi?

NON-HEALTH PROFESSIONALS

Knowledge of cervical cancer
- In your opinion do people know about cervical cancer? Probe for general knowledge, causes, signs and symptoms and risk factors.
  Munofungakutivanhuvanozivanezvegomararaemuromowechibereko? Bvunzapamusoroperuzivorwakajairika, zvinokonzera, zvinoratidza and zvinonzwi kwane vanegomarara remuromo wechibereko ,uye zvinonyanya kuita kuti munhu awanegomarara remuromo wechibereko.

- According to your own understanding what do you think are some of the causes, signs and symptoms and risk factors of cervical cancer that you know?

  Mukuzivakwenyuzviizvanozivazvinoratidzanezvinonzwikwanemhunuanegomarar aremuromowechibereko?

- Can you tell me more about people's awareness of preventing cervical cancer in your community?
  Mungandiudzezvizerepamusoroperuzivorwekudziviriragomararaemuromowechi bereko runevanhuvemunharaundayenyu?

- What are some of the measures that can be taken to prevent cervical cancer? Probe for screening and treatment of precancerous lesions, HPV vaccination and male circumcision of partners.

  Ndezvipizvingaitwemukudziviriragomararaemuromowechibereko? Bvunzapamusoropekuongororwanekurapwakwezvirondazvinovapogomarararisat

iratanga, kubayiwamishongayekudzivirira ne kuchecheudzwakwevarume

- What are your opinions of your communitywith regards to risk of developing this disease and why do you say so?
Mungandiudzezvamunofungapamusoropekutivanhuvemunharaundayenyuvaripa njodziyekuva ne gomararaaremuromowechibereko? Uyeseimuchifungakudaro?

Experiences of cervical cancer

- What have been your experiences with cervical cancer survivors?
Ndezvipizvamakasangananazvomukushananevanhuvakararamashuremekuva ne gomararaaremuromowechibereko?

- What are some of the reasons why women go for cervical cancer screening? Probe for routine screening, health problems, health worker advice, friend or relative advice?
Ndezvipizvimwezvikonzerozvinoitakutivanhukadzivaendekunoongororwagomarar aremuromowechibereko?Bvunzapamusoropekuendakunoongororwanguva ne nguva, matambudzikoehutano, kukurudzirwanevanoshandakuzvupatara, ne shamwari kana hama?

- What are your opinions on the awareness of treatment and palliative(also known as supportive, hospice or terminal)services for cervical cancer inyour community?
Munofungakutivanhuvamunharaundayenyuvanozivanezvekurapwanerutsigirworu nopiwaneavovanochengetavanegomararaaremuromowechibereko?

- Tell me more about your knowledge of cervical cancer treatment and palliative care services in Harare? Probe for where the services are offered.
Mungandiudzezvizerepamusoropezvamunozvivapamusoropekurapwagomararar emuromowechibereko kana kunowanikwarubatsirokunevanochengeta vane gomarara mu Harare?Bvunzakutirubatsirorunopiwakupi?

- Can you tell me what you know about support from partners, friends and families for cervical cancer patents in your community?

Mungandiudzezvamunozivapamusoroperutsigirorunopiwavanhu vane gomararaaremuromowechibereko, kubvakunevarumevavo, shamwaridzavopamwe ne mhuridzavomunharaundayenyu?

- How do you think partner, friend or family support help cervical cancer patients?

  Munofungakutivanhuvanegomarararemuromowechiberekovanowanarutsigirorwu pikubvakuvarumevavo, shamwaridzavopamwe ne mhuridzavo

- What roles are churches in Harare playing to support cervical cancer patients? Probe for social, emotional and spiritual support. What are the general perceptions of people in your community with regards to cervical cancer? Probe for attitudes, beliefs, misconceptions and fears?

  Machechi emu Harare arikuitazvipimukuparutsigirokune vane gomarararemuromowechibereko?
  Bvunzapamusoroperubatsirorunechekuitanemagariro, zvavanonzwa ne mweya. Bvunzapamusoropemafungiroakajairikamunharaundayenyuakanangana ne gomarararemuromowechibereko. Bvunzapamusoropemafungiro, zvavanotenda, zvavazingazwisise ne zvavanotya.

Access to cervical cancer treatment and palliative care
- Tell me about cervical cancer treatment and palliative services in health facilities in Harare? Probe for names of health facilities.
  Mungandiudzemaereranonekurapwauyerubatsirorunopiwa ne vanochengeta vane gomarararemuromowechibereko mu Harare? Bvunzamazitaezvipatara/ kana makirinikiaya.

- Can you tell me your opinions about access to treatment and palliative services in Harare? Probe for who has better access and why?
  Mungandiudzemafungiroenyupamusoropekurapwanerutsigirorunopiwanevanoch engetavanorwaranegomarara mu Harare?Ndeananivanowanarubatsirourururinani? Seimadaro?

- Can you tell me what you know about how cervical cancer is treated in health facilities? Probe if there are other means through which cervical cancer may be treated apart from health facilities?
  Mungandiudzezvamunozivapamusoropekurapwakunoitwagomarararemuromowe chiberekorinorapwaseimumakirniki/zvipatara? Bvunza kana pane dzimwenziradzingashandiswekurapagomarararomuromowechiberekokunzekwek uendakuchipatara/kukiriniki?

- Who do you think can best treat and manage cervical cancer and why do you think so?

  Ndiyaniwamunofungakutianogonakurapagomarararemuromowechiberekozvirina niuyeseimuchifunakudaro?

- What are your opinions about service fees for cervical cancer treatment in Harare? Probe for affordability to patients or their families?
  Mungandiudzezvamunofungapamusoropemaridzinodiwakutimunhuarapwegomar araremuromowechiberekomuHarare? Bvunzapamusoro pekukwanisakubhadarakwevarwere ne mhuridzavo?

- What do you think about the availability of treatment services in Harare are adequate to cover all cervical cancer patients? Probe for reasons of response?
  Munofungakutizvipatara /makirinikianowanikwamuHararezvinorapavanhuvanodarubatsirorwakadaizvakakwa na? Bvunzazvekonzerozvaitakuti ape mhinduroyakadai.

  - What do you think about the adequacy of doctors and specialists to treat cervical cancer in Harare? Probe for reasons of response?
    Munofungakuti mu Harare anachirembanaanamazvikokotavanorapagomarararemuromowechiberokovanok wana? Bvunzapamusoropemhinduroyawapiwa?

  - Do you think about the training of doctors and specialists to   provide good treatment services to cervical cancer patients?
    Munofungakutianachirembanaanamazvikokotavakadzidziswazvakakwanakutivar apevanhuzvakanaka?

  - What do you know about   palliative care in health facilities in Harare? Probe for names of some of the facilities?
    Zvizvamunofungapamusoropenzvimbodzinochengeta/ kubatsira vane gomarararemuromowechibereko mu Harare?

  - Tell me what you know/think about the adequacy of palliative services to cover the patients who need such services?

    Munofungakutizvipatara

/makirinikianorapavanhuvanodarubatsirorwakadaizvakakwana?

- Describe some the challenges that patients in your community have experienced [or experience] in trying to access cervical cancer treatment or palliative care? *Mungatsanangurekutindeapimatambudzikoanosangananeavo vane gomarararemuromowechibereko kana vachidakunorapwa kana kutikunowanarubatsirokuneavovanochengetavanegomarara mu munharaudnayenyu?*

Utilization of cervical cancer treatment and palliative care

- Can you tell me more about yourunderstanding of health seeking behaviors by women in your community for treatment and palliative services for cervical cancer in Harare? *Mungandiudzezvizerepamusoropemazvamunonzwisisapamusoropenziradzinotsvagwanayorubatsiro ne vanhukadzivemunharaundayenyuzvakanangananekurapwa kana kuwanarutsigiromu Harare zvinechekuitanegomarararemuromowechibereko.*

- In your opinion do think your community understands well treatment and palliative services offered for cervical cancer in health facilities? *Munofungakutivanhuvemunharaundayenyuvanonzwisisazvakakwanapamusorokurapwanekubatsirwakurukitwaavo vane gomarararemuromowechiberekokunoshandamumakiriniki/ zvipatara?*

- To your knowledge, tell me more about the treatment and palliative services being accessed by women in your community? *Mukuzivakwenyu, mungandiudzezvizerepamusoropekurapwa and kuchengetwa/kubatsirwakunoitwavanhukadziveraimunharaundayenyu?*

- What is your opinion of the effectiveness of treatment and palliative services provided in health facilities in Harare? *Munofungakutikurapwakurukitwaavo vane gomarararemuromowechiberekomumakiriniki kana zvipatara e/zvemuHararekunoshanda here?*

- What do you think are some of the challenges that cervical cancer patients and their families are facing in using treatment and palliative care services in Harare? *Munofungakutindeapimatambudzikoanosangana ne avovanegomarararemuromowechibereko kana vachidakunorapwa kana kutikunowanarubatsirokunevanochengetavanegomarara mu Harare?*

Health services

- Tell me about the information that health facilities provide about cervical cancer to your community?
  Ndeapimashokoakanangana negomarararemuromowechiberekoamakawanakubvakukiriniki /kana chipataraemunharaundayenyu.

- According your understanding, what are the experiences of women when they notice signs and symptoms for cervical cancer? Probe about early health seeking behaviors?
  Mukunzwisisakwenyuvanhukadzivanosangananezvipi kana vakaona kana kunzwazvinoratidzakuti vane gomarararemuromowechibereko?Bvunzapamusoropekuendakunorapwapachirin enguva?

- What are your opinions about adequacy of equipment, drugs, beds and other infrastructure to provide cervical treatment and palliative care in health facilities in Harare?
  Mukufungakwenyumakiriniki/zvipatara e/zvemu Harare zvinezvakakwanazvakaita se mishini, mibhedha, mishonga ne zvimwezvakadarozvinoshandiswamukurapanekuchengeta vane gomarararemuromowechibereko

- What are your opinions about the adequacy of health workers (nurses, nurse aids, doctors, specialists, pharmacists, radiographers and laboratory scientists) to provide treatment and palliative care of cervical cancer patients in health facilities in Harare?

  Munofungakutimakiriniki/zvipatarazvinevashandivakakwana (anamukoti, anachiremba, anamazvikokota, vanopamishonganevanoshandamumalebhu) vakakwanauyevachikwanisakurapanekuchengeta vane gomarararemuromowechibereko?

- Can you tell me more about your opinions on the fees that are charged for treatment services by your health facility?
  Mungandiudzezvizerepamusoropemafungiroenyupamaridzinodiwakutivanhuvara pwemumakiriniki kana zvipatara?

- To your knowledge what are the experiences of patient who cannot pay or do not

afford to pay for treatment or other procedures at health facilities?

Mukuzivakwenyuvarhwerevasingakwanisekubhadaramaridzinodiwakukiriniki /chipatarakutivarapwevanosangananei?

- What are your perceptions on the quality of services provided at health facilities? Probe for attitudes of nurse aids, nurses, doctors, specialists, radiographers, pharmacists and other health workers?
Mukufungakwenyumungatimhandoyekurapwa/mashandirwoemumakiriniki/zvipat arayakamirasei? Bvunzapamusoropemapfungiroevakoti, anachiremba, anamazvikokota, nevanopamishonganevamwevashandivemuzvipatara?

- In your opinion what are the perceptions and attitudes of your local leadership (herdmen, counsellors, and chiefs) on people   using health services when they are sick or for routine checkups?
Mukuwonakwenyu, akamiraseimafungiroevatungamirivenharaundayako(mahedhimeni, makhanselananamambo) zvakangananekuendakwevanhukuzvipatara/makiriniki kana vachirwara kana kutikunoongororwazvisineikutihavazikurwara?.

- What do you think should be done at health facilities and generally in Zimbabwe to improve cervical cancer treatment and palliative care services?
Ndezvipizvamunofungakutizvinofanirwakuitwamuzvipatara kana makirinikikuvandudzakurapwakwegomarararemuromowechibereko ne kuchengetwa /kubatsirwakwe vane gomararairi mu Zimbabwe?

HEALTH WORKERS, ACADEMICS AND POLICY MAKERS

- Why do you think cervical cancer knowledge is still scarce in Zimbabwe?

- In your professional opinion why are most women not screening for cervical cancer in Harare (ZDHS 2015 reported 24% and our study 29% in Harare had ever been screened for Ca Cx)?

- Why do you think most women have no access to ca cx diagnosis and treatment in Harare?

- What is your opinion of ca cx case definition in Zimbabwe and why is it taking

- long to establish diagnosis for early cases in both the private and public health systems in Harare?

- What are the diagnosis and treatment procedures of different stages of ca cx including reference guidelines that you use in your practice or in Zimbabwe?

- Why does Zimbabwe not have documented standard guidelines for the diagnosis and management of cervical cancer?

- What are some of the causes of late presentation by cervical cancer patients in Harare?

- In communities' total abdominal hysterectomy (TAH) and radiotherapy as treatment procedures for ca cx are received with mixed feelings, what do you think are some of the issues with these procedures?

- What are the estimated costs of diagnosis and treatment procedures in private and public sector in Harare?

- What is your understanding of palliative care and how it is integrated with treatment for ca cx? Probe for reasons why palliative care is poorly developed or integrated into treatment and care of ca cx?

- Why is palliative care not known in Harare including by Ca Cx patients?

- What are your perceptions on spiritual and traditional healing interventions used by some of your ca cx patients?

- Can you give your opinion on the status of the healthcare system in Zimbabwe?

- Can you please describe and explain some of the clinical challenges you face in managing ca cx? Probe for challenges of diagnosis and treatment of ca cx?

- What are some of the challenges with our current policies for cervical cancer in Zimbabwe?

- What policy recommendations would you propose for Zimbabwe in relationship to improving ca cx diagnosis and treatment?

- What are some of the programmatic recommendations that can be implemented to improve access to treatment and palliative care of ca cx and your reasons for them?

Remarks: Thank the participant for their time and proceed to the next one!

-------The End------------

Appendix 12: Focus discussion guide

Introductory questions

- To get started, let's introduce ourselves.
  Kuitirakutititangengatizivisaneikutitiriananai

- Can each person say who they are: health woman (HW), man or partner of cervical cancer patient/survivor (M) or cervical cancer patient/survivor? (CP)
  Mumwenemumwengaataurekutiakamirasei; Munhukadzianehutano, murume kana mumwe we munhuanorwara ne gomararaaremuromowechibereko/ akararamashurekwekuva ne gomarararechibereko

- Can each person say where they stay?
  Tinokumbiramutiudzekutimunogarakupi.

Knowledge of cervical cancer

- Tell us what you have heard about cervical cancer?
  Mungatiudzewozvamakambonzwanezvegomarararemuromo we chibereko

- Why do people not know much about cervical cancer?

  Seiko vanhuvasinganyatsozivanezvegomomararemuromowechibereko?

- Why do some people think that cervical cancer is treatable yet others think it's not treatable? *Seiko vamwevanhuvachifungakutigomorararemuromowechiberekorinorapikavamwevachitiharirapikipe?*

Experiences of cervical cancer

- Can you tell us more about your/partner/community memberexperiences with regards to cervical cancer diagnosis?
  Mungatiudzewozvizerepamusoropekuongororwakwenyu/mumwewenyu/mumwe munhuwemunharaundayenyukutizvizonzi panegomarararemuromowechibereko?

- Can you please tell us what treatment and palliative care for cervical cancer would mean to you? If you are/were or your partner or relative is/were on treatment or palliative care what would be your expectation? *Mungatiudzewozvinorevakurwapwa kana kuchengetedzwakweavo vane gomarararemuromowechiberekokwamuri? Imi kana mudiwawenyu kana hamayenyu kana muchirwapwa kana kuchengetwandezvipizvamunotarisirakuwana?*

- Tell us what you know about 1) treatment and 2) palliative (also known as supportive, hospice or terminal) care services for cervical cancer? Probe for sources of information?
  Mungatiudzewozvamunozivanezve1)kurapwa2) nerutsigirworunopiwanevanochengetavanegomarararemuromowechibereko? Bvunzakutiruzivouruakaruwanakupi?

Access to cervical cancer treatment and palliative care

- Tell us about access tocervical cancer diagnosis (VIAC, histology and colposcopy), treatment and palliative care services in your community? Probe for

reasons?
Tiudzeiwokutivanhuvemunharaundayenyuvanokwanisakuwanarubatsironekuong ororwauyenerutsigirokunevanochengetavanorwaranegomarara?

- Can you explain what you think causes women not to go for regular cervical cancer screening in your community? *Mungatsanangure here zvamunofungaseikomadzimaiasinganyanyoendakunoongororwamuromowechibe rekopachitsvagwauwepohwengomararanguvairipokuzvipatara*?

- Who (classes of people) are most likely to get access to treatment and palliative care for cervical cancer in your community?
Ndezvipizvikwatazvevanhuzvinokwanisakuwanarubatsirorwekurapwa kana kuchengetwa?

- Describe some of the challenges that you/partner or other member of your family or community have experienced or experience in seeking cervical cancer treatment or palliative care?
Mungatsanangurekutindeapimatambudzikoamunosangananawo /kana anosangananemumwewenyu kana kutivanhuvemunharaundayenyu kana vachidakunorapwa kana kutikunowanarubatsirokuneavovanochengetavanegomarara mu munharaudnayenyu?

- What causes people to resort to traditional healers, herbalists, prophets and pastors for alternative treatments for cervical cancer?
Ndezvipizvinoitakutivanhuvaendekun'anga, maporofita and mafundisikunotsvagarubatsirorwekurapwagomararaaremuromowechibereko?

- What are some of the reasons why women present at advanced stages of cervical cancer despite health facilities conducting free cervical cancer screening across the country*?
Ndezvipizvikonzerozvinoitakutimadzimaiaendekuzvipatararagomararaavorakurai kokuinezvirongwazvekuongororrorwamiromoyezviberekokuzvipatarapachenamun yika?*

- Why do our people take their very sick relatives (advanced cancer patients) to rural areas where health facilities and doctors are few? *Seiko kana*

munhuachingearwarisapachivanhupeduachiendeswakumushakubvakumadhorob haikokumishakusinazvipatara kana anachirembavangarapechirwerechakafananenegomorrararemuromowechibereko ?

Utilization of cervical cancer treatment and palliative care

- Generally, under what circumstances would you visit a health facility or health professional for consultation? *Ndezvipizvamungasanganenazvozvingaitekutimuendekuchipatara/kiriniki kana kuonamushandiwezveutano?*

- If you or your partner or relative were diagnosed of cervical cancer what would you do? Probe for reasons of response and where you would go for treatment? *Imi kana kutimumwewenyu kana hamayenyuikabatwagomarararemuromowechiberekomungaitesei? Bvunzapamusoropezvikonzerozvaitakuti ape mhinduroiyoyouyekutimungaendekupikunorapwa?*

- Can you tell us if there are instances you/partner/relative/community memberhave missed appointments or medication for your treatment and if so what were your reasons? *Mungandiudze kana imi/mumwewenyu/hama/mumwewowemunharaundayenyuakamboregedzakuend akwachiremba kana kutoramishongayekurapagomarararemuromowechiberekouyezvikonzerozvakaita kutizvidaro?*

- How do you tell your treatment is working or worked? Probe for reasons of response? *Munoonaseikokutikurapwakwenyukurikushanda kana kutikwakashanda? Bvunzapamusoropezvikonzerozvaitaitakutivape mhinduroiyoyo.*

- Tell us your opinions about the quality of treatment services for cervical cancer patients at health facilities? Probe for reasons? *Tiudzeiwopamusoroperubatsirorwekurapwakurukuitwaavo vane gomarararemuromowechiberekokuzvipatara? Bvunzapamusoropezvikonzero?*

- What are some of the issues around treatment of cervical cancer using surgery

333

(removal of womb) and radiotherapy in your community?
Ndezvipizvimwezvinhuzvinotaurikamunharaundayenyupamusoropekurapwakweg omarararemuromowechiberekonenziradzekubviswachibereko kana kutikupiswa?

- What challenges have you/your partner/relative/community member faced in using treatment or palliative services for your condition?
Ndeapimatambudzikoamakasanganawo kana akasangananemumwewenyu kana hamayenyu kana mumwewomunhuwemunharaundayenyumukushandisamushonga kana kuwanarubatsir o runopiwa vane gomarararemuromowechibereko

- What do you think are some of the challenges that cervical cancer patients and their families are facing in using treatment and palliative care services in Harare?
Munofungakutindeapimatambudzikoanosangana ne avovanegomarararemuromowechibereko kana vachidakunorapwa kana kutikunowanarubatsirokunevanochengetavanegomarara mu Harare?

Health services

- What information have you received from your health facility or community with regards to cervical cancer?
Ndeapimashokoakanangananezvegomarararemuromowechiberekoamakawanak ubvakukiriniki /kana chipatara kana nharaundayenyu?

- If you or a member of your household were to have signs and symptoms of cervical cancer, what would you do and why?
Kana imi kana mumwemunhuwemunharaundainoakavanezvinoratidza kana kunzwazvinonzwikwanevanegomarararemuromo we chibereko, angaitesei? Seimadaro?

- What are your opinions of people in your community with you regards to seeking treatment early when they suspect cervical cancer?
Munofungeipamusoropevanhuvemunharaundayenyupakutsvagarubatsironguvaic hiripo kana vachifungidzirakuti vane gomarararemuromowechibereko?

- Why do you think there are few cervical cancer treatment centres in Zimbabwe despite the high burden of the disease?*Munofunganemhakayeizvipatarazvinorapagomarararemuromowechiber*

ekozvirizvishomamuZimbabwe?

- What do you think about getting treatment for cervical cancer abroad compared to being treated locally? *Ndezvipizvamunofungapamusoropekurapwagomararaaremuromowechiber ekokunzekwenyikatichienzanisanemunomunyika?*

- What do you think should be done in Zimbabwe to improve cervical cancer treatment and palliative care services? Probe for reasons? *NdezvipizvamunofungakutizvinofanirwakuitwamuZimbabwekuvandudzakurapwa kwegomararaaremuromowechiberekonekuchengetwa /kubatsirwakwe vane gomararairi mu Zimbabwe?*

Remarks: Thank the participants for their time.

---**The End**--

Appendix 13: Informed Consent Form (For Patients and Community)

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

Principal Investigator: **Oscar Tapera [University of Pretoria, PhD candidate]**

Phone number(s):**+263 772549345**

What you should know about this research study:

- We give you this consent form so that you may read about the purpose, risks, and benefits of this research study.

- The main goal of research study is to gain knowledge about access and utilization of cervical cancer treatment and palliation services that may help future patients.

- We cannot promise that this research will benefit you in any direct manner; however the information will be used to understand cervical cancer treatment and palliative care services in order to develop a model strategy for Zimbabwe.

- You have the right to refuse to take part, or agree to take part now and change your mind later.

- Your decision to participate or not to participate in this study will not affect your participation in any health programmes in Zimbabwe.

- Please read this consent form carefully. Ask any questions before you make a decision. You will be given a copy of this consent form to keep.

- Your participation is voluntary.

PURPOSE OF STUDY

You are being asked to participate in a research study being conducted by Mr Oscar Tapera for the fulfilment of his PhD studies. The purpose of thestudy is to understand access and utilization of cervical cancer treatment and palliative (also known as supportive, hospice or terminal) services in Harare. You have been selected to participate in this study because we believe that your experiences and your opinions will enable us to obtain better understanding of cervical cancer treatment and palliative care in Zimbabwe.

PROCEDURES AND DURATION

A total of 220 participants will be randomly selected to take part in this study in selected health facilities, urban areas and rural areas communities in Harare. If you take part in this study, you will be asked a series of questions about yourself/household, your views, opinions, experiences and knowledge to understand cervical cancer treatment and palliative services in Harare. Your responses will be helpful to us as we try to understand the factors that influence access and usage of cervical cancer treatment and palliation services in Zimbabwe. This interview will take about 45 minutes. Data collected during interviews/discussions will be recorded using smartphones.

RISKS AND DISCOMFORTS

No physical, social, legal and ethical risks are expected for this research. However, there might be very minimal psychological effects with regard to discussing your health issues. We will also take up some of your time during the interview. In the event that the interview is affecting you psychologically please advise us so that we may discontinue the interview and invite a health professional to provide you with counselling services. We have made prior arrangements with local health facilities so that you may receive counselling should you be affected psychologically by your participation in this study. We also provide you with information sheet with contact numbers of local health facilities or professionals whom you may contact should you need some counselling after the interviews.

BENEFITS AND/OR COMPENSATION

You will not directly benefit by participation in this study. However, the information gathered in this study may help with better understanding of treatment services that are being provided for cervical cancer patients and may also be used to improve current and future programmes in the country.

CONFIDENTIALITY

Some identifying information such as locality names, household names and hospital number will be collected in this study but these will be kept confidential. All identifying information will be de-identified at analysis stage. No identifying information will be reported in this study. The results of this study may be shared with Ministry of Health and Child Care, World Health Organization and other stakeholders involved with cervical cancer treatment. The information from this study may help develop effective strategies and programmes for cervical cancer treatment in Zimbabwe. Any materials related to this study will be kept in secure and safe places, under lock and key cabinets or password protected folders and will only be accessible to the researcher and his supervisors.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with any health service provider or health facility. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty. You are also free not to answer questions that you are not comfortable with.

OFFER TO ANSWER QUESTIONS

Before you agree to participate in this study, please ask any questions on any aspect that is unclear to you. You may take as much time as necessary to think over it.

AUTHORIZATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

_____   _____

Name of Research Participant (please print)   Date/time

_____

Signature of Participant

_____   _____ _____

Name of Person Obtaining Consent   Signature   Date/time

_____   _____ _____

Name of Witness (*if required)*   Signature Date/time

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been

treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Research Ethics Committee, University of Pretoria, Faculty of Health Sciences on telephone +27(12)3563084 or Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines 0784 956 128.   The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

Appendix 14: Informed Consent Form (ForHealth Worker Survey)

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

Principal Investigator: **Oscar Tapera [University of Pretoria, PhD candidate]**

Phone number(s):**+263 772549345**

What you should know about this research study:

- We give you this consent form so that you may read about the purpose, risks, and benefits of this research study.

- The main goal of research study is to gain knowledge about access and utilization of cervical cancer treatment and palliation services that may help future patients.

- We cannot promise that this research will benefit you in any direct manner; however the information will be used to understand cervical cancer treatment and palliative care services in order to develop a model strategy for Zimbabwe.

- You have the right to refuse to take part, or agree to take part now and change your mind later.

- Your decision to participate or not to participate in this study will not affect your participation in any health programmes, your work or interactions with communitiesin Zimbabwe.

- Please read this consent form carefully. Ask any questions before you make a decision. You will be given a copy of this consent form to keep.

- Your participation is voluntary.

PURPOSE OF STUDY

You are being asked to participate in a research study being conducted by Mr Oscar Tapera for the fulfilment of his PhD studies. The purpose of thestudy is to understand access and utilization of cervical cancer treatment and palliative (also known as supportive, hospice or terminal) services in Harare. You have been selected to participate in this study because we believe that your experiences and your opinions will enable us to obtain better understanding of cervical cancer treatment and palliative care in Zimbabwe.

PROCEDURES AND DURATION

A total of 60health worker participants will be randomly selected to take part in this study in three health facilities providing cervical cancer treatment and palliative care services in Harare.   If you take part in this study, you will be asked some questionsabout your views, opinions, experiences and knowledge about cervical cancer treatment and palliation services in Harare. This information will be helpful in our understanding of health services issues that influence access and usage of treatment and palliation services by cervical cancer patients. This interview will take about30minutes. Data collected during interviews/ will be recorded using smartphones.

RISKS AND DISCOMFORTS

No physical, social, legal, professional and ethical risks are expected for this research. We will take up some of your time during the interview.

BENEFITS AND/OR COMPENSATION

You will not directly benefit by participation in this study. However, the information gathered in this study may help with better understanding of treatment services that are being provided for cervical cancer patients and may also be used to improve current and future programmes in the country.

CONFIDENTIALITY

Some identifying information such as age, number of years of professional experience , health facility names and name of profession will be collected in this study but these will be kept confidential. All identifying information will be de-identified at analysis stage. No identifying information will be reported in this study. The results of this study may be shared with Ministry of Health and Child Care, World Health Organization and other stakeholders involved with cervical cancer treatment. The information from this study may help develop effective strategies and programmes for cervical cancertreatment in Zimbabwe. Any materials related to this study will be kept in secure and safe places, under lock and key cabinets or password protected folders and will only be accessible to the researcher and his supervisors.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with your employer or professional body or communities or other organizations dealing with cervical cancer**.** If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty. You are also free not to answer questions that you are not comfortable with.

OFFER TO ANSWER QUESTIONS

Before you agree to participate in this study, please ask any questions on any aspect that is unclear to you. You may take as much time as necessary to think over it.

AUTHORIZATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

_____   _____

Name of Research Participant (please print)   Date/Time

_____

Signature of Participant

_____   _____ _____

Name of Person Obtaining Consent   Signature   Date/Time

_____   _____

Name of Witness (*if required)*   Signature   Date/Time

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact theResearch Ethics Committee, University of Pretoria, Faculty of Health Sciences on telephone +27(12)3563084 or Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines 0784 956 128.   The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

Appendix 15: Informed Consent Form (For In-Depth Interviews)

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

Principal Investigator: **Oscar Tapera [University of Pretoria, PhD candidate]**

Phone number(s):**+263 772549345**

What you should know about this research study:

- We give you this consent form so that you may read about the purpose, risks, and benefits of this research study.

- The main goal of research study is to gain knowledge about access and utilization of cervical cancer treatment and palliation services that may help future patients.

- We cannot promise that this research will benefit you in any direct manner; however the information will be used to understand cervical cancer treatment and palliative care services in order to develop a model strategy for Zimbabwe.

- You have the right to refuse to take part, or agree to take part now and change your mind later.

- Your decision to participate or not to participate in this study will not affect your participation in any health programmesin Zimbabwe.

- Please read this consent form carefully. Ask any questions before you make a decision. You will be given a copy of this consent form to keep.

- Your participation is voluntary.

PURPOSE OF STUDY

You are being asked to participate in a research study being conducted by Mr Oscar Tapera for the fulfilment of his PhD studies. The purpose of thestudy is to understand access and utilization of cervical cancer treatment and palliative (also known as supportive, hospice or terminal) services in Harare. You have been selected to participate in this study because we believe that your experiences and your opinions will enable us to obtain better understanding of cervical cancer treatment and palliative care in Zimbabwe.

PROCEDURES AND DURATION

A total of 15 participants will take part in this study in health facilities, urban and rural areas in Harare. If you take part in this study, you will be asked some questions about your views, opinions, experiences and knowledge about cervical cancer treatment and palliative services in Harare. Your responses will help us understand some of the issues influencing access and usage of cervical cancer treatment and palliative care services

in Zimbabwe. This interview will take about an hour (60 minutes). Data collected during discussions will be recorded using audio-recorder and in writing using notebooks.

RISKS AND DISCOMFORTS

No physical, social, legal and ethical risks are expected for this research. However, there might be very minimal psychological effects with regard to discussing your health issues. We will also take up some of your time during the interview. In the event that the interview is affecting you psychologically please advise us so that we may discontinue the interview and invite a health professional to provide you with counselling services. We have made prior arrangements with local health facilities so that you may receive counselling should you be affected psychologically by your participation in this study. We also provide you with information sheet with contact numbers of local health facilities or professionals whom you may contact should you need some counselling after the interviews.

BENEFITS AND/OR COMPENSATION

You will not directly benefit by participation in this study. However, the information gathered in this study may help with better understanding of treatment services that are being provided for cervical cancer patients and may also be used to improve current and future programmes in the country.

CONFIDENTIALITY

Some identifying information such as locality names, household names and hospital number will be collected in this study but these will be kept confidential. All identifying information will be de-identified at analysis stage. No identifying information will be reported in this study. The results of this study may be shared with Ministry of Health and Child Care, World Health Organization and other stakeholders involved with cervical cancer treatment. The information from this study may help develop effective strategies and programmes for cervical cancer treatment in Zimbabwe. Any materials related to this study will be kept in secure and safe places, under lock and key cabinets or password protected folders and will only be accessible to the researcher and his supervisors.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with any health service provider or health

facility**.** If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty. You are also free not to answer questions that you are not comfortable with.

OFFER TO ANSWER QUESTIONS

Before you agree to participate in this study, please ask any questions on any aspect that is unclear to you. You may take as much time as necessary to think over it.

AUTHORIZATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

STATEMENT OF CONSENT TO BE AUDIOTAPED.

I understand that audio recordings will be taken during the study. *(For each statement, please choose YES or NO by inserting your initials in the relevant box)*

- I agree to **being audio recorded**   **Yes** ☐

                                                                                   No ☐

_____   _____

Name of Research Participant (please print)   Date/time

_____

Signature of Participant

_____   _____   _____

Name of Person Obtaining Consent   Signature   Date/time

_____   _____   _____

Name of Witness (*if required*)   Signature   Date/time

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Research Ethics Committee, University of Pretoria, Faculty of Health Sciences on telephone +27(12)356308 or Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines 0784 956 128.   The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

Appendix 16: Informed Consent Form (For Key Informants)

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

Principal Investigator: **Oscar Tapera [University of Pretoria, PhD candidate]**

Phone number(s):**+263 772549345**

What you should know about this research study:

- We give you this consent form so that you may read about the purpose, risks, and benefits of this research study.

- The main goal of research study is to gain knowledge about access and utilization of cervical cancer treatment and palliation services that may help future patients.

- We cannot promise that this research will benefit you in any direct manner; however the information will be used to understand cervical cancer treatment and palliative care services in order to develop a model strategy for Zimbabwe.

- You have the right to refuse to take part, or agree to take part now and change your mind later.

- Your decision to participate or not to participate in this study will not affect your participation in any health programmes or your work or interactions with communitiesin Zimbabwe.

- Please read this consent form carefully. Ask any questions before you make a decision. You will be given a copy of this consent form to keep.

- Your participation is voluntary.

PURPOSE OF STUDY

You are being asked to participate in a research study being conducted by Mr Oscar Tapera for the fulfilment of his PhD studies. The purpose of thestudy is to understand access and utilization of cervical cancer treatment and palliative (also known as supportive, hospice or terminal) services in Harare. You have been selected to participate in this study because we believe that your experiences and your opinions will enable us to obtain better understanding of cervical cancer treatment and palliative care in Zimbabwe.

PROCEDURES AND DURATION

A total of 15 key informant participants will be selected to take part in this study in urban and rural communities of Harare. If you take part in this study, you will be asked a series of questions to understand cervical cancer treatment and palliative servicesabout your views, opinions, experiences and knowledge about cervical cancer treatment and palliation services in Harare. This information will be helpful in our understanding of issues that influence access and usage of treatment and palliation services by cervical

cancer patients. This interview will take between about hour (60 minutes).Data collected during interviews/discussions will be recorded using audio-recorder and in writing using notebooks.

RISKS AND DISCOMFORTS

No physical, social, legal, professional or ethical risks are expected for this research. We will take up some of your time during the interview.

BENEFITS AND/OR COMPENSATION

You will not directly benefit by participation in this study. However, the information gathered in this study may help with better understanding of treatment services that are being provided for cervical cancer patients and may also be used to improve current and future programmes in the country.

CONFIDENTIALITY

Some identifying information such as age, number of years of professional experience, where you work and name of your profession/occupation will be collected in this study but these will be kept confidential. All identifying information will be de-identified at analysis stage. No identifying information will be reported in this study. The results of this study may be shared with Ministry of Health and Child Care, World Health Organization and other stakeholders involved with cervical cancer treatment. The information from this study may help develop effective strategies and programmes for cervical cancer treatment in Zimbabwe. Any materials related to this study will be kept in secure and safe places, under lock and key cabinets or password protected folders and will only be accessible to the researcher and his supervisors.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with your employer or professional body or communities or other organizations dealing with cervical cancer. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty. You are also free not to answer questions that you are not comfortable with.

OFFER TO ANSWER QUESTIONS

Before you agree to participate in this study, please ask any questions on any aspect that is unclear to you. You may take as much time as necessary to think over it.

AUTHORIZATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

STATEMENT OF CONSENT TO BE AUDIOTAPED.

I understand that audio recordings will be taken during the study. *(For each statement, please choose **YES or NO** by inserting your initials in the relevant box)*

- I agree to **being audio recorded**   **Yes**   ☐

                                              No   ☐

_____   _____

Name of Research Participant (please print)   Date/time

_____

Signature of Participant

_____   _____   _____

Name of Person Obtaining Consent   Signature   Date/time

_____   _____

Name of Witness (*if required*)   Signature   Date/time

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Research Ethics Committee, University of Pretoria, Faculty of Health Sciences on telephone +27(12)3563084 or Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines

0784 956 128.   The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

Appendix 17: Informed Consent Form (For Focus Groups)

Study title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe.

Principal Investigator: **Oscar Tapera [University of Pretoria, PhD candidate]**

Phone number(s):**+263 772549345**

What you should know about this research study:

- We give you this consent form so that you may read about the purpose, risks, and benefits of this research study.

- The main goal of research study is to gain knowledge about access and utilization of cervical cancer treatment and palliation services that may help future patients.

- We cannot promise that this research will benefit you in any direct manner; however the information will be used to understand cervical cancer treatment and palliative care services in order to develop a model strategy for Zimbabwe.

- You have the right to refuse to take part, or agree to take part now and change your mind later.

- Your decision to participate or not to participate in this study will not affect your participation in any health programmesor your work or interactions with communities in Zimbabwe.

- Please read this consent form carefully. Ask any questions before you make a decision. You will be given a copy of this consent form to keep.

- Your participation is voluntary.

PURPOSE OF STUDY

You are being asked to participate in a research study being conducted by Mr Oscar Tapera for the fulfilment of his PhD studies. The purpose of thestudy is to understand access and utilization of cervical cancer treatment and palliative (also known as supportive, hospice or terminal) services in Harare. You have been selected to participate in this study because we believe that your experiences and your opinions will enable us to obtain better understanding of cervical cancer treatment and palliative care in Zimbabwe.

PROCEDURES AND DURATION

Between 48 and 72 participants will take part in this study in health facilities, urban and rural areas in Harare. Participants will be organized into 6 groups for some discussions. If you take part in this study, you will be asked some questions to hear your views, opinions, experiences and knowledge in groups of 8 -12 people to understandabout cervical cancer treatment and palliative services in Harare. The groups in which you will be organized will comprise of different people and these will include: men from Harare urban and rural communities aged at least 25 years old with knowledge or some experience with cervical cancer, men who are partners of women with cervical cancer, healthy women, women with cervical cancer or a history of cervical cancer, health professionals, community leaders, pastors, prophets, traditional healers and

programmes managers from NGOs working in cervical cancer programmes. These discussions will take about one hour (60 minutes). Data collected during discussions will be recorded using audio-recorders and some notes will also be taken in notebooks.

RISKS AND DISCOMFORTS

No physical, social, legal and ethical risks are expected for this research. However, there might be very minimal psychological effects with regard to discussing your health issues. We will also take up some of your time during the discussions. In the event that the discussion is affecting you psychologically please advise us so that we may discontinue your participation and invite a health professional to provide you with counselling services. We have made prior arrangements with local health facilities so that you may receive counselling should you be affected psychologically by your participation in this study. We also provide you with information sheet with contact numbers of local health facilities or professionals whom you may contact should you need some counselling after the discussions.

BENEFITS AND/OR COMPENSATION

You will not directly benefit by participation in this study. However, the information gathered in this study may help with better understanding of treatment services that are being provided for cervical cancer patients and may also be used to improve current and future programmes in the country. We will compensate you with $6after each discussion to cover your travelling expensesshould you have travelled to discussion venue.

CONFIDENTIALITY

Some identifying information such as locality names, household names and hospital number will be collected in this study but these will be kept confidential. All identifying information will be de-identified at analysis stage. No identifying information will be reported in this study. The results of this study may be shared with Ministry of Health and Child Care, World Health Organization and other stakeholders involved with cervical cancer treatment. The information from this study may help develop effective strategies and programmes for cervical cancer treatment in Zimbabwe. Any materials related to this study will be kept in secure and safe places, under lock and key cabinets or password protected folders and will only be accessible to the researcher and his supervisors.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with any health service provider or health facilityor your employer or professional body or communities or other organizations dealing with cervical cancer**.** If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty. You are also free not to answer questions that you are not comfortable with.

OFFER TO ANSWER QUESTIONS

Before you agree to participate in this study, please ask any questions on any aspect that is unclear to you. You may take as much time as necessary to think over it.

AUTHORIZATION

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

STATEMENT OF CONSENT TO BE AUDIOTAPED.

I understand that audio recordings will be taken during the study. *(For each statement, please choose **YES or NO** by inserting your initials in the relevant box)*

- I agree to **being audio recorded**   **Yes**   ☐

                                                      No   ☐

_____   _____

Name of Research Participant (please print)   Date/time

_____

Signature of Participant

_____   _____   _____

Name of Person Obtaining Consent   Signature   Date/time

_____   _____   _____

Name of Witness (*if required)*   Signature   Date/time

YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact theResearch Ethics Committee, University of Pretoria, Faculty of Health Sciences on telephone +2712-3563084 or Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04) 791193 and cell phone lines 0784 956 128.   The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

Appendix 18: UP, Academic Committee Approval of PhD Protocol

Faculty of Health Sciences

29 September 2017

MR OSCAR TAPERA
(16404158)
PhD (Health Systems)

Dear Mr Tapera

Approval Academic Advisory Committee: Protocol

This letter confirms that your PhD protocol was served and approved by the Research Committee on 29 September 2017 after a successful protocol defence. One internal and two external reviewers attended your PhD protocol defence and also reviewed your PhD protocol. All three reviewers approved the corrections that were made.

Your PhD protocol was subsequently served and approved also by the Academic Advisory Committee on 29 September 2017.

Your PhD project title is: **Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe**

You can now submit to the Faculty of Health Sciences Research Ethics Committee.

Sincerely

Prof Janine Wichmann
Chairperson
SHSPH Academic Advisory Committee

cc   Prof Stephen Hendricks (supervisor), Prof Greta Dreyer (co-supervisor)

AAC members: Prof Debashis Basu, Prof Brendan Girdler-Brown, Prof Stephen Hendricks, Dr Neo Ledibane, Prof Halina Rollin, Dr Flavia Senkubuge, Mrs Annette Welman, Mrs Kathy Pieterse

Appendix 19: University of Pretoria, Faculty of Health Sciences Ethics Approval

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

08-Dec-2017

Approval Certificate

New Application

Ethics Reference No.: 487/2017

Title: Equity in access and utilization of cervical cancer treatment and palliation services in Harare, Zimbabwe

Dear Mr Oscar Tapera

The **New Application** as supported by documents specified in your cover letter for your research received on the , was approved by the Faculty of Health Sciences Research Ethics Committee on the 25-Oct-2017.

Please note the following about your ethics approval:

- Ethics Approval is valid from to .
- Please remember to use your protocol number (487/2017) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of 6 monthly written Progress Reports, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

<u>Additional Conditions:</u>

We wish you the best with your research.

Yours sincerely

Dr R Sommers
MBChB MMed(Int) MPharMed
Deputy Chairperson: Faculty of Health Sciences Research Ethics Committee

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

(012 3563084   -   deepeka.behari@up.ac.za   -   http://www.up.ac.za/healthethics
Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 4-60 (opposite the BMW Building), Dr Savage Road, Gezina,

Appendix 20: Harare Hospital Institutional Ethics Committee Approval

Telephone: 621100-19
Fax: 621157

ZIMBABWE

Reference: HCHEC 271017/77

HARARE CENTRAL HOSPITAL
P. O. Box ST 14

SOUTHERTON

Harare

02 November 2017

Mr. Oscar Tapera
5 Gelcon Avenue
Greendale
HARARE

Dear Mr. Tapera,

REF: "EQUITY IN ACCESS AND UTILIZATION OF CERVICAL CANCER TREATMENT AND PALLIATION
SERVICES IN HARARE, ZIMBABWE".

I am glad to advise you that your application to conduct a study entitled: "Equity in Access
and Utilization of Cervical Cancer Treatment and Palliation Services in Harare, Zimbabwe"
(Ref: HCHEC 271017/77), has been Approved by the Harare Hospital Ethics Committee.

This approval is premised on the submitted protocol. Should you decide to vary your protocol in
any material way please submit these for further approval.

You are advised to avail the results of your study whether positive or negative to the hospital
through the committee for our information.

Yours sincerely,

HARARE CENTRAL HOSPITAL
DEPARTMENT OF MEDICINE

0 2 NOV 2017

P. O. BOX ST14, SOUTHERTON
HARARE, ZIMBABWE

DR. C. Pasi
Chairman Harare Central Hospital Ethics Committee

Appendix 21: Joint University of Zimbabwe and Parirenyatwa Hospital Ethics Approval

Joint Research Ethics Committee For The University of Zimbabwe, College of Health Sciences and Parirenyatwa Group of Hospitals

Parirenyatwa Group of Hospitals

JREC Office No. 4, 5th Floor College of Health Sciences Building
Telephone: +263 4 708140/ 791631 Exts 2241/2242
Email:jrec.office@gmail.com/jrec@medsch.uz.ac.zw, website:www.jrec.uz.ac.zw

University of Zimbabwe College of Health Sciences

APPROVAL LETTER

Date: 27th March 2018

JREC Ref: 33A/18

Names of Researcher: Mr Oscar Tapera
Address: University of Zimbabwe, Department of Radiology

RE: EQUITY IN ACCESS AND UTILIZATION OF CERVICAL CANCER TREATMENT AND PALLIATION SERVICES IN HARARE.

Thank you for your application for ethical review of the above mentioned research to the Joint Research Ethics Committee. Please be advised that the Joint Research Ethics Committee has reviewed and approved your application to conduct the above named study. You are still required to obtain MRCZ and RCZ approval before you commence the study if required by the nature of your study.

- **APPROVAL NUMBER:**   JREC/33A/18
- **APPROVAL DATE:**   27th March 2018
- **EXPIRY DATE:**   26th March 2019

This approval is based on the review and approval of the following documents that were submitted to the Joint Ethics Committee:

a) Completed Application Form
b) Full Study Protocol
c) Informed Consent in English and/or appropriate local language

After this date the study may only continue upon renewal. For purposes of renewal please submit a completed renewal form (obtainable from the JREC office) and the following documents before the expiry date:

a. progress report
b. A Summary of adverse events
c. A DSMB report

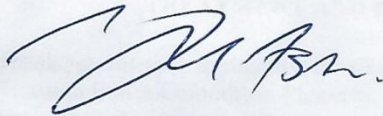Advancing Healthcare Training Research, Innovation and Service

Page 1

- **MODIFICATIONS:**

  Prior approval is required before implementing any changes in the protocol including changes in the informed consent.

- **TERMINATION OF STUDY:**

On termination of the study you are required to submit a completed request for termination form and a summary of the research findings/ results.

Yours sincerely,

Professor R Masanganise
<u>**JREC Chairman**</u>

RM/llm/akm

Appendix 22: Chitungwiza Hospital Approval to conduct study

Telephone: (070) 31850
31038
30828
31138
31489
31861
FAX: (070) 22668

HOSPITAL MANAGEMENT BOARD
CHITUNGWIZA CENTRAL HOSPITAL
P.O. BOX CZA 245
ZENGEZA
CHITUNGWIZA ZIMBABWE

All correspondences to be addressed to the Chief Executive Officer

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20 November 2017

Oscar Tapera
Department of Health Policy and Management Track
School of Health Systems and Public Health
University of Pretoria
South Africa

RE: REQUEST TO CARRY OUT RESEARCH STUDY ON THE EQUITY IN ACCESS AND UTILIZATION OF CERVICAL CANCER TREATMENT AND PALLIATION SERVICES:- CHITUNGWIZA CENTRAL HOSPITAL

The above matter refers. This letter serves to confirm that your request for research on the above study has been approved.

We would therefore be grateful if you could include Dr Obadiah Moyo as one of the co-authors in future publications as he is the designated hospital field supervisor at Chitungwiza Central Hospital.

All the best in your research.

Thank you.

CHIEF EXECUTIVE OFFICER
CHITUNGWIZA CENTRAL HOSPITAL

2017 -11- 2 0

P.O. BOX CZA 245
CHITUNGWIZA, ZIMBABWE

G. Mapokotera
Coordinator - Chief Executive Officer's Office

Appendix 23: Medical Research Council of Zimbabwe Ethics Approval

Telephone: 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL

Ref: -MRCZ/A/2271

20 December, 2017

Oscar Tapera
University of Pretoria
School of Health Systems and Public Health
Pretoria
South Africa

RE:- Equity in Access And Utilization Of Cervical Cancer Treatment and Palliation Services in Harare, Zimbabwe
Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review:-
a) Study Protocol version 2.0 dated 18 December, 2017
b) Research Summary
c) ICF- Patients & Community version 1.0 dated 31/10/17 (English and Shona)
d) ICF – FGD ,version 1.0 dated 30/10/17(English and Shona)
e) ICF- IDI, version 30/10/17(English and Shona)
f) ICF- KII, version 30/10/17(English and Shona)
g) ICF-HCW Survey, version 1.0 dated 31/1-/17
h) Data Collection Tools (English and Shona)

- **APPROVAL NUMBER** : MRCZ/A/2271

This number should be used on all correspondence, consent forms and documents as appropriate.
- **TYPE OF MEETING** : **Expedited**
- **EFFECTIVE APPROVAL DATE** : **20 December, 2017**
- **EXPIRATION DATE** : **19 December, 2018**

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted three months before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw
  Other
  - Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
  - You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

....
MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABW

MEDICAL RESEARCH COUNCIL OF ZIMBABWE

2017 -12- 2 0

APPROVED
P.O. BOX CY 573 CAUSEWAY, HARARE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH