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FACTORS AFFECTING THE ACCESSIBILITY OF CERVICAL CANCER SCREENING SERVICES AMONG WOMEN WITH PHYSICAL AND SENSORY DISABILITIES IN LUSAKA DISTRICT

BY

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Declaration

I hereby declare that this report is my own work and effort and that it has not been submitted anywhere else for any reward. Where other sources of information have been used, they have been accordingly acknowledged.

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Certificate of Approval

I am satisfied that this work is the result of the student's own effort under my supervision, as partial fulfilment for the award of a Masters Degree in Public Health by the University of Zambia.

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Abstract

Introduction

Cervical cancer is one of the major health challenges amongst women in Zambia. While cervical cancer screening has been available in Zambia since 2006 with a relatively wide coverage in Lusaka District, it remains questionable whether women with disabilities have access to these cervical cancer screening services. The aim of this study was to determine factors which influence the accessibility of cervical cancer screening services among women with physical and sensory disabilities.

Methodology

Using a qualitative case study, data was collected through in-depth interviews and key informant interviews from 12 women with disabilities and 6 representatives from health centres and disability organisations respectively in Lusaka District. The data was collected focussed on factors which affect accessibility of cervical cancer screening services amongst women with physical and sensory disabilities. Supplementary document study and field observations were done. Data was analysed using Nvivo 10.0 Windows Evaluation Version to conduct thematic content analysis of key themes and sub-themes of service accessibility of cervical cancer screening.

Results

Results showed that cervical cancer screening services were not easily accessible for women with disabilities, with the type and severity of disability being major catalysts. Several factors were found to influence accessibility of cervical cancer screening services; among them were previous negative medical experiences, limited knowledge, communication challenges, social support, inadequate income, distance to nearest screening centre, inappropriate transport, little implementation of legislature and failure to incorporate women with disabilities into existing health policies.

Conclusion

Efforts should be directed at improving service delivery of cervical cancer screening by integrating women with disabilities in health promotion activities. There is need to devise strategic ways in which existing legislature can be efficiently enforced so as to compel health facilities to be more accessible to women with disabilities. It is important that future health policy planning should consider the interests of vulnerable populations such as women with disabilities.

Key words; Accessibility, Cervical Cancer, Disability, Screening

Dedication

I dedicate this work to the memory of my beloved late husband, Jeff Mulenga Bowa. Despite having supported me in furthering my studies, you did not live to see the completion of my work. Thank you for tutoring me in preparation for my major exams, thank you for having put your own work on hold in order to ensure I had a chauffeur during my field work. Your academic success and support in my education will forever inspire me.

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Contents

List of Abbreviations

AIDS	:	Acquired Immune Deficiency Syndrome
ART	:	Antiretroviral Therapy
CSO	:	Central Statistics Office
CRPD	:	Convention on the Rights of Persons With Disabilities
DDA	:	Disability Discrimination Act
HPV	:	Human Papilloma Virus
HIV	:	Human Immunodeficiency Virus
IDI	:	In-depth interview
IEC	:	Information, Education and Communication
IADL	:	Instrumental Activities for Daily Living
KII	:	Key informant interviews
PAP	:	Papanicolau Test
PWD	:	Persons with Disabilities
VIA	:	Visual Inspection with Acetic Acid
VCT	:	Voluntary Counselling and Testing
WHO	:	World Health Organisation
ZAPD	:	Zambian Agency for Persons with Disabilities

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Definition of Terms

Access

"Access is a broad concept which includes both structural (physical) and functional (sociological) barriers that emerge when a person with special needs attempts to access and use services and facilities available to persons without disabilities." (Mele, Archer and Pusch, 2005, p.2)

Accessibility

"Accessibility refers to what the law requires to enable reaching or approaching something" (WHO, 2011, 170)

"Accessible health services are those which are physically available, affordable, appropriate and acceptable. Health services can be inaccessible if they do not acknowledge and respect cultural factors, physical barriers, economic barriers or if the community is not aware of the available health service" (Ware, 2013, 3).

Accommodation

"Necessary and appropriate modification and adaptation and adjustments not imposing undue burden, where needed in a particular case; to ensure to persons with disabilities enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" (PWD Act, 2012, 72)

User-friendly

Refers to something that is easy to use

Disability

"Permanent physical, mental, intellectual or sensory impairment alone or in combination with social or environmental barriers, which hinders the ability of a person to fully or effectively participate in society on an equal basis with others" (PWD Act 2012, 72).

Discrimination

"Any distinction, exclusion, or exclusion on the basis of disability which has the purpose or effect of impairing or nullifying the enjoyment or exercise on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field and includes all forms of discrimination such as denial of reasonable accommodation, and then the term "discrimination on the basis of disability" shall be construed accordingly" (PWD Act, 2012, 72).

Key-informant interviews

This involves interviewing people who have expert information on the case being explored; in this case, key informants were those experts who had informed perspectives of women with disabilities in relation to cervical cancer screening services.

Physical Impairment/ Disability

Limitation in a person's physical functioning or mobility for example, muscular dystrophy, spina-bifida, cerebral palsy and many more others (WHO, 2007).

Sensory Impairment/ Disability

Refers to visual impairment (partial sight or blindness) and hearing impairment (deaf or hard of hearing) (WHO, 2007)

CHAPTER ONE

1.0 Introduction

Cervical cancer ranks as the most frequent cancer among women aged between 15 and 44 years of age and accounts for about 30% new cancer cases per year in Zambia (Liu et al. 2012). There has been growing evidence that in Zambia, cervical cancer has posed a serious reproductive health problem for women (Bruni et al. 2014; Liu et al. 2012; Mwanahamuntu et al. 2011). In all this, women with disabilities have been caught in a web of inequitable access to health facilities (Iezzoni et al. 2000; Nixon et al. 2014). Programmes for cervical cancer screening are among the leading cost effective strategies for cancer control. However, it still remains highly questionable whether screening services are user-friendly for women with disabilities. Participation in screening is variable across populations. Smeltzer (2006) argues that people with disabilities, especially women, have for a long time faced significant barriers in accessing health care through inaccessibility of health screenings, which are an important first step in using health care resources, including medical care, and health promotion interventions. The Persons with disabilities Act (2012, p.72) defines disability as "permanent physical or other impairment alone or in combination with social or environmental barriers, which hinders the ability of a person to fully or effectively participate in society on an equal basis with others." Understood in this manner, it is apparent that factors that contribute to disability extend beyond the environmental barriers outside the control of the person with a disability. As a result, women with disabilities are less likely than those without a disability to receive a pelvic examination on a regular basis, and women with more severe functional limitations are significantly less likely to do so (Bussie're, Sicsic and Pelletier-Fleury, 2014).

Studies have shown that women without disabilities tend to be more likely than those with disability to participate in cervical cancer screening, and those with severe functional difficulty are significantly less likely to do so at all (Angus et al. 2012). Global findings show that the persons with disability (PWD) population are well recognized as a particularly vulnerable population that is consistently underserved: they present substantial health disparities and are often under-screened (Iezzoni et al. 2000; Ramirez, 2005; Wisdom et al. 2010). Access to cancer screening services is minimal in the Sub-Saharan region where few countries have policies on the disease. Chingore- Munazvo (2012) notes that Zambia and

Namibia in particular do not have comprehensive guidelines on the management of the disease because it is minimal and focuses mainly on screening with little emphasis on access. To a large extent, access to cervical cancer screening in Zambia is determined by geographical location, there are very few screening centres available across the country. Botswana on the other hand stands out as one of the few countries in the region with a broad, accessible cervical cancer policy which in turn has resulted in an increase in number of screenings from 5,000 per year in 2002 to 32,000 per year in 2009 (Chingore-Munazvo, 2012).

In light of this, cervical cancer screening ought to be accessible on an equal basis as with others. This paper endeavours to establish the factors affecting access of cervical cancer screening services amongst women with physical and sensory disabilities in particular with the intention of boosting action in the form of practical implementation and enforcement of those commitments towards achieving accessible health care.

1.1 Background

Cervical cancer is a major public health problem in Zambia. Current estimates indicate that approximately two-thousand three hundred and thirty (2330) women are diagnosed with the disease annually, whereas 1380 die annually (Bruni et al. 2014). Cervical cancer in Zambia ranks as the most frequent cancer among women between 15 and 44 years of age and accounts for about 30% new cancer cases per year in Zambia (Liu et al. 2012). Despite cervical cancer being among the most common cancers in women it is curable if detected early. Visual inspection with acetic acid (VIA) has been adopted in developing nations such as Zambia as a cost effective way of detecting cervical cancer. When using VIA, precancerous cells which are found are simply be excised or frozen, thereby eliminating the need for an immediate follow up visit (Chingore-Munazvo, 2012 ; Mwanahamuntu et al. 2011). High laboratory and human capacity requirements of Pap smear cervical cancer screening and the expense of HPV-based screening has led the Zambian government to chose VIA which is less costly. In an effort to fight cervical cancer, the Zambian government has had an on-going cervical cancer VIA screening program since 2006 with an aim of early identification so as to reduce the cervical cancer disease burden in the country (Mwanahamuntu et. al. 2011).

Persons with Disabilities as Distinct Health-Care Consumers

According to CSO (2010), 2 million Zambians have a disability, representing 15% of the Zambian population. Women with disabilities account for about 2.4% of the Zambian population. This study will concentrate on physical, sight and hearing impairments which dominate the proportion of disabilities.

Table I: Types of disabilities in Zambia (ZAFOD, 2008)

Disability type	**Percentage**
Physical disability	35.2
Partially sighted	27.4
Hard of hearing	11.2
Mentally ill	7.4
Deaf	5.7
Mentally retarded	4.9
Blind	4.8
Ex-mental patients	3.3

Persons with disabilities report a broad range of health care access problems which are distinct from the general population, and more pronounced in those with severe disabilities (Drainoni et al. 2006). Studies by Nixon et al. (2014) argues that health needs of PWDs are more complex and ongoing than those without disabilities and therefore their demands from health services are distinct, often requiring specialised service or equipment. In addition, accessibility studies by Drainoni et al. (2006) found that PWDs are often less likely to be in employment, and more likely to earn low incomes or to be dependent on other individuals or entities for financial support. As a result, most PWDs have low socio-economic status. This factor alone can cause a person in need of a health service to delay or forgo the service altogether. The Government of the Republic of Zambia has since recognised PWDs as a vulnerable population, hence the formulation of the Persons with Disability Act of 2012 to address the various concerns of this distinct population.

Models of disability

In a quest to understand disability, models of disability have been created, namely, medical and social model. The medical model views disability as inherent in oneself, therefore the person with the disability is the problem; as a result they are excluded from most mainstream activities (Due Plesis and Van Reenen, 2011). It is argued that disability is not influenced by the environment in which one finds him/herself because disability is purely biological. On the contrary, the social model argues that disability results from failure of the social and physical environment to take into consideration the needs of people with disability (WHO, 1997; ILO, 2007). Society constructs the ideal norms of a mentally and physically fit person and organises society based on these norms. This study derives its influence from the social model which promotes the idea that the physical environment ought to be structured in a manner that is accessible to all people.

Accessibility of Health Services

According to Ware (2013), an accessible health service ought to be physically available, affordable, appropriate and acceptable for it to qualify as accessible. Cervical cancer screening in Zambia is available but there is still need to ascertain its accessibility, more so for women with disabilities. Provision of cancer screening in an accessible manner requires that the service providers receive training to address operation of specialised equipment, assisting with transfer or positioning of individuals with disabilities and how not to discriminate against clients with disabilities (ADA, 2010). People with physical impairments differ in type of disability and level of disabilities. Hence they need assistance in different ways to undergo a comfortable screening.

Cervical cancer examinations require that the client strategically positions herself on an examination table. To promote accessibility, medical equipment must be accessible too. Such includes height adjustable examination tables with padded adjustable leg support, portable floor lifts and overhead track lifts (ADA, 2010). This would greatly assist women with disabilities during the screening process. Transfers to and from the examination table can be eased by using a patient lift, a stretcher or simply training staff how to safely transfer clients with mobility problems safely without injuring themselves or the client. According to ADA (2010) and Ware (2013), an accessible examination room allows for free movement of

individuals, whether on a wheelchair or not. There must also be enough floor space to allow for transfer of patients to and from the examination table. An accessible examination room ought to be complimented by an accessible route to the room and other areas of the facility. The corridors must be wide enough for manoeuvre and clear of obstacles that may hinder movement.

Disability and legislature

The Zambian government has adopted a number of progressive laws and policies pertaining to PWDs; the Persons with Disability Act (2012), a provision in the Zambian constitution and ratification of the Convention on the Rights of Persons with Disabilities (CRPD). These documents obligate the Zambian government to provide equitable access to reproductive health care and public health programs. The state is compelled to avail people with disabilities (PWDs) equal range and quality of free or affordable health care and public health programs as provided to others who are not disabled.

Article 25 of the CRPD stresses the need for people living with disabilities to access high standards of health care without discrimination. To achieve this, the Zambian government ought to provide a favourable environment which will enable the achievement of accessible health care services by availing the necessary manpower, appropriate facilities and instruments for testing and examination purposes suitable for women with disabilities. The CRPD recognises the importance of accessibility to health and other services which will allow PWD exercise their fundamental human rights. Accessibility of the cervical cancer screening service is not only dependent on accessible infrastructure but also accessible screening or testing equipment and accommodating staff which ultimately work together to create an accessible service, information, care and support.

1.2 Problem Statement

Cervical cancer burden in Zambia is one of the highest in the world with an alarming crude incidence rate of 33.7% thus making it a major health problem (Bruni et al. 2014). In fact it is the leading cause of cancer deaths in the nation accounting for 30% of all cancer cases (Liu et al. 2012). Of those diagnosed with cancer, most die due to late diagnosis and treatment (Chingore-Munazvo, 2012). Women living with disabilities are vulnerable to cervical cancer, just like any other woman. Being a 'special' group in society by nature of vulnerability, their health needs are rather distinct from the rest of the population (Ware, 2013). Cervical cancer screening is no exception and calls for specialised attention in order for a woman with a disability to benefit from it. This brings to question whether screening services are accessible to them.

According to Bedding et al. (2013, 12) "Government regards disability as a non-life threatening condition and so is not among the National Health priorities categorised under i) public health priorities and ii) health system priorities... and currently the welfare of PWDs has continued to deteriorate." In light of this, little has been done to uplift the accessibility of reproductive health care for women with physical and sensory disabilities. In addition, people with disabilities are a distinct population who are particularly vulnerable to deficiencies in health care services. Moreover, they are rarely targeted by health promotion and prevention programs (Lofters et al. 2014). Issues of accessibility raise questions on whether or not women with physical and sensory impairments are able to utilise health services.

1.3 Rationale of the Study

Barile (2004) notes that women with disabilities encounter multiple barriers when accessing primary health care services and are less likely to participate in screening programs. Consequently, this group of women is at higher risk of later diagnoses and higher mortality than other women. The Zambian government through the PWD Act (2012) has pledged to identify and eliminate barriers to accessibility in services and facilities, including medical ones. In this regard, this study stands in line with the government's plan for persons with disabilities.

The results of the study will contribute to just and equitable public health policies that will help enhance accessibility of health services by ensuring that they are physically available, affordable, appropriate and acceptable. In addition, the study has contributed to the body of

knowledge concerning access to health services among minorities. This is important because there are few Zambian studies that have tackled this matter, particularly in relation to physical and sensory impairments. Furthermore, this study has provided a basis for more responsive health promotion programmes relating to cervical cancer screening.

1.4 Research Questions

1. What are the individual/interpersonal factors which influence the accessibility of cervical cancer screening among women with physical and sensory disabilities?
2. How do services related factors influence cervical cancer screening among women with physical and sensory disabilities?
3. Which socio-economic factors influence cervical cancer screening among women with physical and sensory disabilities?
4. Do existing policies address cervical cancer screening for women with disabilities?

1.5 Aim of the Study

The aim of this study was to determine factors influencing the accessibility of cervical cancer screening services among women with physical and sensory disabilities

1.6 Specific Objectives

Specific objectives were to;

1. Explore the individual/interpersonal factors which influence the accessibility of cervical cancer screening among women with physical and sensory disabilities.
2. Examine service related factors which influence cervical cancer screening among women with physical and sensory disabilities.
3. Identify socio-economic factors which influence cervical cancer screening among women with physical and sensory disabilities.
4. Examine the extent to which existing policies address cervical cancer screening for women with disabilities

CHAPTER TWO

2.0 LITERATURE REVIEW

Overview

This chapter presents literature reviewed from policy documents and different scholars, taking into consideration different views and approaches concerning access to health care, especially cervical cancer screening among women with disabilities. Several broad themes emerged from the literature, namely; physical factors, interpersonal association, service related factors, economic factors, cognitive influences and awareness.

2.1 Policy and Regulatory Context

The Zambian government has adopted a number of progressive laws and policies pertaining to persons with disabilities (PWDs); the Persons with Disability Act (2012), a provision in the Zambian constitution and ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). These documents obligate the Zambian government to provide equitable access to reproductive health care and public health programs. The state is compelled to avail people with disabilities (PWDs) equal range and quality of free or affordable health care and public health programs as provided to others who are not disabled.

Health policy documents such as The National Health Strategic Plan 2011-2015, and the Zambian Strategic plan 2013-2016 on Non communicable diseases are available to cover cervical cancer screening. However, these documents do not have any particular mention of people with disabilities. Therefore, although the service is required to be available to all persons, it is a rather vague statement for persons with disabilities who require specialised recommendations.

2.2 Access to Healthcare Settings

Ware (2013) argues that an accessible health service ought to be physically available, affordable, appropriate and acceptable. Looking at this in the context of disability, an individual with a disability ought not to be hindered in receiving healthcare of any kind because of the limitations that the environment imposes on them, therefore, it goes beyond merely the healthcare setting as suggested by Rajan (2012), who found that access to breast cancer screening for women with disabilities can be affected by physical, communication,

attitudinal and economic factors. It is evident therefore that a spectrum of factors interrelate to achieve accessibility of health care settings.

2.3 Barriers in Accessing Cancer Screening Services

According to Nosek and Howland (1997), in an early study on breast and cervical cancer screening among women with physical disabilities found that the severity of the disability was significantly linked to failure to access health services. Dominant barriers which were cited include environmental, attitudinal and information factors. Drainoni et al. (2006) conducted a study to gain an in-depth understanding of the barriers to health-care access affecting consumers with disabilities, particularly in light of their functional abilities. The study records a range of barriers ranging from personal, cultural, structural and financial. Meanwhile, a review of women with disability and breast cancer screening study by Rajan (2012), similarly noted that there are various categories of barriers for women with mobility disabilities in accessing breast cancer screening services; physical, communication, attitudinal and economic. Interestingly, all these studies report similar findings despite the gap in their years of study.

Local studies such as Smith et al (2004) notes that women with disabilities in developing countries are exposed to restrictive cultural norms, service limitations, poverty and gender inequality. Zambian people who are living with disabilities are among plenty of others who face socio-economic challenges which in turn lead to social exclusion which inhibits disability. In contrast to international studies in developed nations, accessibility to healthcare is seen to be much more complex for Zambian women with disabilities. This can be attributed to cultural norms, health policies and economic stability of the nation. Physical barriers to mobility and access to buildings add on to the many complex hindrances to benefit from services such as health care. Nixon (2014) in a study on access to HIV care and treatment amongst Zambians living with disabilities notes that barriers include communication barriers and threats to confidentiality, lastly, movement and mobility challenges. However, discrimination stood out prominently.

2.4 Individual and Interpersonal Factors

Rajan (2012) notes that some women with disabilities believe that the disadvantages of screening outweigh the benefits because most of the women screened did not have the disease in question. Psychological implications of increased anxiety about developing the disease can

be gruesome for some women. Physically, it can be cumbersome for a person with a disability to access a pelvic examination especially when the investigations prove that one is free from any trace of cervical cancer. Unusual positioning of one's body for cervical cancer screening may be uncomfortable and painful for women with particular types of physical disability and may cause fright and anxiety over physical privacy for women with psycho-social disabilities especially PWDs who have been sexually or physical abused, it is believed to do more harm than good.

Lofters (2014) found that misconceptions exist among medical personnel that women with disabilities are not sexually active and therefore do not need reproductive health education. On the contrary, PWDs can be as sexually active as others. As a result of this misconception, they are often viewed as low risk culprits for developing reproductive health problems such as cervical cancer and yet this is not true. Different levels of disabilities warrant voluntary sexual engagement amongst these women. Others have been sexually abused, thus involuntarily engaged in sexual activity at some point.

Smith et al. (2004) reports that health care workers tend to give women with disabilities priority when they seek reproductive health care. Although this is done n the best interest of the women with disabilities, Smith argues that it is not the right thing to do as it brings out the notion that it is not normal for women with disabilities to seek reproductive health services. This can be debatable as the practice can also work positively to encourage the women to access the services knowing that they will not have to wait in a long queue.

Lack of awareness of cervical cancer has been a major concern for several women involved in a study by Ouellette-Kuntz (2005). It was found that public health information on primary health care is not available in alternative accessible formats such as Braille or large print. Communication considerations for the visual and hearing impaired is often overlooked. Access to information through various media such as brochure, television, radio or billboard ought to be practically implemented so as to reach out to a wider population of PWDs so as to maximise their utilisation of cervical screening facilities across the country. Angus et al. (2012) had similar findings but goes on to discuss findings that because people with disabilities frequently have limited access to education and have low literacy/comprehension rates, health promotion resources and campaigns are often ineffective for them. It has also been found that the health sector tends to neglect health promotion activities aimed at people with disabilities. To a large extent, as a result of this, women with disabilities are less likely

than women without disabilities to receive pelvic examinations on a regular basis and are thus at a higher risk for delayed diagnosis of cervical cancer.

Communication challenges pose barriers to care and threats to confidentiality. Barile (2004) found that women with disabilities have different communication requirements depending on the nature of their disability. Deaf women do not use speech to communicate and women with intellectual disabilities may have speech impediments or be non-verbal or have limited verbal capacities, these two groups of women experience the most difficulties in communicating with staff at medical centres.

Likewise, a study by Nixon et al. (2014) on HIV related services for PWDs who are HIV positive shows that there are significant challenges in communicating within antiretroviral therapy clinics due to the breakdown in communication, especially in the absence of sign language interpreters for deaf clients. Several participants recounted how they were denied voluntary counselling and testing (VCT) because counsellors felt unable to handle the encounter. With regard to information and education communication (IEC), it was discovered that it was impossible to access education materials for people who were blind, even adherence to medication was a challenge for some because they could not read the labels on the containers, "somehow to us it is like hidden information" explained one participant.

Drainoni et al. (2006) supports assertions of communication barriers in their study of cross-disability barriers to health care access. Findings showed that most women with speech or hearing impairments often postponed or abandoned medical check-ups in order to avoid the frustration of communicating with service providers who could not understand them. The report further highlights the inadequate accommodations for communication challenges. Clinical staffs were often impatient with patients who had speech difficulty. To compound the situation, service providers often used inappropriate communication styles with the patients.

2.5 Socio-Economic Factors

Bussie'er (2014) found that socio-economically disadvantaged women face difficulty by not being able to afford transportation or child care which can enable them to go for screening. In the Zambian context this scenario is quite practical considering that the majority of Zambians live in abject poverty, especially PWDs who are rarely economically empowered. As if that is not enough, not every health centre has the cervical cancer screening facility hence the need

to move between suburbs in order to access the service. As a result, financial hindrance coupled with long distance is highly likely to discourage women with disabilities from utilising screening services, especially if they have mobility impairments. Smith (2004) also reports that the cost of mini-buses and taxis are often beyond the affordability of many women with disabilities.

Maxwell et al. (2001) identified economic barriers on the part of the service provider in a Canadian study, which may keep women from accessing health care. The researchers noted that additional time is often required to attend to a woman with a disability, hence health care providers may be reluctant to attend to them because the more time they spend on one patient, the less money they earn. Health care centres charged a fee for each patient that received service, thus they benefit from fast and efficient service provision if they increase the number of patients seen in a day. These circumstances however, may not be applicable in the Zambian setting because screening services are offered free of charge at all designated government run health centres, unless of course, a patient opts to use a privately run health facility.

2.6 Service Related Factors

Bussie'er (2014) in studies pertaining to cancer screening in obese women with disabilities reports on disrespectful treatment, embarrassment and negative attitudes of providers as well as insensitive comments about physical conditions are all barriers to routine gynaecologic cancer screening. Such behaviour usually stems from negative attitude of service providers towards persons with disabilities. In support of this, a study by Wisdom et al. (2010) indicates that some health practitioners would rather not examine a woman with a disability because the examination is likely to take longer. This is negativity that is infringing on her right to access medical care and should not be encouraged.

Lagu et al. ((2013) in a study addressing care for patients with mobile disability discovered that PWDs have been made to feel as though they cannot make decisions for themselves. Many participants who sought medical attention narrated how clinical staff would not address them directly but rather through their companion. This should not be the case, all issues pertaining to them must be addressed to them personally unless in extreme cases of disability where one cannot reason for herself. Feelings of inadequacy were also reported in studies by Rimmer (2004) on physical activity participation among persons with disabilities which

reveal that medical personnel had a tendency of requesting PWDs to attend medical examinations with a companion. Not only did this remind the women that they cannot fend for themselves but it also infringes on one's right to confidentiality.

Similar studies which have been conducted among HIV positive people with disabilities showed that PWDs face discrimination at the clinics when they attend their routine appointments. One participant in particular said people would point fingers and utter statements such as "How could he contract AIDS considering his condition?" Such sentiments arose from erroneous assumptions that people with disabilities are not sexually active. Consequently, women and young girls are often left out of HIV education. It also extends to the community where young girls with disabilities are excluded from traditional rituals where sex is discussed.

A contributing factor to inaccessibility is the common trend in addressing the disability and not the medical concern. Clinical workers have been reported to be more focused on disability rather than the screening itself. Rajan (2012) and Lofters et al. (2014) account for studies that examined access to health care for girls and young women with disabilities and found that many women with disabilities have had negative childhood experiences with the medical profession. For instance "teaching" rounds in hospital often involved medical staff making them objects of pathology by objectification of their bodies in front of numerous doctors without regard for modesty and privacy. Experiences of such nature are likely to cause women with disabilities to have a negative attitude towards health care providers and eventually shun seeking health care completely. The research works noted above all reflect on the fact that the negative experiences that women with disabilities have had with the medical profession have a great effect on their attitudes, expectations and behaviour when considering screening. This often ends with the result that they are less likely to participate in regular screening of any sort.

It has been recognized that functional limitations represent a barrier to cancer screening use. In studies concerned with access to cancer screening for women with mobility disabilities, Angus et al. (2012) found that people with mobility limitations often face logistic and architectural obstacles in accessing buildings, machines and examination tables. These findings are similar to Lagu et al. (2013) who reports on a study recently conducted among physicians in the United States of America confirmed a lack of accessibility to gynaecological care among people with a physical impairment. An accessible examination

room has features that make it possible for patients with disabilities to receive appropriate medical care. A patient ought to freely enter the examination room, move around in the room and utilise the equipment provided.

Acquiring necessities to improve accessibility however may prove to be difficult in resource constrained nations such as Zambia, however with proper planning the necessary requirements can be sought. In fact, The PWD Act (2012) states that assistive devices shall be exempted from tax. This therefore ought to encourage health service providers to purchase assistive devices such as adjustable examination tables which can help ease the cervical cancer screening procedure.

Examination tables are often inaccessible for women with physical disabilities because pelvic examinations for cervical cancer require specific positioning for viewing of the cervix. However, Devaney et al. (2009) in their report explain that women with disabilities may find it painful or physically impossible to position appropriately on basic medical equipment and yet it is necessary for precise pelvic examination. Drainoni (2006) reaffirms that service providers often do not have adjustable examination tables for use during screening. Accessible examination tables can be height adjusted by being lowered and raised, they may also have removable or adjustable support rails with gripping surfaces. Use of appropriate equipment makes the examination more comfortable or accessible for the patient and easier for the service provider to perform the screening.

A study on access to breast cancer screening among women with disabilities by Ware (2013) shows that participants were frustrated and did not like to be seen as dependent. They expressed disappointment at the inability of service providers to make simple adjustments to the environment that would accommodate their special needs. Similar sentiments by women were recorded in Nixon (2014). Women who expressed a desperate cry for help, a cry to be recognised in society, recognition that is acknowledged by planning for women with disabilities as they plan for the health of other persons without disabilities. These findings show that simple adjustments can be made, even in resource restricted nations, simple adjustments that would be appreciated by women and in turn make the cervical cancer screening more accessible to them.

Smeltzer and Bare (2004) in evaluating screening programmes for gynaecological cancer argues that some medical providers turn away patients with disabilities simply because they lack accessible medical equipment. This ought not to be the case because it is unethical to

deny an individual medical attention because of their disability; Hence the need to bring into the open such challenges if present so that they can be addressed by relevant stakeholders.

Bussi'er (2014) in a study on the effects of obesity and mobility disability in access to breast and cervical cancer, reports that although it is essential, dealing with limitation-related barriers through environmental modification is not enough to achieve a high level of participation in screening programs for PWDs. This indeed is worth considering because developed nations have high compliance to locally enacted laws and international standards which require adaptation of infrastructure and medical equipment to suit the needs of PWDs and yet they still cannot classify their health services as entirely user friendly. Zambia lags behind due to its limitations as a developing country and therefore falls short in achieving universal accessibility to buildings and medical equipment despite presence of laws which ought to penalise those who do not make their buildings accessible (Bedding, Banda Chalwe and Mtonga, 2013). Although developed nations have by a large margin complied in making infrastructure accessible, they still fall short in achieving high screening rates among PWDs. This indicates a need to look into accessibility issues on a wider capacity when promoting participation of women with disabilities in cervical screening. This may include communication, knowledge, beliefs and many others.

Findings by Ouellette-Kuntz (2005) in a study to understand health disparities and inequities faced by individuals with intellectual disability shows that the burden of inaccessible transportation systems is another barrier to screening often making women late for appointments and missing pick-ups. Ware (2013) acknowledges these findings through findings that transportation to the health centre was costly and often cumbersome. The Zambian government through the PWD Act (2012) acknowledges that the government shall facilitate the personal mobility of PWDs at an affordable cost. This alone ought to encourage PWDs to seek screening without facing mobility problems in terms of transport to and from the screening centre. It still remains to be verified if this service is actually running in full swing.

Ongoing staff training on how to handle patients with disabilities and associated medical equipment was noted by Drainoni et al. (2006) in a study on cross-disability experiences of barriers to health care access as yet another critical component necessary for the success of cervical cancer screening. Similarly Ware (2013) acknowledges through findings that staff who are trained to handle persons with disabilities are more efficient and therefore make the

service more accessible. Clinical staff should be aware of how to handle specialised medical equipment such as adjustable examination tables. They also ought to be skilled in interacting appropriately with an individual with a disability to avoid. The Zambian PWD Act (2012) in fact addresses this concern by stating that there will be provision of training in mobility assistive devices. However, there is need to find out for sure if cervical cancer screeners receive any training at all.

2.7 Summary

There are few studies in direct relation to women with physical and sensory disabilities and accessibility of cervical cancer screening. The majority of these studies focus on at least one of the components of this study, namely, disability or access to health care. Furthermore, most of these studies have been conducted in developed countries whose cultural context and economic conditions differ to a large degree to that of Zambia. This study will fill the gap for a locally conducted study whose findings reflect the cultural norms of most Zambians.

Common barriers identified in the studies include stigma, physical access to buildings, accessible examination tools, communication barriers, privacy during examinations, bad attitude of health workers and the community at large. This proposed study will embrace all these elements and explore their impact on accessibility of cervical cancer screening in the Zambian context so as to enable future recommendations for improved cervical cancer screening accessibility.

Some methodologies used in the reviewed studies are quantitative in nature. Quantitative approaches cannot adequately measure perceptions nor enable understanding of circumstances in an in-depth manner. For example, Bussier'e (2014) analysed findings from a survey, Lofters et al. (2014) used a retrospective cohort design. Drainoni (2006) and Mele (2008) used qualitative means of collecting and analysing, they however do not explicitly state the designs they used. Although these reviewed studies are all similar, they do not precisely look at the exact subject matter of this proposed research, for instance, Drainoni et al. not only sampled persons with disabilities but proxies such as parents, caregivers. This study will have particular interest in women with disabilities, their views must be sought.

Developed nations have taken measures to increase equitable access to cervical cancer screening, although not fully accessible, they are heading in the right direction by integrating persons with disabilities in the mainstream health services. Zambia can learn a lot of lessons

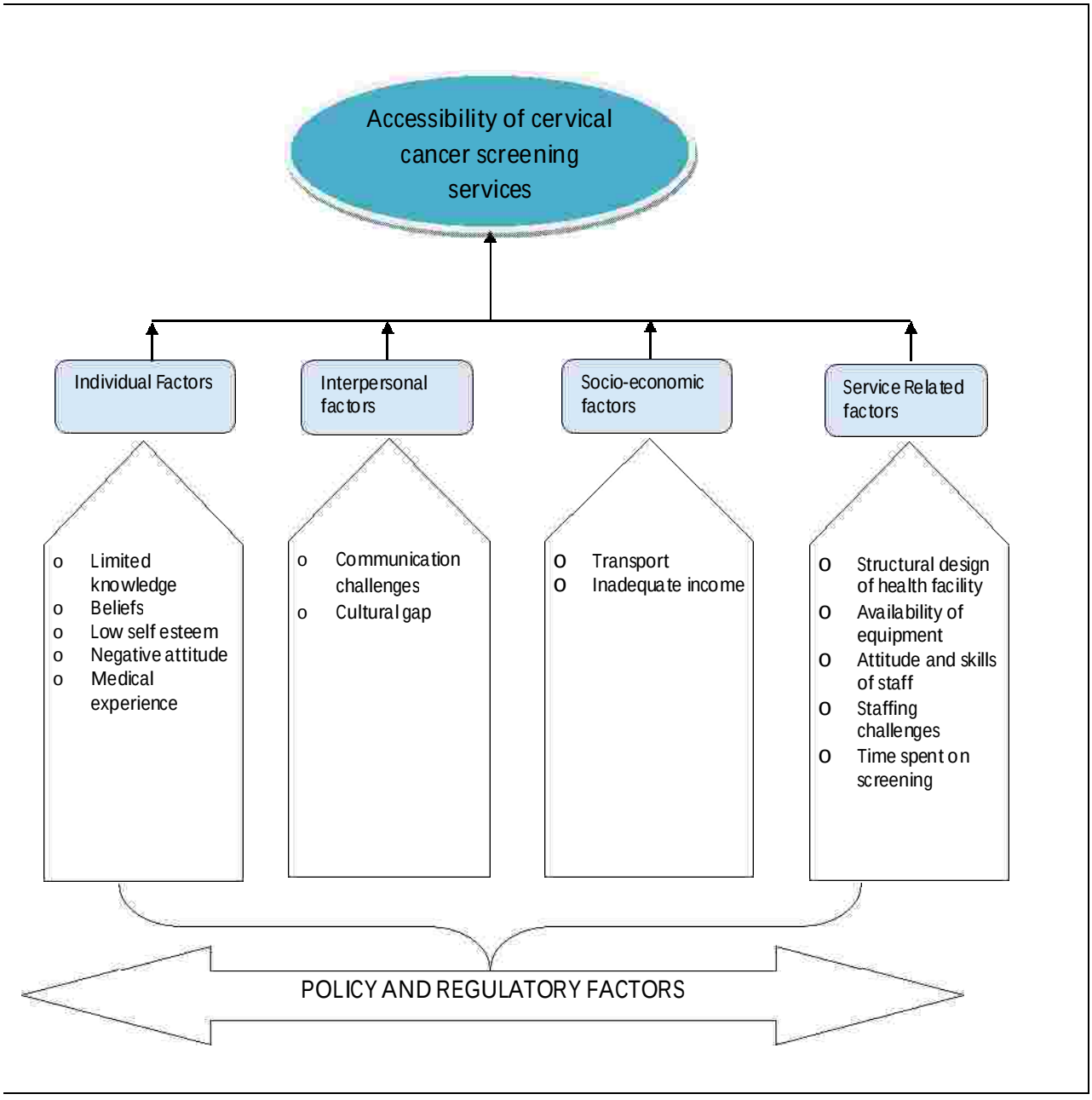
from developed nations that have continued refining measures to promote the cervical cancer screening services for women with disabilities.

2.8 Conceptual Framework

Figure 1 represents the understanding of how different variables from the literature review connect with one another to influence cervical cancer screening. This provided a basis for planning the study through the formulation of research questions and objectives which were drawn from the various variables.

Having reviewed the literature on studies related to disability and access to health care, it appears that there is an interaction of factors which are likely to influence accessibility of cervical cancer screening. Characteristics of individual women are likely to influence perception towards cervical cancer and consequently their decision to access the screening service. Interpersonal factors include interactions with the health system in either positive or negative ways. Socio-economic factors include issues inherent to society that may place individuals at an advantage in terms of accessing the service. The service related factors comprise of issues related with the quality of the actual service delivery in the health centers. All these factors, namely; individual, interpersonal, socio-economic and service related factors are mostly influenced by policy and regulatory factors in different ways.

Figure 1: Conceptual Framework as Adapted from the Literature Review



CHAPTER THREE

3.0 METHODOLOGY

Overview

This chapter presents the methodology, which includes the study design, study setting, population, sampling methods, data collection, data analysis and the ethical considerations.

3.1 Study Design

The study was a qualitative case study of women with physical and sensory disabilities in accessing cervical cancer screening services. The case study design was used because the scope of this study itself was dependent on the perceptions and experiences of women with disabilities, suggesting that qualitative methods were appropriate to explore the issue in a detailed contextual analysis within a limited scope and the relationship therein (Cresswell, 2007). This enabled a thorough investigation of cervical cancer screening within the different defined groups of women with disabilities. As a result, an evaluation of the complexities of the real life situation of accessibility of cervical cancer screening among women with disabilities was enabled. Ultimately, this qualitative method enabled the researcher to uncover diverse opinions, perceptions, and unexpected results in order to understand processes, behaviors, and conditions as they were perceived by the participants.

3.2 Study Setting

The study was conducted in Lusaka District, in the Lusaka Province of Zambia. According Central Statistical Office (CSO)(2010), Lusaka urban has a total disability population of 6,079; females in particular are recorded at 2,748. Lusaka urban has a diverse population residing in low and high density suburbs and is home to various disability groups. Lusaka District in particular was purposely selected because it has a relatively high number of screening centres which have grown from two (2) to eleven (11) since the inception of the program in 2006 (Parham et el. 2014), thus making it necessary to ascertain accessibility levels due to its availability. The study focused on Lusaka urban due to the relatively higher availability of cervical cancer screening centres, there was need to determine whether available services offered by these screening centres were inclusive, accommodating both women with and without disabilities.

Study sites included the Zambia Library, Cultural and Skills Centre for the Visually Impaired. Among its many functions, this institution aims to rehabilitate visually impaired persons. It was a donation from the Finish Federation of the Visually Impaired and is situated in Lusaka's Chilenje residential area. It was officially opened in 1993. The other site visited was Miracle Disabled Association which is located in George Compound in Lusaka. The Association was founded by a Zambian woman with a physical disability in 2009. The association identifies individuals with any form of disabilities within George Compound and assists in rehabilitating them, provides social support and also provides elementary education to children. The Zambia Agency for Persons with Disabilities (ZAPD) was also visited, it is situated in Kabulonga area of Lusaka. Having been put in place by the government of the Republic of Zambia in 1996, ZAPD is the mother body of all disability organisations in Zambia, some of its functions are to plan, promote, habilitate, rehabilitate, and administer services to persons with any form of disabilities.

ZAPD was chosen because it is the mother body of all disability organisations in Zambia. The Zambia Library, Cultural and Skills Centre for the Visually Impaired and Miracle Disabled Association were chosen as a result of Snowball technique so as to meet the requirements of participants needed.

The other study sites included health facilities; University Teaching Hospital (UTH), Kanyama Clinic and Chawama Clinic. UTH is situated in Lusaka's Ridgeway area and is a third level national referral hospital. Kanyama and Chawama are first level hospitals situated in densely populated areas of Kanyama and Chawama respectively. UTH was purposively chosen because of its large capacity to offer cervical cancer services, Kanyama and Chawama were conveniently chosen.

3.3 Study Population

The study population comprised of women with physical and sensory disabilities (sight and hearing impairment) who were drawn from various disability centres in Lusaka District. Women who had multiple disabilities inclusive of cognitive impairment were not enrolled in the study in order to avoid compromising the rights of those who were unable to make independent decisions and provide informed consent. To get additional information, key informants from cervical cancer screening centres and also from disability organisations who deal with matters of health for the disabled were interviewed.

3.4 Sampling Procedure and Sample Size

Sampling in a qualitative approach is dependent on selecting cases that will provide rich information (D'Eath et al. 2005), therefore participants were purposively selected. In particular, maximum variation sampling method was used to select women with disabilities (Lofters et al. 2014). Maximum variation sampling strategy was used in this study because it enabled the representation of a wide range of variation among the women with. A sampling plan was designed to maximise the range of features in the population as shown in table II (Hancock et al. 2007). The severity of disability was determined using the Lawton Instrumental Activities of Daily Living Scale (IADL) (Appendix XIV).Considering that older women are more prone to cervical cancer, the sample was further grouped by age 18-35 and 35-49 (Chingore-Munazvo, 2012).

Snowball sampling technique was also used to select the women with disabilities because of the nature of the population of women with disabilities which is rather small and would ultimately rely on referrals to acquire the targeted number of participants. Through the snowball technique, key informants at the disability organisations introduced the initial primary participants to the researcher; it was from here that the participants were able to recommend other women with the required characteristics of physical or sensory disabilities, bearing in mind their level of disability and age. The research was explained to potential participants, those who were willing to participate provided written consent, those who were not willing were not forced to participate in the study. The total number of women with disabilities who were enrolled in the research was 12. This was achieved using a sampling frame (figure II) which had specific characteristics to look for in the participants, each specified characteristic had to be met for the women to be enrolled in the study. One woman for each category of disability was selected to participate based on the type of disability, severity of disability, age and location. By so doing, a sample size of 12 was acquired.

Expert sampling was used to select key informants from the disability organizations and health facilities. One key informant was selected from each institution visited, these were 6 in total.

Table II: Sampling Frame for Women with Disabilities

Setting	Disability type	Severity	Age
Urban	Physical (3) Sensory (3)	Mild Moderate Severe	18-35
Urban	Physical (3) Sensory (3)	Mild Moderate Severe	36-49

3.5 Data Collection Methods

Various methods were used to collect data, namely, key informant interviews, in-depth interviews, observation, and document review. Data collection was done in the order presented below.

3.5.1 Key Informant Interviews

Key informant interviews, particularly disability organisational leaders were important to this study because there was need for the researcher to understand the population of women with physical and sensory disabilities who were the focal point of this study. Key informants from the Zambia Library Cultural and Skills Centre for the Visually Impaired, Miracle Disabled Association and ZAPD facilitated access to the women with disabilities by acquainting the researcher with disability etiquette, and provided important expert information about the disabled community and their culture.

Having introduced herself to the directors of the disability organisations, the researcher was then directed to relevant administrative leaders who could provide the information required. After obtaining informed consent, an appointment was arranged at their time of convenience. All interviews were conducted privately within the study sites. Key issues which were raised include the measures which have been put in place to support cervical cancer screening for women with disabilities.

Key informants at the selected health facilities were important as they provided the necessary first-hand information concerning the screening procedure. The nurses who screened for cervical cancer provided information on their experience at the screening centre. Furthermore, there was need to know how they defined 'accessibility' of their services and whether the staff were competent enough to handle women with disabilities.

Varied expert views were collected concerning accessibility of the service to women with disabilities. Only the nurses who actually screened for cervical cancer were interviewed upon arranging an appointment. All the interviews were conducted privately in an examination room. The participants were informed about the study through an information sheet, they were all assured of maximum confidentiality. Key issues realised from interviews with these nurses include the fact that women with disabilities actually do go for screening but they are not going in large numbers hence the need to address this. Concerns were also raised about the inability to communicate with hearing impaired women.

3.5.2 In-depth Interviews

Having established a formal relationship with the key informants at the Miracle Disabled Association and the Zambia Library Cultural and Skills Centre for the Visually Impaired, the researcher was then introduced to the members of the organisations who were eligible to participate in the study. The women were then informed about the purpose and implication of the study. Those who were not comfortable withdrew and those who accepted proceeded to be participants. Interviews were held one on one within the various disability organisation premises. Women with hearing impairment however, were interviewed with the assistance of a sign language interpreter; this helped to ease communication boundaries. Through the in-depth interviews, the women highlighted their experiences encountered in accessing cervical cancer screening.

3.5.3 Observations

Observations were conducted at all selected health facilities for this study to determine how user friendly the facilities were for persons with disabilities. The researcher observed the physical structures, posters, signage, and hospital equipment among many other things. Photographs of the physical structures, hospital equipment and communication material were taken as a way of documenting what was observed and also to objectify the reality of the

situation which was found. Notes were also taken describing descriptions of the key components of the health facility using the checklist in table III.

Table III: Checklist of Case considerations for Observations

MOBILITY IMPAIRED CLIENTS
CASE CONSIDERATIONS
Clear signage
Disability parking
Accessible entrance to facility
Patronising medical staff
Exam rooms; Accessible route to and through the room, Accessible door with clear width and manoeuvring clearance, Adequate clear floor space for side transfers,
Patronising registry clerks
Examination tables Adjustable examination table-ability to lower to the height of the wheelchair Elements to support a person during transfer and whilst on the examination table (rails, straps, stabilisation cushions)
VISUALLY IMPAIRED CLIENTS
CASE CONSIDERATIONS
Clear signage; Braille markings for signage Large print for clients with minimal vision
Availability of resource people to orient or help locate specific areas of the clinic
Patronising medical staff
HEARING IMPAIRED CLIENTS
CASE CONSIDERATIONS
Availability of interpreter services
Patronising medical staff

3.5.4 Document Review

A document review of information, education and communication materials (IEC) was done in order to assess the accessibility of printed IEC materials for those with sensory impairments. IEC materials which were accessed include brochures and posters. Particular attention was paid to use of Braille and the ability of visual features to speak the message intended in the IEC materials. Availability of these materials was also considered. Documents relevant to the study were also analysed, namely standard operating procedures for cervical cancer screening, Persons with Disability Act and Health policy documents. The documents which were reviewed were the Persons with Disabilities Act (2012); the National Health Strategic Plan 2011-2015; the Zambian Strategic Plan 2013-2016 on Non Communicable Diseases; the Screen and Treat Manual (2014). These documents were read and re-read, brief notes of important findings were then taken note of.

3.6 Data Management

Thematic analysis was used to analyse data because it enabled the researcher to better organise qualitative information for analysis purposes (Cresswell, 2007). The different phases of thematic analysis include; familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining the themes, and lastly producing the report.

To begin with, interviews were recorded with a digital audio recorder. In order to facilitate familiarisation with the data, the audio-recorded data was transcribed verbatim. Transcribed interviews were then entered into Nvivo 10 software. The researcher then familiarised herself with the data by repeated reading whilst searching for meanings and patterns. Important ideas were noted.

Thereafter, codes were created to identify key words, concepts and reflections within the data. Braun and Clark (2006) define a code as a basic segment of raw data that can be assessed in a meaningful way regarding the phenomenon, a phrase can be used to represent aspects of the data. This was done by tagging and naming selections of text within the data. These codes were deductively arrived at through information gathered from the literature review. By reading through the transcripts, the researcher was able to ensure the consistency and validity of the codes.

The next step was to generate themes from the coded data. Themes emerged from patterns in the conversation topics in the transcribed interviews, frequency of occurrence of these

patterns were noted. The different codes were sorted into potential themes. Notes gathered from observations and documentary reviews were integrated into existing themes. However, some information from the document analysis called for the creation of more themes. Table IV illustrates themes and their sub-themes.

The next step was define and name the themes, this involved identifying the meaning behind each theme and determining the aspect of the data that the theme portrayed. A critical analysis of each theme was conducted in order to gain deeper understanding of the subject matter. This method allowed for a thorough analysis which allowed the researcher to capture information as perceived by the interviewee. After a thorough analysis the data was interpreted accordingly. Finally, a report was written.

Table IV: Themes Emerging from the Findings

CODES	THEMES
Limited knowledge Beliefs Negative previous medical experiences	**Individual Factors**
Communication challenges Social support	**Interpersonal Factors**
Inadequate income Inappropriate transport Distance to nearest health facility	**Socio-economic and Political factors**
Structural design of health facility Inappropriate equipment Inappropriate IEC materials Inappropriate skills of service providers Confidentiality of service	**Service related factors**
Inadequate enforcement of legislature Lack of inclusive health policies	**Policy and legal factors**

3.7 Ethical Consideration

The study was submitted to the University of Zambia Biomedical Research Ethics Committee (UNZABREC) for ethical clearance and the reference number is 014-06-15.

3.7.1 Respect for Persons and Confidentiality

All participants were fully informed about the research and provided written consent without being pressured to do so. Varying levels of literacy were considered by the researcher reading out and explaining the informed consent sheet for those who were unable to read. Those who were unable to write were allowed to sign using their thumb print. In addition, the interviews were conducted in a private environment to allow for confidentiality. Permission was requested to record the interview using an audio recorder; identification numbers were assigned to the interviewees to avoid use of their names. Furthermore, the sign language interpreter was asked to sign a confidentiality agreement form in order to maximise confidentiality (see appendix VII). In addition, the researcher ensured that all written and recorded information gained from the research was protected. Written documents and audio records were kept under lock and key and restricted to the researcher in order to maximise confidentiality.

All participants were subjected to the same interviews regardless of their disability. In addition the language used was chosen by the participant to maximise comfortability and understanding. Sign language was used to communicate with hearing impaired participants. A sign language interpreter was engaged to assist in this task.

Each participant was given the chance to express themselves freely without being rushed through the interviews. Those who got tired due to the nature of their disabilities were allowed to take refreshment breaks. This was experienced with one pregnant visually impaired woman and also a severely physically impaired woman.

This study was sensitive because of the nature of persons who were the focal point of the study, the women with disabilities. The researcher exercised care in the terminology used to describe ‘disability’. Therefore the term ‘disabled’ was not used at all in this study when referring to the participants. In order to maximise transparency of the research findings, disability organisations from which the participants were sought were included in the dissemination of the research findings.

3.7.2 Beneficence

The participants were informed that there would be no direct benefit from participating in the study. However, it was emphasised that their participation would contribute to scientific knowledge. There was no reward for the time spent during the interviews. Refreshments were however offered to participants after the interview. The need for transport reimbursements was eliminated because all interviews were conducted at the study sites during the participants’ regular visits there.

The nature of participation was through verbal interaction, participants were assured that no physical harm would come upon them. Participants were however informed of the likelihood of uneasiness in responding to some questions, they were however encouraged to freely share their experiences and opinions.

3.7.3 Fairness

The criterion used for the selection of participants was fully explained beforehand. Eligible participants were accorded the same opportunity to participate or decline. Ethical clearance was sought from UNZABREC.

CHAPTER FOUR

4.0 RESULTS

Overview

This chapter presents findings from the study in line with the objectives which aimed to ascertain the accessibility of cervical cancer screening. The term 'accessibility' in this study, refers to the ability of women with disabilities or their potential to use the cervical cancer screening service in public health facilities. The results are presented under five major themes, namely; Individual factors; interpersonal factors; socio-economic factors; service related factors; and policy/regulatory factors. The findings of the study are illustrated through the themes, sub-themes and average responses derived from the study.

4.1 Participant Characteristics

As illustrated in table V, a total of twelve (12) primary respondents participated in the study. Six (6) of these had sensory impairment, in particular, hearing and visual impairments. The remaining six (6) represented physical impairments. The levels of disability varied per individual, representing mild, moderate, and severe disabilities. Five (5) of these women were married, one (1) was widowed whilst the remaining six (6) were married. Four (4) were employed, two (2) were doing business activities while the remaining were unemployed. Only four (4) of these women had received tertiary education, three (3) had been to secondary school, three (3) had primary education while two (2) had never been to school.

Table V Characteristics of Primary Participants

PARTICIPANTS	AGE	DISABILITY TYPE	MARITAL STATUS	EMPLOYMENT STATUS	EDUCATIONAL LEVEL
IDI 01	30	Moderate hearing impairment	Single	Employed	Tertiary
IDI 02	32	Mild hearing impairment	Married	Employed	Tertiary
IDI 03	43	Severe hearing impairment	Married	Employed	Tertiary
IDI 04	28	Moderate visual impairment	Single	Unemployed	None
IDI 05	36	Mild visual impairment	Single	Business	Senior secondary
IDI 06	45	Severe visual impairment	Widowed	Employed	Tertiary
IDI 07	43	Moderate physical impairment	Married	Business	Primary
IDI 08	30	Moderate physical impairment	Married	Unemployed	Junior secondary
IDI 09	36	Severe physical disability	Married	Unemployed	Primary
IDI 10	30	Severe physical disability	Married	Unemployed	Primary
IDI 11	28	Mild physical impairment	Single	Unemployed	Senior secondary
IDI 12	49	Mild physical impairment	Married	Business	None

4.2 Individual Factors

The first objective of the study was to explore the individual factors which influence the accessibility of cervical cancer screening among women with physical and sensory disabilities.Individual factors are issues which affect women with disabilities in accessing cervical cancer screening at a personal level. As shown in table VI, themes which emerged from the data are limited information and negative previous medical experiences. Each category of disabilities related differently towards the themes with some having similar sentiments.

Table VI: Theme-Individual Factors

	INDIVIDUAL FACTORS	
SUBTHEMES	**Limited information**	**Negative previous medical experience**
HEARING IMPAIRED	Did not know much about cervical cancer	Reluctance to access healthcare in future
VISUALLY IMPAIRED	Did not know much about cervical cancer	Reluctance to access healthcare in future
PHYSICALLY IMPAIRED		Reluctance to access healthcare in future

4.2.1 Limited Information

Regardless of disability types, most of the women reported that they were aware that cervical cancer was a disease but did not know much about it in detail in terms of causes and risk factors. "*There's nothing much I know about cervical cancer, only that it affects the private parts of a woman"(IDI 01).*

The health service providers were all in agreement that women with disabilities were not showing up for screening in large numbers, this was attributed to limited information. "*I think that maybe you should also amplify on the importance of them also coming in for screening because we are not seeing them much, though the message is given to everyone" (KII03.)*

The limited availability of information in a form that can be clearly understood by women with disabilities clearly contravenes the PWD Act (2012) which clearly states that information should be made available and accessible in Braille, sign language and anyother appropriate formats for people with disabilities in order for them to have necessary information on health matters.

4.2.2 Negative Previous Experience

Some who had previous negative medical experience did not easily make a decision to go for screening due to fear of harsh treatment. For instance, some women with hearing disabilities reported that sometimes the doctor would not even write back to them when they tried to use writing as a way to communicate. Other women complained that women with disabilities did not always receive the kind of care that they needed, as a result they did not feel motivated to visit the clinic.

> ... If you find those that do not have that heart to attend to disabled people, it really discourages us, if you find good medical officers it is good and even tomorrow you will be there (IDI 07).

Discouragements to visit the hospital also arose from discrimination which reportedly had been experienced by some of the women in various forms as illustrated in the following quote where a woman with physical disability was being addressed by other patients at a named clinic;.... "haha no, this one *kwati nifwe tabalemanike....*" (as if it is us who made them disabled) (IDI 12).

Clearly, the sentiments above were against the PWD Act (2012) which emphasises that women with disabilities should not be discriminated against. They should be free to access any available services without fear, just like any other member of society.

4.3 Interpersonal Factors

The study explored the interpersonal factors which influenced the accessibility of cervical cancer screening among women with physical and sensory disabilities. Interpersonal factors are issues which arise through interaction with other people. Table VII illustrates that most of the women shared similar sentiments on the communication challenges and social support issues.

Table VII: Theme- Interpersonal Factors

	INTERPERSONAL FACTORS	
SUBTHEMES	**Communication challenges**	**Social support**
HEARING IMPAIRED	Difficulty expressing themselves to service providers	Important for friends and relatives to assist with resources or accompany them to the clinic
VISUALLY IMPAIRED	Unawareness of activities in their surroundings leads to uneasiness	Important for friends and relatives to assist with resources or accompany them to the clinic
PHYSICALLY IMPAIRED		Important for friends and relatives to assist with resources or accompany them to the clinic

4.3.1 Communication Challenges

Challenges in communication were a common factor amongst women with hearing impairment regardless of the level of severity. Some women lamented that clinical staff were not able to communicate with them in sign language and that there were no sign language interpreters at the hospitals.

> ...they were a asking me questions that time which I wasn't hearing. Then they told me that, which other means can we talk to you? Can we sign? Then I told them no, but I will write, then I will be answering you back and that's how one started writing for me (IDI 01).

> If there are no interpreters you are required to write. Most of the times doctors and nurses are in a hurry they don't even explain, they are in a hurry ... those are the

challenges we have (IDI 03).

Those who were literate were able to write down what they wished to communicate to the health care provider, However, some participants with hearing impairment expressed concerns about hearing impaired clients who were unable to write.

> ...When you go to the hospital you have to write to speak to the doctor, now how about the deaf who cannot, it would be difficult explaining these things to them (IDI 03).

Problems in communicating resulted in some women shunning visits to clinics completely due to frustration, especially when there was no one available to interpret results.

> Most of the time I'm put off, even when I'm sick when I go there I always have to have someone accompany me, if there is no one to help me speak by interpreting for me, it's usually a problem so I prefer not to go (IDI 09).

Availability of someone to help with interpretation was said to ease visits to the clinic. Women with hearing impairment mentioned that it is difficult to visit the clinic on their own, but having an interpreter would make it easier for them.

> If interpreters were prepared adequately it would be easier but for a deaf person to go on their own it would be very difficult (IDI 03).

Some cervical cancer screening service providers reported that communicating with a client by writing to each other was not an ideal method to ease communication because it did not allow for adequate collection of information. It also can be disadvantageous for clients who are illiterate because they are not able to read or write.

> ...we would give them a paper and they would write. Though sometimes we wouldn't get comprehensive feedback because when we ask like, have you ever had an HIV positive test in writing and that person does not understand what you are trying to say you can't get anything, but then for those are able to write you can get something (KII 05).

Some cervical cancer screening service providers also stated that when appointments were made for individuals with communication challenges, it was easier to attend to them, unlike when they arrived unexpectedly.

> ...like those ones who had problems with just the ears and speech, the person that came to make an appointment came earlier than the patient so we knew what we were expecting so it didn't come as a surprise. There are times when we had clients who came on their own and they had problems with speaking and hearing... (KII 05).

It also came to light that service providers prefer women with communication challenges to be accompanied because it becomes easier to attend to them.

> Sometimes I might receive a person with disabilities who is unaccompanied. It becomes a challenge for me to give the needed care or quality care for that client because maybe there is difficulty maybe in communication, maybe she's using sign language and the same time she's lame, she comes alone, it becomes very difficult because there is this breakdown in communication (KII 04).

Lack of training on how to handle persons with disabilities reduces effective communication and this can often lead to frustration on the part of the client when not handled in a fitting manner.

> You are in a queue but you are deaf, and then they call the name of a deaf person but you are deaf and you can't hear that name so you continue sitting and they get tired of calling thinking the person has gone somewhere so the deaf person will be at the hospital the entire day (IDI 03).

Health facilities are required by law to enable effective communication to take place within their premises. This is outlined in the PWD Act (2012) which calls for health facilities to ensure that appropriate measures are put in place in order to ensure that persons with disabilities are enabled to communicate effectively. The PWD Act also calls for health service providers to provide the same quality of care through relevant training.

4.3.2 Social Support

Out of 12 women with disabilities, 11 of them reported social support to be important in accessing cervical cancer screening regardless of the disability. Social support was described in various forms. For instance some women explained that they received financial assistance from friends and relatives for logistical purposes when there was need to visit the hospital.

The women with visual impairment noted that it was very difficult to find their way around without assistance, so without somebody to accompany them they could not visit the clinic. "*...a blind person like myself, I can't travel on my own. It's very difficult to be mobile, I need a guide"* (IDI 06).

Those with hearing impairment mentioned that having social assistance helped with mobility but limited their privacy whilst others said that there was no need to have social support because they were independent and could manage a tricky situation should communication become a challenge. "*I do not depend on other people... there's no need to bother other people*" (IDI 03).

Women with severe physical impairment received assistance in getting medical attention through assistance in pushing the wheelchair or organising transport. Most women mentioned that when need arose they were accompanied to the hospital by friends and relatives to ease mobility.

> ...families or our neighbour, they usually sometimes organise some transport money.... they get some taxi if money is available. Sometimes they can even carry at their backs (IDI 07).

Disability organisations were recognised as part of social support networks for some women with disabilities. Some organisations were able to organise support to assist their members when need arose. At a named organisation, some members were able-bodied, these volunteered to assist with ferrying ailing members to the health centre whenever need arose. Sometimes assistance was given to members in form of money. "*In case of sickness, yes they come... if we have we help them*" (KII 01).

4.4 Socio-Economic Factors

The second objective was to identify socio-economic factors which influence cervical cancer screening among women with physical and sensory disabilities. Socio-economic factors are those issues which involve a combination of aspects which affect lifestyle and economic realities that influence a woman's decision to go for cervical cancer screening. The themes that emerged through this study were inadequate income; long distance to health facilities; and inappropriate transport.

Table VIII: Theme- Socio-economic factors

THEMES			
SUBTHEMES	**Inadequate income**	**Distance to nearest health facility**	**Inappropriate transport**
HEARING IMPAIRED		It is inconveniencing trying to locate the nearest cervical cancer screening centre	
VISUALLY IMPAIRED	Unable to afford transport fares limited access to information because not everyone can afford a newspaper or television		Unable to afford fares
PHYSICALLY IMPAIRED	Unable to afford transport fares limits access to information because not everyone can afford a newspaper or television		Depending on the severity, buses can be difficult to use because of inadequate space and leg room

4.4.1 Inadequate income

Women with disabilities, who were unemployed and not engaged in any business activities, reported that they did not have enough income to sustain their needs. This challenge affected their access to cervical cancer screening in two ways. To begin with, many of them were unable to afford to buy televisions, newspapers or magazines from which they could possibly obtain information on cervical cancer coincidentally. Secondly, transport fares were often not affordable to the women *"... even if I had to book a taxi, where would the money come from?"*(IDI 10).

Disability organisations such as Miracle disabled were aware of the low socio-economic status of most of their members. Because of this, efforts were made to assist them in any way possible when need for financing arose. ZAPD was also able to finance medical bills such as examination fees, or procurement of prescribed drugs and assistive devices.

> ...since 2014, we have a program under medical support program where we are able to pay depending like...let's say that maybe someone comes for an x-ray that's what we are able to pay for, and maybe buy them medication, as long as they have a prescription. And also on the medical part, we are talking about assistive devices such as looking for artificial limbs, we are able to pay for them, so that's what we are doing medically and through health (KII 03).

4.4.2 Transport

Women with physical and visual disabilities reported the most difficulty in getting to health centres due to the inappropriate type of public transport available. Space was necessary for comfort and also to store wheelchairs when necessary was reportedly too little in most mini-buses which were a comparatively cheaper mode of transport.

> It is difficult to use mini-buses, especially the small ones, space is little. The worst part is that taxis are expensive so it is better to just find someone to push me on a wheelchair (IDI 12).

Although buses were a cheaper mode of public transport, most women with physical disabilities preferred taxis due to issues of space and comfort and convenience of being dropped right at their destination. *"... I cannot manage to walk a long distance, even when going to the clinic, I need maybe a taxi"*(IDI 08).

Limited availability of appropriate transport contravenes the PWD Act (2012) which states that persons with disabilities ought to be accorded the opportunity to access transportation on an equal basis with others. In addition, the Act encourages the purchase of disability friendly vehicles as well as gadgets which can enhance accessibility of public service vehicles.

4.4.3 Long Distance to Screening Centres

Long distance to cervical cancer screening centres was a common problem regardless of the type or severity of the disability a woman had. *"What makes it difficult is maybe distance from our homes to the clinic"* (IDI 12). A hearing impaired woman went on to bring out the fact that if she had a health facility closer to her, she would go for screening.

> ...I'm sure I would go instead of having to move, right now you have to go to Chilenje clinic or Chainama but I'm here right now, If I had somewhere closer something closer to me, it could be a one-stop thing, just go there! (IDI 02)

The need to travel long distances without any form of vehicle was reported to be a cause of great discomfort amongst many women, especially those with visual and physical disabilities. *"...my condition makes it very difficult to go to the clinic because it is far, it is very uncomfortable to get there without transport"* (IDI 11).

4.5 SERVICE RELATED FACTORS

The third objective was to examine service related factors which influence cervical cancer screening among women with physical and sensory disabilities.Service related factors refer to the capacity of health facilities to facilitate the cervical cancer screening service for women with disabilities. Sub-themes which came out prominently include the following, structural design of the health facility; inappropriate equipment; access to information, education and communication (IEC) materials; confidentiality of service; limited skills of service providers. A brief summary of major points is outlined in table VIII below.

Table IX: Theme- Service Related Factors

THEMES	**SERVICE RELATED FACTORS**					
SUBTHEMES **HEARING IMPAIRED**	**Structural design of health facility**	**Inappropriate equipment**	**Access to IEC materials** Print media alone is not enough because not all hearing impaired people are literate	**Confidentiality of service** The need to have an interpreter compromises confidentiality of the service	**Limited skills of service provider** Communication challenges with service providers	**Rumours about the service** Delay/ reluctance in seeking screening services
VISUALLY IMPAIRED	Difficulty finding their way around the health centre		Need for alternative ways to pass on information i.e. Braille transcribed brochures and interactive programs		Engaging the individual in conversation and keeping them aware of what is happening around them is often difficult for the service provider	Delay/ reluctance in seeking screening services
PHYSICALLY IMPAIRED	Difficulty in properly using the facilities	Difficulty in using the available examination tables	There is need to reach out to the women, interact with them one on one	Severely impaired individuals have problems with confidentiality when there is need for someone to assist in lifting	Physically handling individuals without causing discomfort is often a problem	Delay/ reluctance in seeking screening services

4.5.1 Structural Design of the Health Facility

Field observations revealed that the health centres were not easily accessible. Each health facility observed had its own unique number of issues, these were; narrow doorways, steps at entrances, narrow corridors and inappropriate toilet facilities.

Figure II: A crowded corridor at a named health facility

For example, the crowded corridors in figure II did not allow for free movements of people. This corridor was the route to the cervical cancer screening examination room. Some benches along the corridors provided seating space which apparently made the corridor narrower, an individual with a severe physical disability could face difficulty manoeuvring in such an environment.

Observations also revealed that out of the three health facilities visited, one had an examination room which was very small. All the necessary equipment was fitted inside but there was little room for manoeuvre.

Figure III: A step/ narrow doorwayat a named health facility

It was also observed that steps were present at some of the entrances to the buildings from which cervical cancer screening was carried out. Figure III shows a step at a door which could cause difficulty for persons with physical disability. In addition only one side of the door was kept open thus causing the doorway to be narrow.

Two out of three cervical cancer screening service providers did not see anything wrong with the architectural designs of their clinical surroundings, and the space in which they conducted cervical cancer screening. This was because they felt that the environment was suitable for conducting screening. *"I see nothing wrong with this place, women are able to enter the building and find their way around"* (KII 06).

Disability organisations were in agreement that the structural designs of many hospitals and clinics were not good enough to allow women with disabilities to access their services.

> At least every disabled person should have access to the building like even the toilets, they are not all that good. They are not friendly for a person who is disabled.... who cannot use the type of toilets that are there. It all contributes to people with disabilities not going to the clinic also. And then again the buildings, their doors, maybe we can say that the wheelchair cannot go in so all those are challenges (KII 01).

The current situation shows little implementation of the PWD Act. Through document study it was found that the PWD Act (2012) urges health facilities to identify and eliminate barriers to accessing health care. It goes on to say that minimum standards must be prescribed at health facilities.

4.5.2 Inappropriate Equipment

Field observations showed that all the health facilities visited had appropriate equipment for the screening of cervical cancer except for the examination tables. The examination tables were of fixed height, thus posing a challenge for individuals who were unable to get onto it with their own strength.

Figure IV: A fixed examination table

For example, figure IV shows an examination table of fixed height. It cannot be lowered to the level of the client. This type was found in all the health facilities visited.

The step next to the examination table is provided to assist women to climb onto it. However, this step cannot be used easily by all individuals.

A health service provider observed that the examination tables were posing a challenge to women with disabilities. "*I think the one that I can say... the difficulty is in trying to get on the examination table because you usually have to help them get on the examination table*"(KII 05).

The examination table was identified as a difficult item to use by the women who had physical disabilities. Getting onto the examination table was said to be a challenge. "*The bed was a little bit high so I wouldn't have managed on my own getting on the bed. I needed a little help and the nurse was able to help me to get onto the bed"*(IDI 12).

Some service providers argued that the equipment which their centres had was good for screening but its use on women was disabilities was dependent on the disability involved. "*...with equipment, I think what we are using is conducive but it depends with what disability*" (KII 03).

One service provider argued that the available equipment was inappropriate and went on to suggest having a special screening room for clients with disabilities alone.

> And then the physical, maybe the severe ones, those that are on a wheelchair there would probably be a need to... a room that is made especially for them so that they can be more comfortable... probably they need a specialist room with a bed that they can use so that we are able to provide them with a service (KII 02).

A document analysis revealed that it is clear that the cervical cancer screening manuals have served a practical purpose because the set up of the cervical cancer examination rooms which were found in the health facilities fit the ideal examination room suggested in the cervical cancer screening manual.

Figure V: An ideal screening room
Screen and treat training manual (2014) p.56

The picture in figure V was extracted from the Screen and Treat Training Manual (2014), it reflects an ideal screening room for a resource constrained setting. Although this room had the necessary equipment for a screening procedure, it could cause great difficulty for women with severe physical

disabilities to access it. To begin with, the examination table cannot be adjusted neither does it have rails on either side. Although the room is relatively spacious for movement, the way in which the bed is positioned does not allow a client to mount onto the examination table from either side. This may prove difficult to some clients who can only use a particular side of their body, left or right.

Although the cervical cancer screening manual has no mention on how to effectively screen women with disabilities, it has some practical suggestions which can work for women with disabilities.

Figure VI: Stirrups supporting a woman's legs
Screen and treat manual (2014) p.59

For example, the picture in Figure VI shows an examination where a woman's legs are being supported by stirrups. The use of stirrups in the examination can help ease the difficulty that women with physical disabilities affecting their lower limbs may face when positioning themselves on the examination table. When stirrups are not used, the client must correctly position her legs at the end of the examination table using her own strength, this may be a challenge to some women.

It is evident that examination tables are not accessible in all health facilities despite having legislature through the PWD ACT (2012) which states that health facilities must procure appropriate equipment to aid assessment of persons with disabilities.

4.5.3 Access to Information, Education and Communication (IEC) Materials

Regardless of the type of disability, the women reported having difficulty in accessing information related to their health.

> ...it's not all that easy for persons with disability to access such information. You have to struggle, like I said, you just have to struggle to make sure you participate in what is going on in society (IDI 03).

It was generally agreed that people with disabilities were not considered when formulating health messages because the women with disabilities felt left out.

> ... ok it's not the first time that people are talking about cervical cancer... I'm sure that they have never heard of it, unless those like myself who have heard about it on the TV. So it's very difficult to have people come into the community and talk about it. Sometimes ok not only about this cervical cancer, maybe about some other things. These people they don't think about coming to us so we as disabled people we are always left behind (IDI 01).

Health facilities used various ways to sensitise the community on cervical cancer screening. Some of the tactics involved were health talks with members of the public as they access out-patient services and also awareness campaigns within the community itself.

> We do sensitise as a clinic on a daily basis, because even in OPD, the outpatient, we do sensitise on a daily basis, ART clinic we do sensitise on a daily basis. Sometimes we even target the people in our community, we send our volunteers to sensitise to the people there (KII05).

However, their methods of delivery did not have much consideration for persons with disabilities. Common methods of sensitising the community included cervical cancer awareness talks with outpatients as they waited to receive medical attention; community health talks where peer educators or volunteers went into the community to spread the news on cervical cancer, posters and also brochures.

> I: So in that sensitisation package, do you have any special package for women with disabilities?
>
> R: I would say yes we have because ... the message is the same for everyone, whether they have a disability or not, except for those that use sign language but if they are

> able to read we still give them the same brochures. But then for the visually impaired we don't have anything that we can give them in (KII 04).

ZAPD and Miracle disabled were aware of the challenges in sensitising women on reproductive health matters and agreed that there is need to be more rigorous in their approach.

> First and foremost, may be, like lack of information just like the way you have come , sometimes we need to do may be sensitisation, then after that awareness, we need to go around, may be like us, especially us like myself because if I tell them all this disease affect us as women, may be from me there will understand, we go around in the community, we do the sensitisation or may be call up a meeting, we meet together and may be, we talk about it (IDI 07).

Out of three disability organisations visited, only one had a standing program to target women separately by having informative discussions with them and organising reproductive health services for them. The others simply chose to have a collective program for both men and women. "*Women in particular, we have not touched that surface, we have not marginalised the women. You see, what we are doing is collective, it's for everybody*" (KII 06).

It was emphasised that there ought to be a clear cut strategy on informative programs targeted at persons with disabilities because their ability to take in information varied. Reproducing material in Braille format was noted as a challenge because it was expensive.

> ...there should be some difference for persons with disabilities because they are more challenged than the able bodied person.... persons with disabilities should be able to get some \information in one way or another....with the deaf some pictures with a bit of writing.... Braille is expensive, to put things into Braille is an expense... (KII 06).

It was generally agreed that there was need to go down to the grassroots, at the level of persons with disabilities in order to better deliver the message to them.

> you need to go with people who understand them because persons with disabilities ... I don't mean to say that they are not educated but the level of understanding is different from other people so when going there you need to be at their level (KII 06).

It was observed that posters and brochures were used to inform the public on cervical cancer.

However, the way in which this information was relayed had no deliberate effort to reach out to persons with disabilities in mind. For instance, relatively large print materials would be preferable for somebody with limited vision unlike the normal printed material which was found on the ground. In addition, no Braille was seen on the brochures and posters.

Figure VII: Cervical cancer sensitisation poster

For example, figure VII is a poster that is intended to promote cervical cancer screening. Awoman with limited vision may find it difficult to read because of the small font which was used.

4.5.4 Confidentiality

Women with disabilities faced challenges in achieving confidentiality depending on the type and severity of disability. The presence of a third person during a physical examination was necessary for various women depending on the severity and type of disability. For instance, severely physically challenged women needed assistance being transferred from their wheelchairs and in dressing whereas severely hearing impaired women needed assistance with interpretation.

> ...These days it's very hard to have privacy, wherever you go, you have another person to interpret... so when you are getting your results, another person gets them before you. Interpreters spread the news about a deaf person (IDI 03).

Although confidentiality proved to be a challenge to accessibility, some health service providers argued that it was impossible to handle the client alone when the disability was severe. This was also seen as a problem when there was a communication challenge with to hearing or speech impaired clients.

> It is difficult to handle those who are on the wheelchair because they need to be lifted

> onto the bed, somebody has to help me to do that. And then there are those who cannot speak, but most of the time they come with someone, they rarely come alone (KII 06).

The health service providers acknowledged that they gave the clients a choice to choose whether or not to have a third party present during the examination. "*...I ask if the relative can stay during the exam, if the client is not comfortable I tell the relative to wait outside*" (KII04).

4.5.5 **Limited skills of service providers**

It was revealed that health workers did not receive any form of training regarding individualised care for persons with disabilities. Whilst various forms of disabilities were learnt in the curriculum, there was no special mention on how to care for or communicate to a person with a disability. Individual service providers talked to mentioned that they saw no problem in handling persons with disabilities, adding that one just had to reason on how to handle such a client so as to deliver a quality service to their clients.

> There's no form of training that is done specifying on disability alone, ya, we just receive everyone. But when we see a disabled person we just have to know to say this one, ok, we'll need time with them, trying to assist that client that we have... Well, we learn disability but not really special care, sign language, things like that, no, ok (KII 04).

At least two of the three service providers were of the opinion that they needed additional skills to improve their service delivery.

> especially the communication part of it, especially those that are deaf and dumb because it's quite difficult if this woman comes to seek a service and then you can't communicate so we face a very serious barrier so I think the sign language part of it, I think we need it (KII 05).

4.5.6 Rumours about the Service

Rumours were found to be common, influencing women's decisions to go for screening by delaying their visits to the hospital. The most common rumour found was that of the procedure being painful and use of the same instruments on different clients without sterilisation. Although some women had been for screening despite hearing these rumours,

they reported having delayed their decision to actually get screened upon hearing these myths.

> Yes I delayed a bit because I heard that the instrument that they use is very painful so I got scared, especially that I'm disabled so I didn't know if I would be able to handle it. Eventually, I comforted myself saying that even if it hurts, the pain will stop so I must get tested. Anyway, I discovered that it wasn't painful at all, people were telling lies (IDI 10).

Health service providers were aware of the beliefs that women in the community held.

> ... the fear is associated with the examination process itself because the word that has gone out in the community is that the examination itself is uncomfortable because of the speculum which they call '*inshimbi*' (metal) they say it's painful and stuff like that..... and then the other belief is when they start bleeding, they are probably symptomatic of cancer but they think they have been bewitched. So that also causes delay in seeking treatment (KII 05).

Despite these rumours spreading in the communities, cancer screening centres reported that they still received a good number of clients went go for screening. "*Then there are myths which are there to say that "no, this thing is painful, they put in a big instrument" but people still flock in, they come"* (KII 04).

4.6 POLICY/ REGULATORY FACTORS

Policy or regulatory factors refer to principles by which the Zambian government is guided in providing health services. A document study was done to ascertain what measures have been put in place to ensure that cervical cancer screening is made more practical for women with disabilities.

4.6.1 Poor Implementation of legislature

A review of the PWD Act (2012) reveals clearly outlined guiding principles to make health services accessible, however, there has been little implementation of this Act. The Act covers most of the issues which were brought up in this study, namely, structural designs, transport; screening equipment; communication strategies; professional skills; and discrimination. The

document goes further to mention that inspectors will be appointed to ensure that institutions comply with the guidelines, however, what is happening on the ground does not fully match what has been prescribed in the document.

4.6.2 Exclusion of Women with Disabilities from Health Policies

It also came to light that women with disabilities were excluded from national health policies. Two documents were analysed in view of health policies concerning cervical cancer, these were, the National Health Strategic Plan 2011-2015 and the Zambian Strategic Plan 2013-2016 on Non communicable Diseases discusses. The documents mention the need to make health care services equitable for all persons in Zambia, however, there is no specific mention of women with disabilities. The Screen and treat Manual (2014) serves as a guideline for correct and efficient cervical cancer screening and management, However, screening of women with disabilities was not mentioned in the manual. However, the document does mention measures to aid screening which can be applied to women with disabilities, such as providing a stool to assist women to get on the examination table.

Summary

This study sought to ascertain factors that affect the accessibility of cervical cancer screening. From the data collected, three major themes stood out, these were; individual and interpersonal factors; Socio-economic and political factors; and service related factors.

Women with visual impairment described a sense of unawareness of the activities that took place around them when they weren't actively engaged in communication with service providers. The negative experiences which most of them had, led them to shun seeking medical attention even when a need for it arose. Social support was seen as a necessity for them to acquire medical attention due to the various difficulties encountered when done alone. These women had limited personal income thus making them vulnerable by having limited access to information on cervical cancer and also difficulties in accessing transport to distant health centres which offered cervical cancer screening. Access to appropriate formats of IEC materials is limited. The fairly friendly structural designs of health facilities make it difficult for women with visual impairments to find their way around the health facilities.

Like visually impaired women, hearing impaired women also find communication to be a major obstacle. These women have limited information, this could be caused by limited

access to appropriate IEC materials. Their negative medical experiences also appear to have affected their usage of medical facilities. Social support was seen as important but not a necessity in accessing health care. When affected by the long distance to the health centre, they find it inconveniencing that they cannot use a health facility closer to them. Hearing impaired women have their confidentiality compromised when interpreters are used during cervical cancer screening.

Women with physical impairment have a major obstacle in the structural design of the health facility, especially when they have a severe impairment. Severe impairment in the lower limbs also seriously hampers the ability to use examination tables without experiencing any discomfort. Inappropriate medical equipment inadvertently leads to minimal interruption of confidentiality due to the need to engage a third party to assist in transfers from one point to another. These women are made vulnerable due to limited income which in turn affects ability to afford informative materials and transport fares to far off health facilities.

Legislature through the PWD Act (2012) fully covers the accessibility of health services ranging from communicative materials, access to buildings, access to transport and even the appropriate skills of the service providers. Health policies however do not exclusively single out persons with disability, mention is simply made on the need to make health services accessible to all Zambians.

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CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS

Overview

The study set out to determine factors influencing the accessibility of cervical cancer screening services among women with physical and sensory disabilities in Lusaka District. In relation to the objectives, factors that affect accessibility of cervical cancer screening were categorised based on individual/interpersonal factors; socio-economic factors; services related factors and policy/legal factors. This chapter discusses how the results from this study compares with similar studies based on the mentioned categories.

5.1 Individual Factors

This study found that most women with disabilities have limited knowledge about cervical cancer. Most women with information on cervical cancer only knew that it was a reproductive health problem for women. Few women actually knew what cervical cancer was all about in detail, thus missing out on important information such as risk factors and preventive measures. The struggle is quite significant regardless of the disability that a woman has.

Other findings show that previous negative experiences in accessing health services are likely to obstruct one's intentions of accessing healthcare in future. Results from this study point out that negative experience often leaves a permanent scar of fear of the unknown in women with disabilities, this results in hesitation to seek medical assistance of any kind, cervical cancer screening inclusive. Common complaints experienced by the women include discrimination due to their disabilities and also lack of disability courtesy both from members of the public at health facilities and medical staff.

Findings on women with disabilities having limited knowledge is consistent with Mele et al (2005) who found that women with disabilities had limited knowledge due to inappropriate formats of disseminating information. Challenges in communication was also noted by Drainoni et al. (2006) who aimed to document barriers to health care for people with disabilities reports similar findings to that of this study which indicated that women with disabilities often feel agitated or vulnerable when unable to communicate effectively with

clinical staff. Negative medical experiences which affect future decisions to seek health care services relates with Mele et al. (2005) who found that women whose medical experiences were negative often felt degraded and insulted.

It is evident that when women with disabilities have a friendly experience at a health facility, they are more likely to return for medical attention when need arises. This is more so when members of staff themselves provide a welcoming environment for them. Medical staff should be encouraged to treat all patients and clients which respect, women with disabilities in particular have special needs for courtesy which ought to be recognised. There is need to evaluate reasons behind negative medical experiences so as to encourage positive experiences.

Collective effort is needed from all stakeholders in order for women with disabilities to have more information on cervical cancer and its screening services. Keeping women with disabilities informed on health matters is not the task of disabled persons organisations alone, but also the health sector. Interestingly, relative authorities have not taken as much effort to sensitise the public on cervical cancer and yet it is responsible for most cancer deaths amongst women in Zambia.

5.2 Interpersonal factors

Findings show that women with sensory disabilities often face significant challenges in communicating with service providers at health facilities. Communication breakdown with visually impaired women occurs when they are not informed on all the activity going on around them, this may be at any point during a visit at a health facility. When visually impaired women find themselves facing a communication breakdown, they tend to feel uneasy in the environment in which they are in. Hearing impaired women are also affected by communication breakdown as they can get frustrated due to failure to communicate with the health care providers.

Findings of this study also revealed that the availability of social support networks contributes to the accessibility of cervical cancer screening services in a positive way. Social support is derived from friends, relatives, neighbours and well-wishers from organisations which an individual may be affiliated with. Social support is an aspect of Zambian culture which calls for people to help one another as individuals do not exist in isolation. It is a great way of enhancing the well-being of women with disabilities as it boosts their mental and

physical health. Most women in this study reported receiving social support in form of money when there was need to visit the health facility. This money is often used for transport and other logistics. Other support which was commonly received is moral support rendered in form of accompanying or encouraging one to visit the health facility.

Dissemination of information about cervical cancer seems to side-line persons with disabilities. Although information is available, not all this information is designed to reach out to persons with disabilities as it is rarely delivered in disability-friendly formats. It is assumed that the more knowledgeable people are about a disease and health services, the more likely that action can be taken to prevent contracting the disease. Having information empowers women with disabilities to make healthy choices and knowledge on how to prevent cervical cancer.

When clients with hearing impairments are unable to communicate effectively, the provision of cervical cancer screening is seriously hampered. Procedures and diagnosis are more likely to be poorly comprehended in the absence of reciprocated communication. Inappropriate or unresponsive communication between women with hearing impairments and health workers is the reason why most of these women shun health facilities. Communication between deaf people and health workers is made even more complex owing to deaf culture which is not understood by a the health worker who is often a layman to this regard. The government should consider training interpreters who can be stationed at every health centre.

Social support has been particularly helpful for individuals with severe disabilities because of the limitations that they have in participating in regular mainstream activities on their own. There is need to encourage this trend amongst families and within disabled persons organisations. More research is required to ascertain how prominent social support is for persons with disabilities within Zambian communities.

5.3 Socio-Economic Factors

In this study we have found that women with an inadequate income are less likely to be able to access cervical cancer screening services. These findings relate with Lofters (2014) who found that women with disabilities are made vulnerable due to less income amongst other factors which makes it difficult to access cervical cancer screening. This study also found that most women with disabilities face significant challenges in having their transport needs met. Transport was not affordable to many women due to limited income. These were similar to

findings reported by Smith et al (2004) where it was found that transport was a major obstacle in accessing reproductive health services. The two major issues recorded in this study concerning transport were affordability and appropriateness. The majority of the women who participated in the study were unemployed, most of them did not even complete their education, this translated into poverty for most of them. As a result, it can be a challenge acquiring funds for bus fares when need arises to access health care. It was also found that long distances to the nearest cervical cancer screening centre discouraged some women from seeking the service. The issue of distance was not covered in any of the literature accessed. The issue of distance and transport are somehow related, however, long distance falls more on the inconvenience of having to go too far off places to access the service.

Generally, the less income that individuals have, the more difficult it may be to access cervical cancer screening. The majority of Zambians with disabilities have little or no reliable source of regular income to survive on. Little or no income makes women with disabilities vulnerable to health matters in various ways. Some of the factors which come into play include the inability to afford media through which cervical cancer screening is publicised, for instance, television or newspapers. As a result, they are likely to miss out on important information which may be publicised through such mediums. Furthermore, these women are made vulnerable by being unable to afford public transport to distant clinics or hospitals, as a result, they tend to shun going to the health facilities.

A sustainable income base can be difficult to acquire for most Zambian women with disabilities, this is largely due to low literacy levels and low uptake of skills training. Being a minority population with special needs, there is need for relevant stakeholders to brainstorm and put measure in place to equip women with disabilities not only with survival skills but also skills with which to be able to raise an income. This would be dependent upon the type and severity of disability that an individual has.

The suitability of public sector transport for women with severe physical impairment is a cause for concern. This scenario however, is surprising because the PWD Act (2012) provides for equality in transport by stating that public service vehicle operators must ensure that their vehicles are fitted with the necessary gadgets so as to be able to carry at least two people with disabilities. This could mean ensuring enough leg room or fitting the vehicle with the necessary gadgets that will ease comfortability of persons with disabilities. Clearly, the accessibility of public transport can help to ease access to health centres. Therefore this issue

must be seriously looked into by relevant authorities and advocates. There is need to investigate further on this issue and establish measures which can be put in place to alleviate this problem

Although cervical cancer screening services are provided within local health facilities, this service is not present in all community health facilities in Lusaka. As a result, residents are forced to first locate a service provider closer to them. If the facility is not within their comfort zone, this can be quite cumbersome for women who face significant financial difficulties due to issues of transport. Parham et al (2015) reports that the cervical Cancer Prevention Program in Zambia (CCPZ) managed to expand from 2 to 12 cervical cancer screening centres in Lusaka District. These measures need to be supported so as to have a wider coverage in possibly all health facilities around Lusaka.

5.4 Service Related Factors

Architectural designs of the clinical facilities were observed not to be accessible for women with physical and visual disabilities. This is similar with findings recorded by Angus et al. (2012) who found that architectural obstacles were a cause for concern in accessing buildings. The major problems noted in this study were with steps at some entrances, narrow doorways, and toilets which were too close to the wall thus causing difficulty mounting onto the toilet. Lack of Braille signage in the premises of the health centre equally puts visually impaired people in a position of extreme dependency on others for guidance. This study also found that the examination rooms lacked adjustable examination tables, thus causing difficulty for clients to get onto them. As a result, women reported that it was either painful or physically impossible to position appropriately on basic medical equipment which they found there and yet it is necessary for a basic pelvic assessment for cervical cancer. Similarly, Mele et al (2005) reports on a study where women with disabilities had never seen or used an adjustable examination table.

Further findings of this study revealed that few women with disabilities have information about cervical cancer due to limited access to IEC materials. Similarly, Gudlavalleti et al (2014) who looked at access to health care for persons with disabilities reports that persons with disabilities had significantly higher levels of ignorance about availability of health services than those without disabilities. Findings also revealed that rumours about cervical cancer screening were a common phenomenon in the study which created false beliefs about the way it is carried out. Beliefs were also identified in a similar study which sought to

ascertain if reproductive health needs of women with physical disabilities were being met, Smith et al (2004) found that different beliefs prevailed which inadvertently stood as barriers towards accessibility of reproductive health care. Women reported being afraid because the screening is done with a 'big metal object' which causes a lot of pain. This in itself is untrue because cervical cancer screening by VIA which is the most widely used method, is a painless procedure. Thus fear of pain delayed a lot of women's final decision to go for screening. The other rumour noted was the idea that the same instrument is used on all the women minus sterilisation, as a result, some women fear due to hygiene reasons. It however was established that this is not true because screening centres only screen in accordance to the number screening instruments that they have to enable sterilisation.

Additional findings show that women with disabilities had challenges in confidentiality when accessing cervical cancer screening, this was dependent on the type and severity of disability which an individual had. The issue of confidentiality as a factor did not appear in the literature which was accessed for review. Ultimately, the type and severity of the disabilities which women have determine the level of confidentiality that they can receive. The issue of compromised confidentiality during an examination normally occurs when there is need for the presence of a third person to assist in transferring the client from one point to another, assistance in dressing or undressing and also assistance in communication.

Women with visual and physical disabilities often face problems regarding confidentiality when accessing health services. Respondents cited the issue of having a third party present during a visit due to inability to effectively communicate or inability to physically carry out tasks such as getting on or off the examination table and getting dressed or undressed. Because the nurse carrying out the screening may not be able to do these tasks on their own, there is need to allow another individual for assistance if the client is willing. As a result, the screening procedure may be a very uncomfortable one for women with disabilities who may be reluctant to share certain information when people other than medical personnel are present, this is more so due to the fact that cervical cancer screening requires a sexual history to be taken.

Interestingly, although the structural designs of the health facilitieswere found not to be entirely accessible, women did not complain about it being a reason not to go for cervical cancer screening. Perhaps this is because they are accustomed to finding such environments in most places that they go to around Lusaka. Although the PWD Act (2012) states that all

public places must be made accessible, little has been done to make this a reality on the ground, as such, most public places are not easily accessible. As a result, most of these women, especially those who are not educated have come to accept it as a normal way of life. The PWD Act (2012) provides a platform for making buildings physically accessible; however, more efforts need to be made by relevant authorities to ensure that these ideals are met.

In order to ease accessibility, suggestions were made by health service providers to have a separate examination room for women with disabilities which can cater for their special needs. This lack of appropriate equipment inadvertently results into loss of privacy due to the need for the service provider to request assistance from a third party so as to lift clients on to the examination table or indeed help the client to undress. When cervical cancer screening service providers are equipped with adequate skills to handle women with disabilities during screening, this may minimise the need to have third parties present due to the sensitivity of the nature of the examination, thus maximising confidentiality.

Without adequate information about cervical cancer and it's screening services, a woman is likely not able to access the service. However, this study revealed that there is no distinction in information on cervical cancer for women with disabilities, information produced is generally designed for an able bodied audience. The health service providers reported that their health promotion messages do not cater for any particular group of people but the public in general, as a result these women do not benefit as they ought to. There have been no deliberate efforts to make information inclusive to everybody through Braille transcription or sign language interpretation for example.

False beliefs about cervical cancer have the potential to keep people away from screening centres and are a reflection of limited knowledge about cervical cancer. Combating this will require that women have adequate information about cervical cancer and the screening procedure thereof. These rumours were found to influence women's decisions to go for screening by delaying their visits to the hospital. Although some women had been for screening despite hearing these rumours, they reported having delayed their decision to actually get screened upon hearing it.

5.5 Policy/Regulatory Factors

The study revealed that current health policies are not responsive to the special needs of persons with disabilities. These documents do recognise the presence of vulnerable persons in society who need to access health services but do not make explicit mention of persons with disabilities who ought to be given special consideration. The National Health Strategic Plan 2011-2015 and the Zambian Strategic Plan 2013-2016 on Non communicable Diseases both mention the need for equitable health care services but there is no specific mention of women with disabilities. The screen and treat guidelines didn't have any information on how to screen a woman with a disability. As a matter of fact, legislature is there through the Persons with Disabilities Act to support accessible health service provision, however, there appears to be lack of clear cut policies and guidelines to support this.

A document analysis in this study found that health facilities are legally mandated to ensure that their facilities are accessible. This was in line with findings by Smeltzer (2006) who studied preventive health screening for breast and cervical cancer in women with physical disabilities, Smeltzer found that the American Disability Act (ADA) was not being adhered to in a lot of health facilities, thereby rendering their services inaccessible to some clients. The Zambian Persons with Disabilities Act (PWD) 2012 provides a framework for the legality of accessibility issues pertaining to persons with disabilities in Zambia. The document generally covers for the attainment of equitable standards in all areas of life for an individual with a disability, including health care and Public Health programs for women. Although these legally binding documents are in place, there seems to be little being done to ensure that all health care, including cervical cancer screening is inclusive for people with disabilities.

Despite having several articles in the PWD Act in support of promoting inclusive health service delivery, there appears to be little stringent measures put in place to ensure compliance. This is notable because most health centres are not yet fully accessible, not only in terms of infrastructure but also in terms of service delivery. Interestingly, the Act in section 57 article 5 states that institutions or persons who adapt their premises and provide amenities for persons with disabilities are entitled to a tax rebate. This ought to encourage health institutions to ensure that their environment meets the needs of persons with disabilities so as to provide a service which is accessible to all persons.

Interestingly, although equitable access is addressed in the PWD Act, there is little mention of exactly how to make these services accessible. The Act is rather vague, with no clear directions to follow. For instance, there is no mention on how big an accessible examination room should be, or how wide doors or corridors should be. Mention is made on providing amenities in buildings, but these amenities are not clearly stated. This differs from the American Disabilities Act (ADA) which lays down specific guidelines to follow by clearly stating how wide the doors should be for example and also specific equipment that an examination room ought to have. Although our American counterparts have not yet reached full accessibility levels in cervical cancer screening, they are much more ahead in terms of developing these legal frameworks, Zambia can take a leaf from them for future planning of equitable health programs so as to achieve accessibility.

5.6 Limitations

The generalizability of the findings of this study may not be possible due to the small sample size selected; therefore the results may not be representative of the entire population of women with disabilities. Furthermore, the population of the study was limited to defined disability groups (physical, visual and hearing impairment) thus missing out on information that could have been obtained from a general overview of all disability groups.

Additionally, the selection of hearing impaired participants was dependent on their skill in sign language thus restricting selection to educated individuals with hearing impairment. This may have created bias which in turn limited the information which would have been gathered from a representative population. Lastly, in-depth interviews ought to be one-on-one, however, communication barriers resulted in the use of interpreters among the hearing impaired participants, thus neutralising the confidential atmosphere initially planned for. The women may have been uncomfortable expressing themselves fully in the presence of a third party. Furthermore, difficulty was experienced in interviewing women who were not fluent in Zambian Sign Language. In addition, some terms in spoken English lacked direct translation into Zambian Sign Language

In spite of the identified limitations, the study had it strengths. The methodology which was used allowed for discovery of rich information through document studies, observations, in-depth interviews and key informant interviews. Moreover, the study was not restricted to

women with disabilities, but extended to other stake holders so as to gather wider information about the topic under question.

CHAPTER SIX

6.0 CONCLUSION

Women with disabilities are at risk of developing cervical cancer just as able bodied women because they too engage in risk behaviours. This study aimed to determine the accessibility of cervical cancer screening for women with physical and sensory disabilities. Cervical cancer screening services were found not to be easily accessible. A range of factors were found to influence accessibility of cervical cancer screening, namely, individual and interpersonal factors, socio-economic factors; service related factors; and also legal and policy related factors. Although this study focused on cervical cancer screening, women revealed multi-faceted issues not restricted to the hospital environment alone. A complex relationship exists between the factors which hinder accessibility of cervical cancer screening as they are not mutually exclusive.

The physical environment was identified as the biggest barrier for women with physical disabilities. For visually impaired women, not only was the physical environment a major hindrance but accessible information too. Hearing impaired women were seen to have a unique pattern of service use owing to communication barriers. Improper communication exchange with health care providers is their major barrier causing reluctance to access these services. Common issues that affected most of them and made them vulnerable regardless of disability include low literacy levels, limited finances, attitude and beliefs amongst other factors.

When accessibility of cervical cancer screening is limited, it is evident that this leads to a damaged relationship between the health system and the client characterised by loss of trust in the system and avoidance of health systems. A missed window of opportunity is then raised in combating cervical cancer screening. When this is the case, women expose themselves to worsening health conditions due to failure or delay in seeking medical attention. Despite having legislature in place in full support of accessibility, much leaves to be desired on the ground. Stake holders must step up actions to ensure that health institutions understand fully what an accessible environment entails.

6.1 Recommendations

Research Related Recommendations

There is need for a more comprehensive research on cervical cancer screening considering all types of disabilities in Zambia. Further research should be considered to explore means of improving health care initiatives for the health of people with disabilities in Zambia.

Individual and Interpersonal Related Recommendations

Partnerships should be encouraged between women with disabilities and health advocates. This will enable awareness programmes specially tailored for persons with disabilities not only will this increase knowledge levels, it will also ensure that communication strategies can adequately reach out to women with disabilities.

Socio-economic Recommendations

Where possible, persons with disabilities should be empowered through education and or skills training so as to enable them acquire a steady income and be as self reliant as possible.

Service Related Recommendations

Because they are the voice for persons with disabilities, disability organisations should take it upon themselves to sensitise other stakeholders on the importance of accessibility of cervical cancer screening services and other health services. Furthermore, in-service training of clinical staff members should be considered to equip service providers with the necessary skills needed to handle clients with disabilities. Voluntary training of sign language interpreters should be encouraged to enable their availability in all health centres.

Policy or Regulatory Recommendations

Policy makers must consider policy reform so as to make health policies more inclusive. Legislature is already in existence to promote accessibility of cervical cancer screening however, monitoring systems need to be strengthened to ensure that health centres are accessible. In addition, there must be standard guidelines to guide administrators on what constitutes an accessible health centre.

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APPENDICES

Appendix I: Information sheet 01-Key informant interview

Reading grade level: 9.6

INFORMATION SHEET

(KEY INFORMANT)

Study Title: Factors affecting the accessibility of cervical cancer screening among women with disabilities in Lusaka district

Principal Investigator: Ms. Mazuba Hachipola

IRB No.:

Purpose of research project

I am a student at the University of Zambia, this study is part of my training in Public Health. The purpose of this study is to find out about the factors which affect the use of cervical cancer screening among women with disabilities in Lusaka district. To achieve this, I would like to find out which things in particular have affected women with disabilities, and then I would like to know about what things have been done to make cervical cancer screening accessible.

When I finish the study, I will share my results with you and the public in general. It is hoped that this study will open up doors for creating highly accessible health services for people living with disabilities.

Why you are being asked to participate?

I plan to interview health workers who are involved in cervical cancer screening and officials from disability organisations. You have been asked to participate because you fit the necessary description. I expect a total of about 16 people to participate in the study.

Procedures

If you agree to participate in the study,

I will ask you to sign a consent form. I will then ask you to take part in a face to face interview with me. The Interview will last about 30 minutes. With your permission, I will record the interview to help me capture all that you will say, if not, I will ask to write down details of the interview. The information that I will collect will be typed in full to help me fully understand what you will say. Your name will not be included in any of the documents.

Risks/discomforts

There is no physical harm that you will experience by participating in the research. However, I recognize some information you may tell me may be personal or sensitive to others. However, I would like to assure you the information that we get from you will not be shared with anyone outside the research team.

Benefits

There are no direct benefits to you by participating in this research. However, by taking part in this study you will contribute to the better understanding of factors which influence accessibility of cervical cancer screening. You would have helped to provide information which may be necessary to advocate for equitable and just health practice. In the future, this may benefit all persons with disabilities to access health services in a comfortable manner.

Payment

There is no payment for participating in the research.

Protecting data confidentiality

All information collected in this study will be confidential and used only for research purposes. The collected information will be locked in a safe place. All data collected will be destroyed at least 5 years after typing the information. Your identity will not be revealed under any circumstances.

What happens if you do not want to participate in the study?

You are free to decide whether you want to take part in the study. This will not bring any problem to you.

Who do you call if you have questions or problems?

- Call me, Mazuba Hachipola

  Cell: +260-969-372059 Email: hachipolae@gmail.com

- Call or contact the University of Zambia Biomedical Research Ethics Committee office for any ethical concerns. The Ethics Committee contact information is:

Address: Chairperson of the Biomedical Research Ethics Committee at University of Zambia, Ridgeway Campus, 50110, Lusaka.

Telephone: 260-1-256067 Fax: 250753 Email: unzarec@zamtel.zm

Appendix II: Information Sheet 02-In-Depth Interview

Reading grade level: 7.9

INFORMATION SHEET

(IN-DEPTH INTERVIEW)

Study Title: Factors affecting the accessibility of cervical cancer screening among women with disabilities in Lusaka district

Principal Investigator: Ms. Mazuba Hachipola

IRB No.:

Purpose of research project

I am a student at the University of Zambia; this study is part of my training in Public Health. The purpose of this study is to find out about the things which make it hard to get checked for cervical cancer among women with disabilities in Lusaka. To find out, I need to know which problems affect women with disabilities, then I need to find out how the experience was if you have gone for one before.

When I finish the study, I will share my results with you. I hope that this study will open up doors for making health services easier to use by people living with disabilities.

Why you are being asked to participate?

I want to interview women with physical, hearing and eyesight disabilities. You have been asked to participate because you are the type of person I am looking for. I hope to have a total of 16 people to take part in the study.

Procedures

If you agree to participate in the study,

I will ask you to sign a consent form. Then I will then ask you to take part in a face to face interview with me at a private place that suits you. The Interview will last 30 minutes. If you allow me, I will record the interview to help me catch all that you will say, if you do not

allow me, I will ask to write down what we will talk about. What we will talk about will be typed to help me fully understand what you will say. Your name will not be written in any of the documents.

Risks/discomforts

There is no physical harm that you will experience by taking part in the research. I know some things you may tell me may be private or sensitive to other people. However, I would like to promise you that whatever I hear from you will not be shared with anyone outside the research team.

Benefits

There are no direct benefits to you by joining this research, but you may find useful the information sheet that I will give you on cervical cancer after the interview. Also, by taking part in this study you will contribute to the better understanding of things which make it hard for you to go for cervical cancer screening. You would have helped by telling me things which may be important to fight for fair health service. In the future, this may help all people with disabilities to use health services in a comfortable way.

Payment

There is no payment for taking part in the research.

Protecting information

All information collected in this study will be private and used only for research reasons. The collected information will be locked in a safe place. All information collected will be destroyed at least 3 years after typing the information. Your name will not be given away to anyone.

What happens if you do not want to participate in the study?

You are free to decide if you want to take part in the study. This will not bring any problem to you.

Who do you call if you have questions or problems?

- Call me, Mazuba Hachipola

  Cell: +260-969-372059 Email: hachipolae@gmail.com

- Call or contact the University of Zambia Biomedical Research Ethics Committee office for any ethical concerns. The Ethics Committee contact information is:

Address: Chairperson of the Biomedical Research Ethics Committee at University of Zambia, Ridgeway Campus, 50110, Lusaka.

Telephone: 260-1-256067 Fax: 250753 Email: unzarec@zamtel.zm

Appendix III: Information Sheet 03 In-Depth Interview (Cinyanja Translation)

Mutu wofufuza: Zomwe zipangisa ukhala cobvuta upeza matenda akhansa yakucibalilo kwa azimai olemala m"boma la Lusaka.

Wofufuza: Ms Mazuba Hachipola

IRB No:_____

……

……

Zolinga zofufuzira nkhani iyi

Ndine mwana wa sukulu Pa sukulu la pamwamba la Zambia,Ufufuza uku ndi mbali yamaphunziro anga pokhudza zaumoyo. Colinga ndi kupeza zifukwa zomwe zipangitsa ukhala cobvuta kuti azimai olemala asapezeke namatenda ya khansa yakucibalilo. Pofufuza, nifunika kudziwa mabvuto yamene yapezeka na zimai olemala ndiponso kufufuza m'mene zinalili ngati wina anayesedwapo kale.
Ngati nasiliza ufufuza kwanga, nizakufotokozerani zofufuzazo. Ndikuyembekera kuti kufufuza kwanga kuzathandiza upanga nchito yofufuza zaumoyo kwa anthu olemala ukhala yopepuka.

Cifukwa wapephedwa kutengako mbali?

Ndifuna kufunsako azimai olemala, kapena ogontha ndi akhungu. Imwe mwapephedwa utengako mbali cifukwa ndimwe mtundu wa anthu ndi kufunafuna. Ndiyembekezera ukhala ndi anthu khumi, asanu ndi umodzi (16).

Ndondomeko

Ngati mwacibvomekeza utengako mbali m'maphunziro aya ndizakupemphani kusindikiza cipepala cacilolezo.Ndiponso ndi zakupemphani utengako mbali Ku mafunso Pa maso ndi maso ndi ine patawiri pamene Imwe mungakonde.Mafunso athu azakhala amphindi makumi atatu.Ngati munganilole ndingajambule ukambisana kwathu kuti kundithandize kusunga zonse zamene tizakambisana, koma ngati simungavoereze ujambula, nizapempha kuti nizilembako zamene tizakambisana.Zamene tizakambilana ndi zazijambula pa kopiuta kuti

ndi kazimvetse zamene takambirana. Dzina lako silizalembedwa pena paliponse pazolembedwa.

Ngozi/zodometsa

Palibe ngozi iliyonse yakuthupi imene ingacitike mkatengako mbali pokambitsilana kwathu.Ndi dziwa kuti zina zamene munganiuze, ndizaumwini kapena zoopsa Ku anthu ena.Cifukwa caici, ndifuna ulonjeza kuti zilizonse zamene namvera ucoka kwanu sindizauza wina aliense wamene satengako mbali kuzofufuza izi.

Phindu

Palibe ubwino wacindunji potengako mbali mkufufuza pa nkhani iyi,koma mungapwze uthenga wonthandiza pa pazamene ndizakupatsani zokamba Pamatenda akhansa yakucibalilo pambuyo yamakambitsirano yathu. Komanso mwakutengako mbali m'phunziro aya, muzathandizika umvetsetsa cifukwa ciani nchobvuta upita kuti akakuunguzeni pamatenda ya khansa yaku cibalilo.Mungathandize pofotokoza zinthu zomwe zingafunike upnjetsa bvuto la zaumoyo makamaka pa matenda aya. Mtsogolo,anthu angathandizidwe pazaumoyo mnjira yosabvuta.

Malipiro

Palibe malipilo alionse potengako mbali pa maphunziro awa.

Uteteza uthenga

Uthenga ulionse wafufuzidwa uzakhala wacinsinsi komanso ugwritsira tchito pazifukwa zofufuzira.Uthenga onse uzasungidwa pamalo oyenerera.Komanso uthenga uyu uzaonongedwa zaka zitatu pambuyo pojambulidwa. Dzina silidzatchulidwa pena paliponse. Miciani cingacitike ngati sifuna utengako mbali mkufufuzaku?Aliense ndi womasuka usankha utengako mbali kapena ai kumakambitsilano.Sizingabweretse mabvuto kwanu mnjira iriyonse.

Ndani wamene ungatumire ngati uli ndi mafunso kapena mabvuto?

Nditumireni: Mazuba Hachipola
Foni namba: +260969372059
Email: hachipolae@gmail.com

- Tumani kapena funsani the University of Zambia Biomedical Research Ethics Committee office for any ethical concerns. The Ethics Committee contact information is:

Address: Chairperson of the Biomedical Research Ethics Committee at University of Zambia, Ridgeway Campus, 50110, Lusaka.

Batumireni: 260-1-256067 Fax: 250753 Email: unzarec@zamtel.zm

Appendix IV Consent Form

What does your signature (or thumbprint/mark) on this consent form mean?

Your signature (or thumbprint/mark) on this form means:

- You have been told about the reason for the research, how it will be done and any problems or advantage.
- You have been given the chance to ask questions before you sign.
- You have freely agreed to be in this research

_____ _____ _____

Print name of Participant Signature of Participant Date

_____ _____ _____

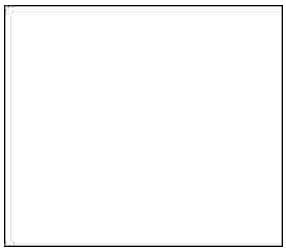
Print name of witness Signature of witness Date

_____ _____ _____

Print name of Person Obtaining Signature of Person Obtaining Consent Date

Consent

Ask the participant to mark a “left thumb” impression in the box below if he/she is unable to sign.



Appendix VI : Consent Form (Chinyanja Translation)

PEPALA LA CHILOLEZO

Kodi kusindikiza kwanu (ndi cala) pepala la cilolezo kutathauza ciani?

a. Mwauzidwa kale zolinga zakufufuza m'mene zizacitidwira komanso mabvuto ndi ubwino wake
b. Mwapatsidwa mpata wofunsa mafunso mukalibe usindikiza.
c. Momasuka mwabvomekeza utengako mbali mkufufuza.

_____ _____

Jambulani dzina la otengako mbali. Cisindikizo ca wa mkulu otengako mbali.
Tsiku

_____ _____

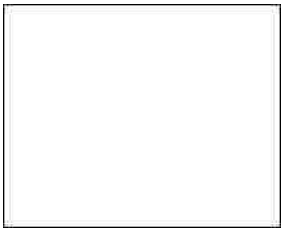
Jabulani dzina la mboni Cindikizo ca mboni
Tsiku

_____ _____

Jabulani dzina la munthuyo Cisindikizo ca munthu otengako cilolezo
Tsiku

Cilolezo

Pemphani otengako mbali kuti asindike cala cacikulu caku manzele, ubvomekeza mkabokosi munsi ngati sangathe kusindika kolemba.



Appendix VII: Confidentiality Agreement

To be completed by the sign language interpreter

With regard to the confidential information, I agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g discs, tapes,transcripts) with anyone other than the researcher.
2. Not to use the information therein other than according to the boundaries set by the researcher
3. Keep all research information in any form or format secure while it is in my possession.
4. Return all research information in any form or format to the researcher when I complete my task.

_____ _____ _____

Name Signature Date

Researcher

_____ _____ _____

Name Signature Date

Appendix VIII: **Interview Guide 01 Women with Disabilities**

Topic: Factors Affecting Accessibility of Cervical Cancer Screening Services among Women with Disabilities in Lusaka District

Date of Interview:

Place of Interview:

Interview Number:

INSTRUCTIONS

Participants must read through, understand and sign the consent form provided before they participate in the interview. Remember to probe and get concrete examples. Let the informant speak at length and make sure that you use this only as a true guide in the interview process, and not as a list of questions to be covered one after the other.

There are no right or wrong answers in this discussion. Please feel free to be open and share your point of view. It is very important that we hear your opinion.

A. Health Literacy

1. Have you ever heard about cervical cancer?……..
    a. What do you know about cervical cancer?
    ……..
2. How did you come to know about cervical cancer screening?
    a. Friends
    b. Relatives?
    c. Media?
    d. Other…….……..
3. What do you think about cervical cancer screening?
    ……
    a. What is good about it?
    ……
    b. What is bad about it?
    ……..

4. Have you ever gone for cervical cancer screening? ……
    a. Yes
    b. No

    I. If not, why?

    ……

B. Perception of Cervical Cancer Screening

(Women who have never gone for screening)

1. Would you go for screening?
    a. Yes
    b. No
    i. Why? , why not?

……..……..……

2. What do you think about screening services in general?

    ……

3. How has your disability influenced your decision not to utilise cervical cancer screening services?

    ……

    ……

4. Do you think these health services are meeting the needs of people with disabilities?

    ……..

5. What would you like to be done to encourage you to access cervical cancer screening?

    ……..

C. Experiences by Women who Accessed Cervical Cancer Screening

1. If yes to the question 4 above, how did you make a decision to go for screening?
    a. Voluntary?
    b. Ill health?
    c. Other...

2. Do you know of other women with disabilities who have gone for screening?

    ……..

    i. If yes, what type of disabilities did they have?

    ……

ii. What were their experiences?

……..

3. Did you find yourself putting off the cervical cancer screening before actually going?

……..

i. If yes, why?

……..……..

a. Difficulty with transport?

……

b. Medical problems?

……

c. Difficulty getting someone to care, for those dependent on care?

……

D. Service Related Factors

1. Please describe your experience in receiving cervical cancer screening?
   a. Positive?
   b. Negative?
2. How was your experience with the clinical staff?

   ……..

   i. Denied appointment?

   ……..……

   ii. Attitude of clinical staff towards making accommodations?

   ……..……..……

   iii. Assistance with transfers?

   ……
3. How would you describe the quality of care that you received during screening?

   ……

   i. Was privacy respected all the time?

   ……

   ii. Was the test well explained?

   ……..……..

   iii. Was the test difficult to perform?

   ……..……..

iv. Was it painful?

……..……

4. How did you travel to and from the clinic?…….

i. Type and cost of transport?

……..……..

ii. Availability?

……..

iii. Was it comfortable?

……..

5. Was the screening centre accessible?
    a. Parking?
    b. Ramps?
    c. Accessible bathrooms?
    d. Adjustable exam tables?
    e. Alternate format for education?
6. What makes it easier/difficult for you to attend cancer screening?
    a. Regular reminders?
    b. Disability accommodation?
    c. Disability awareness?

7. Did your disability influence, in any way, your decision to go for screening?
    a. Severity?
    b. Accommodations?

E. Interpersonal Factors

1. Have you ever experienced any form of stigma/discrimination in access health services?
    a. From the clinic setting?
    b. From community/neighbourhood setting

2. Do you receive any support from others when you want to go to the hospital / clinic?
   i. Emotional support-family, friends, others...?
   ii. Financial support...from whom?
   iii. Logistical support....from whom?

3. What do you think makes cervical cancer screening difficult for women with disabilities?
4. Please suggest ways to improve uptake of cervical cancer screening.

Appendix IX: In-Depth Interview Guide (Women with Disabilities) Chinyanja Translation

Tsiku:

Malo:

Malangizo:

Wotengako mbali afunika Kuwerenga,ubvetsetsa komanso usindika papela la cilolezo comwe caperekedwa makambiailano asanayambe. Kumbukirani kufunsa komanso utenga zitsazo zenizeni. Lolani kukambitsana kudzakhala kwa kaphindi komanso lolani ugwiritsira ntchito kukhale cisonyezo ceni-ceni cisakhale ndondomeko yamafunso yomwe yanga finsidwe mondondezana.

Palibe mayakho abodza kapena azoona m'makambitsirano awa.Conde masukani pa maganizo anu.Ndicofunikira kuti timve maganizo anu.

A. **Kudziwa zaumoyo**

1. Kodi munamvako zamatenda ya khasa ya kucibalilo? Mudziwapo zotani pa matendawa?
2. Mundziwa bwanji za kaunguzidwe ka matenda ya khansa?
   i. Kumabwenzi
   ii. Acibale
   iii. M'mawailesi
3. Kodi muganiza ciani pa kaunguzidwe ka matenda amenewa?
   i. Zabwino ndizotani pa matendawa?
   ii. Zoipa nzotani pa matendawa?
4. Kodi munapitako ukaunguzidwa pa matendawa?
   i. Ngatimukalibe,cifukwa ciani?

B. Malingalo ya kuunguzidwa kwa khansa yakucibaliro.(azimai amene sanapite ukaunguziwa)

1. Mungakonde upita ukaunguziwa?
   i. cifukwa? Komanso cifukwa simungakonde?
2. Kodi mumaganiza zotani pa mbali younguzidwa?
3. Ndobvuto lotani lomwe ulemala kwanu kwakupangitsani usagwiritsira ntchito mpata wounikidwa?
4. Kodi mumaona kuti kuunikidwa kumeneku kumakwaniritsa zolinga za anthu olemala?

5. Ndizotani zomwe mungakonde ukucitirani zomwe zinga kulimbitseni upeza mpata wounikidwa pamatendawa?

C. **Maphuziro azimai anapeza omwe anaunikidwapo pa matenda ya khansa.**

1. Ngati ndi inde pafunso la pamwambapa, ndimotani m'mene munapangira ganizo lopita ukaunikidwa?
   a. Modzifunira
   b. Cifukwa Codwala
   c. Pazifukwa zina
2. Kodi mudziwako azimai ena olemala amene anapitako ukaunikidwa?
   a. Ngati ni inde, ulemala nkotani komwe ali nako?
   b. Anaphuzirapo zotani?
3. Munapeza maganizo ozicotsa pa matendawa mukalibe upita ukaunikidwa?
   Ngati ndi inde, cifukwa?
   a. Mayendedwe ndi yobvuta?
   b. Nimatenda?
   c. Usowa wina ukusamala pokhala udalira cisamaliro

D. **Zintchito zidalira pazocitika**

1. Conde fotokozani momwe mungacilandilire mutaunikidwa
   a. Wocibvomereza
   b. Wosacibvomereza
2. Zinari motani ndi omwe asewenzera kucipatala?
   a. Anakana mapangano yoonana?
   b. Macitidwe anyantchito ukonza malo yogona?
   c. Thandizo yosamuka
3. Mungafotokoze bwanji thandizo la cisamaliro lomwe munalandira panthawi yo kuunikani?
   a. Cinsinsi cinasamalidwa paliponse?
   b. Zopeza zao zinafotokozedwa bwino?
   c. Kodi zinali zobvuta ufotokoza bwino?
   d. Zinali zowawa
4. M**un**ayenda bwanji upita komanso ubwerako kucipatala?
   a. Mayendedwe komanso ndalama zolipira?
   b.Kodi mayendedwe yamapezeka?
   c.Kodi mayendedwe yanali ya bwino?

5. Lodi malo younikirako niyofikirika?
    a. Poimila mpabwino?
    b. Zoyenderapo mzabwino?
    c. Mosambira mwabwino?
    d. Zopimira matenda nzabwino?
6. Niciani comwe cimapangitsa ukhala copepuka kapena cobvuta kuti muunikidwe?
    a. Kodi nukumbutsidwa pafupi-pafupi?
    b. Manyumba yosayenerera?
    c. Maphunziro yosayenerera?
7. Kodi ulemala kwanu kunakukhudzani munjira ili yonse kuti mupite ukaunikidwa?
    a. Mobwereza-bwereza?
    b. Manyumba kapena pogona?

E. Zaumwini

1. Kodi munakumanapo na citonzo kapena tsakho Ku thandizo lakucipatala?
    a. Kapena mapangidwe acipatala?
    b. Kapena ucokera Ku anthu kapena kumalo amene mukhala?
2. Lodi mumalandila thanizo kwa ena pofuna upita kucipatala?
    a. Thandizo locokera kwa acibale kapena kwina?
    b. Thandizo la ndalama, komanso licokera kuti?
3. Niciani comwe muona cipangitsa matendawa kukhala yobvuta upita nayo kucipatala maka-maka kwa olemala?
4. Conde pezani/ganizani njira yo wonjezera upita patsogolo kuunikidwa kwa matenda ya khansa yakucibaliro.

Appendix X: Interview Guide 02: Disability Group Leaders

Topic: Factors affecting the accessibility of cervical cancer screening among women with disabilities in Lusaka district

Instructions

Participants should read through, understand and sign the consent form provided before they participate in the interview. Remember to probe and get concrete examples. Let the informant speak at length and make sure that you use this only as a true guide in the interview process, and not as a list of questions to be covered one after the other.

There are no right or wrong answers in this discussion. Please feel free to be open and share your point of view. It is very important that we hear your opinion.

A. Introduction

1. What is your role in this community?

   ……..

2. How does the population think of you in light of your position?
   a. Do they regard you highly?

      …….……..

   b. In which situations does the population ask for your advice?

      …….……..

   c. What do you think about your influence in this community?

      ……..……

1. Do you play a role in women's decisions to access health services?

   ……..

a. Do you encourage cervical cancer screening?

   …….

2. How do you go about encouraging access to health services?

   ……

   a. Are you able to reach the whole population under your wing?

3. How has been the community's response in accessing cervical cancer screening?

   a.Have they shown willingness to go for screening?

B. **Accessibility**

1. Do you think that cervical cancer screening is accessible?.....

   a. Explain……

i. If not accessible,

   a. How has your organisation addressed this inaccessibility?

   ……

   b. Explain

   ……..

ii. If accessible,

   a. How has your organisation ensured its continued accessibility?

   ……...

   b. Explain

   ……..

iii. What barriers prevent accessibility of cervical cancer screening?

   a. Explain

   ……..

C. Interventions

1. In what ways are your organisation's efforts useful in increasing access to health care?.....
    a. How do you keep track of utilisation of health services by women with disabilities?

    ……

    b. How about cervical cancer screening in particular?

    ……..

2. In what ways does your organisation assist women who want to go for screening?
    a. Transport?
    b. Carers?
3. How does your organisation advocate for equity in access to health services on a wide scale?
    a. Cervical cancer screening?

……..

Appendix XI: Interview Guide 03- Health care workers

Topic: Factors affecting the accessibility of cervical cancer screening among women with disabilities in Lusaka district

Instructions

Participants should read through, understand and sign the consent form provided before they participate in the interview. Remember to probe and get concrete examples. Let the informant speak at length and make sure that you use this only as a true guide in the interview process, and not as a list of questions to be covered one after the other.

There are no right or wrong answers in this discussion. Please feel free to be open and share your point of view. It is very important that we hear your opinion.

A. Introduction

1. For how long have you been providing cervical cancer screening to clients?

2. Based on your experience, have you ever attended to women with disabilities?

   If yes,

   a. What was your initial impression upon seeing a client with a disability?
   b. Where u able to screen?
   c. What type of disability did they have?
   d. Were u comfortable screening such a client?
   e. Do you think the client was comfortable?

3. How many visits are needed before a client can be screened?

   ……

4. What is the total cost of cervical cancer screening?

   ……

   a. Do they pay anything for the procedure?

   ……

B. Experiences with women with disabilities

1. How do women with disabilities' health complaints compare with your average non-disabled patients of the same age?

……..

   a. How are they the same / different from women without disabilities

……

2. How do you think your experience with these clients differs from that with your other clients without disabilities?

……

   a. Do they have a longer set of issues, types of services, number of visits per year, amount of time per visit, staff accommodations, etc.?

…..……..

3. Are there any special considerations that they require?

……

   a. These considerations may be things that you do provide, or things that you are not able to provide

……..

C. Delivery of Service

1. What access issues might arise for this patient at the clinic? Consider:

……

   a. Transit to and from the appointment, structural barriers in the facility

……

   b. The exam, diagnostic procedures, and follow up or referral

……

2. What difficulties might arise for clinic staff in meeting this patient's access needs? ……
3. What information could assist the clinic in advance, and how might this be obtained? ……
4. What supporting aids or services might be required to facilitate access?

5. What assistance or safety precautions might be required from staff or the patient's companion or personal assistant, and how would this be arranged?

6. How are staff members trained to handle clients with a disability?

7. What else, if anything, do you need in order to be able to provide what you consider excellent care to your patients with disabilities?

C. Attitudinal, Social Barriers

1. What social barriers might a person with disability encounter in a medical situation?

2. What issues regarding dignity, privacy, or autonomy might arise?

3. How comfortable are staff at your clinic in handling clients with disabilities

4. What is their level of motivation, confidence?

D. Rapport and Interview

1. What issues might arise in communication or in establishing rapport?

2. Is a sexual history taken? (Often neglected due to the stereotype of asexuality)

3. How can an atmosphere of trust and safety be created to ensure that clients with disabilities are not exploited or disrespected because of their disability?

E. Exam, Diagnosis and Treatment

1. What access or rapport issues might arise in diagnosis or treatment? ……..
2. What accommodations or assistance will be required during screening? ……..
3. What factors for this patient might need to be addressed to improve adherence andtreatment compliance if necessary after screening?

4. Which special equipment do you have to assist women with physical disabilities to get on the screening table?
5. How do you help them adjust to a position that is appropriate for screening?
    - Cushions, adjustable exam tables, chairs... etc?

F. Referral

1. What are clear indicators that a specialty referral would be appropriate?

2. In referring the patient for diagnostic testing, what access difficulties might arise?

G. Follow-up Care

1. How do you follow up clients who do not show up for appointments?
2. What barriers might arise for this patient in obtaining follow-up care?

H. Sensitisation

1. How interested do you think the community at large is, in cervical cancer screening?

2. Have you in any way sensitised the community at large on cervical cancer screening services?
    a. Has it been successful?
    b. What is the best way to inform the community about the service?

3. How would you cater for persons with disability within your marketing strategy?

Appendix XII: Observation sheet

Observation Sheet

Time:

Date:

Purpose:

Occasion:

Activities/actions:

Reflections:

CASE CONSIDERATIONS

For Mobility-Impaired Patients, Consider:

- Is there accessible parking, including disability parking, which means room for the lift or ramp to deploy, not just car-width spots?
- Is there an accessible entrance to the facility? Is it clearly marked?
- Are exam rooms accessible to wheelchair users?
- Are reception area, medical assistants and medical staff educated to be non patronizing and to assume that a wheelchair user is potentially fully employed, competent and knowledgeable about self-care?
- Is there an adjustable exam table to allow a full exam?
- Medication: Is the pharmacy able to supply medication in easy-to-open containers accessible to quadriplegic individuals?

For Blind or Visually Impaired Patients, consider:

- Are there Braille markings on elevators?
- Are resource people available in the lobby to assist blind people? Are they trained to assist in orienting a blind person to locate specific areas in the facility?

- Are reception area, medical assistants and medical staff taught to be non-patronizing and to assume that a blind person can be, for example, a competent parent, fully employed, and an independent individual?
- Attitudinal: ‘Don’t assume or expect a sighted child accompanying a blind parent to be a guide or guardian in any way.’
- Does the pharmacy have Braille labelling capability, and if not, who is available to verbally instruct the patient?

For speech Impaired patients, consider:

- Is there sufficient time allowed for speech impaired persons to communicate verbally or via a word board or computer display?
- Is there adequate time scheduled in the appointment for the patient to adequately communicate without pressure to hurry?

For Deaf or hard of hearing patients, consider:

- Are interpreter services appropriately contacted and scheduled?

· Are medical and non-medical staff aware that they may not charge the patient for interpretation, nor should family members be pressured to interpret to save time or expense?

- Are medical and non-medical staff trained to be patient, respectful and non-patronizing, not complete sentences or second guess the patient, directly the address the patient and not a companion or sign language interpreter?
- Are staff ready to provide auxiliary aids and services? These include visual aids, written instruction or communication via writing if necessary

Appendix XIII: Audio-visual analysis sheet

Audio-Visual Analysis Sheet

Time:

Date:

Purpose:

Activities/actions:

a. Are patient education materials available in alternative format, such as large print, audio cassette, Braille or computer disk?

b. Checklist

Visual tool	**Braille**	**Large print**	**Sign language**
Brochures			
Posters			
Documentaries			
Billboards			
Awareness adverts			
Others...specify			

Appendix XIV: Disability Assessment Tool

The Lawton Instrumental Activities of Daily Living Scale

A. Ability to Use Telephone

1. Operates telephone on own initiative; looks up and dials numbers ……..…… 1
2. Dials a few well-known numbers …….…….. 1
3. Answers telephone, but does not dial …….…….. 1
4. Does not use telephone at al …….…….. 0

B. Shopping

1. Takes care of all shopping needs independently…….…... 1
2. Shops independently for small purchases..…….. 0
3. Needs to be accompanied on any shopping trip..…….. 0
4. Completely unable to shop..…….. 0

C. Food Preparation

2. Plans, prepares, and serves adequate meals independently ……..…… 1
2. Prepares adequate meals if supplied with ingredients ……..…….. 0
3. Heats and serves prepared meals or prepares meals but does not maintain adequate diet ……..…….. 0
4. Needs to have meals prepared and served …… 0

I. Housekeeping

1. Maintains house alone with occasion assistance (heavy work)..…….. 1
2. Performs light daily tasks such as dishwashing, bed m..…….. 1
3. Performs light daily tasks, but cannot maintain acceptable level of cleanliness ……..……..…….. 1
4. Needs help with all home maintenance tasks …….…….. 1

5. Does not participate in any housekeeping tasks..... 0

J. Laundry

1. Does personal laundry completely..... 1
2. Launders small items, rinses socks, stockings, etc……..... 1
3. All laundry must be done by others..... 0

K. Mode of Transportation

1. Travels independently on public transportation or drives own car..... 1
2. Arranges own travel via taxi, but does not otherwise use public transportation..... 1
3. Travels on public transportation when assisted or accompanied by another..... 1
4. Travel limited to taxi or automobile with assistance of another..... 0
5. Does not travel at all..... 0

L. Responsibility for Own Medications

1. Is responsible for taking medication in correct dosages at correct time..... 1
2. Takes responsibility if medication is prepared in advance in separate dosages..... 0
3. Is not capable of dispensing own medication..... 0

M. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income..... 1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc..... 1
3. Incapable of handling money..... 0

Scoring: For each category, circle the item description that most closely resembles the client's highest functional level (either 0 or 1).

0=low function, dependent 8= high function, independent
