

Factors affecting accessibility of cervical cancer screening services for women with physical and sensory disabilities in Lusaka District, Zambia

Mazuba Hachipola, Oliver Mweemba, Doreen Sitali

ABSTRACT

Aims: The study sought to examine service related factors which influence cervical cancer screening among women with physical and sensory disabilities. **Methods:** The study used a qualitative case study design using in depth interviews, field observations and document study to collect data. A purposive sample of primary respondents included 12 women with physical and sensory disabilities aged between 18 years old and 49 years old, these were recruited based on type and severity of disability. Six key informants were recruited from organizations working with people with disabilities and cervical cancer screening service providers. Key informants from disability organizations identified eligible primary participants. Thematic analysis was done using Nvivo 10 software. **Results:** Women with disabilities identified various factors which affect accessibility of cervical cancer screening services, namely; structural design of the health facility, inappropriate screening equipment, inadequate access to information, education and communication (IEC) materials, confidentiality of service, and limited skills of service providers.

Conclusion: Women with physical and sensory disabilities encounter various barriers in accessing cervical cancer screening. This may lead to delayed detection and increased complications on clients who are found with an advanced stage of cervical cancer. Health service providers require skills in working with women with disabilities. Although legislature exists through the Persons with Disability Act of Zambia to promote accessible health services, it has not been fully enacted, therefore, there ought to be rigorous enforcement of existing legislature which promotes accessible health services.

Keywords: Accessibility, Cervical cancer, Disability, Screening

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INTRODUCTION

Being the fourth most widespread cancer affecting women worldwide, cervical cancer has become a growing global burden [1]. One leading cause of cancer deaths in sub Saharan Africa is cervical cancer [2]. In Zambia particularly, there has been growing evidence that cervical

cancer has posed a serious reproductive health problem for women, it ranks as the most frequent cancer among women, accounting for about 30% new cancer cases per year [3, 4].

Access to cancer screening services is minimal in the Sub-Saharan region where few countries have comprehensive policies on the disease. The Zambian government has had a robust program on cervical cancer prevention since 2006 and since has managed to establish screening centers in all of its 10 provinces [2]. However, Zambia like many countries in the region, does not have comprehensive guidelines on the management of the disease because its main focus is on the provision of the cervical cancer screening service with little emphasis on its accessibility [5].

Global findings show that the population of persons with disabilities (PWD) are well recognized as a particularly vulnerable group that are consistently underserved: they present substantial health disparities and are often under-screened [6–8]. Women with disabilities have for a long time faced significant barriers in accessing health care through inaccessibility of health screenings. Health screenings are an important first step in using health care resources, including medical care, and health promotion interventions [9]. Zambian women with disabilities have not been spared from barriers in accessing healthcare as they have had inequitable access to health facilities for a long-time. It is apparent that factors that contribute to disability extend beyond the environmental barriers outside the control of the person with a disability [10, 11]. As a result, women with disabilities are less likely than those without a disability to receive a pelvic examination on a regular basis, especially women with more severe functional limitations [12, 13]

This paper endeavored to establish the factors affecting access of cervical cancer screening services amongst women with physical and sensory disabilities in Lusaka, Zambia. Although the cervical cancer screening service has been available in Lusaka urban, the extent of its accessibility to women with disabilities remains questionable. It is hoped that practical implementation and enforcement of those commitments towards achieving accessible health care can be boosted.

MATERIALS AND METHODS

This study employed a qualitative case study design. This enabled a thorough investigation of factors affecting cervical cancer screening based on the different categories of women with disabilities.

The study was conducted in Lusaka District, because it had a relatively high number of screening centers which have grown from two to eleven since the inception of the program in 2006, thus making it necessary to determine whether available services offered by these screening centers were inclusive [2].

Twelve in-depth interviews were conducted with women who had either a physical disability or sensory disability. Particular sensory disabilities which were targeted were hearing and visual disabilities. Women with physical disabilities had mobility impairments in particular. The levels of disability were determined using participant's personal clinical assessments. Key-informant interviews were conducted with three cervical cancer screening service providers, additional key-informant interviews were conducted with three representatives from disability organizations. Field observations of clinical surroundings were also conducted to ascertain the physical accessibility of clinical sites of this study (Table 1). In addition, a document study was conducted to ascertain what measures have been put in place to support accessibility of cervical cancer screening for women with disabilities. 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; and the screen and treat manual (2014).

Maximum variation sampling strategy was used to determine the sample size of primary participants in this study because it enabled the representation of a wide range of variation in terms of age, type of disability and severity of disability among the women with disabilities. A sampling plan was designed to maximize the range of features in the population as given in Table 2 and Table 3 [14]. From each category of disability, one woman was picked based on age, type and severity of disability. The reproductive age group of 18–49 years was targeted, bringing the total number of primary respondents to twelve.

Audio recorded interviews were transcribed verbatim and imported into Nvivo software version 10 in order to facilitate data management and analysis. Thematic analysis was used to better organize qualitative information for analysis purposes by identifying and analyzing patterns within the data [15]. Data was coded based on similar patterns of information. Coded data was used to determine themes. A number of themes were predetermined based on the questions from the interview guide, additional themes were generated based on responses from the participants.

Ethical clearance was granted by the University of Zambia Biomedical Research Committee (UNZABREC), reference number 014-06-15.

RESULTS

The study revealed a variety of interrelated barriers to cervical cancer screening. These include structural design of the health facility, inappropriate equipment, inability to access information, education and communication (IEC) materials, limited confidentiality and limited skills of service providers.

Table 1: Checklist of case considerations for observations

Mobility Impaired Clients
Case Considerations
Clear signage
Disability parking
Accessible entrance to facility
Patronizing medical staff
Exam rooms;
Accessible route to and through the room,
Accessible door with clear width and maneuvering clearance,
Adequate clear floor space for side transfers,
Patronizing 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, stabilization 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
Patronizing medical staff
Hearing Impaired Clients
Case Considerations
Availability of interpreter services
Patronizing medical staff

Structural Design of the health facility

Health facilities were not easily accessible to women with disabilities each health facility observed had its own unique number of issues. Crowded corridors in some health facilities posed a threat for individuals with mobility problems as it was likely to hinder easy movements (Figure 1). Observations also revealed that not all the health facilities had spacious examination rooms. Although the necessary equipment was fitted inside, there was little room for manoeuvre. Narrow doorways and steps at doorways were also likely to pose a challenge for entry into buildings. The current situation shows little implementation of the Zambian PWD Act of 2012, which urges health facilities to identify and eliminate barriers to accessing health care [16]. Most of the 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”
(key informant 06)

Table 2: Sampling frame for selection of women with disabilities

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

Disability organizations on the other hand, argued that the structural designs of many hospitals and clinics were not good enough to allow women with disabilities to access cervical cancer screening services.

“At least every disabled person should have access to the building like even the toilet, 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”
(key informant 01)

Inappropriate equipment

The biggest challenge with suitable equipment for women with disabilities was the lack of adjustable 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 because it could not be lowered to the level of the clients. 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”
(key informant 05)

Women who had physical disabilities acknowledged that getting onto the examination table posed 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”
(interviewee 12)

However, some service providers argued that the equipment which their centers had was good for screening but its use on women with disabilities was dependent on the disability involved.

“...with equipment, I think what we are using is conducive but it depends with what disability”
(key informant 03)

One service provider argued that the available equipment was inappropriate and went on to suggest

Table 3: Summary of findings

Subthemes	SERVICE RELATED FACTORS				
	Structural design of health facility	Inappropriate equipment	Access to IEC materials	Confidentiality of service	Limited skills of service provider
Hearing Impaired			Print media alone is not enough because not all hearing impaired people are literate	The need to have an interpreter compromises confidentiality of the service	Communication challenges with service providers
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
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
Health Service Providers	Most service providers felt that their premises were disability friendly	Difficulty has been faced in using the available screening equipment	There is no deliberate effort to tailor messages for a particular audience, the message is the same for everyone	Sometimes confidentiality must be breached in order to offer a proper service to the client	There is lack of disability specific training for health workers.
Disability Organizations	Recognized that health facilities need to be made more physically accessible	There is need to ensure that persons with disabilities are able to use equipment like able bodied persons	Sign language interpreters are few and Braille transcription is expensive so it's difficult to reach out to everyone	Depending on the severity of the disability, there may be need to have a third person present	

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”
(key informant 02)

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

Access to information, education and communication 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”
(interviewee 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”

(interviewee 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 accessed out-patient services and also awareness campaigns within the community itself.

“We do sensitize as a clinic on a daily basis, because even in OPD, the outpatient, we do sensitize on a daily basis, ART (antiretroviral therapy) clinic we do sensitize on a daily basis. Sometimes we even target the people in our community, we send our volunteers to sensitize to the people there”

(key informant 05).

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.

“... 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”

(key informant 04)

Miracle Disabled (ZAPD) 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 sensitization, 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 they will understand, we go around in the community, we do the sensitization or maybe call up a meeting, we meet together and may be, we talk about it”

(key informant 01)

Out of three disability organizations visited, only one had a standing program to target women separately by having informative discussions with them and organizing 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 marginalized the women. You see, what we are doing is collective, it’s for everybody”

(key informant 06).

It was emphasized 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...”

(key informant 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”

(key informant 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 printed material which was found on the ground, a woman with limited vision may find it difficult to read because of the small font which was used. In addition, no Braille was seen on the brochures and posters.

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”

(interviewee 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 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”

(key informant 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”

(key informant 04)

Limited skills of service providers

It was revealed that health workers did not receive any form of training regarding individualized 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...”

(key informant 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”

(key informant 05).

DISCUSSION

Key findings of the study indicate that women with disabilities faced various service related barriers in accessing the cervical cancer screening service. For some of them, these barriers deterred their decision to ever go for screening whilst for others, who had already been for screening, these barriers made their visit to the clinic uncomfortable. Few of the women with disabilities were content with the service that they had received. The major barriers include; structural design of the health facility, inappropriate equipment, inability to access IEC materials, limited confidentiality and limited skills of service providers.

Structural design of the health facility

Architectural designs of the clinical facilities were observed not to be accessible for women with physical and visual disabilities. This is similar to findings which found that architectural obstacles were a cause for concern in accessing buildings [12,17]. 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 (Figure 1 and Figure 2). 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. Interestingly, although the structural designs of the health facilities were found not to be entirely accessible, women with disabilities 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 Zambian legislation states that all public places must be made accessible to persons with disabilities, 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 Zambian PWD Act 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.

Inappropriate equipment

This study also found that the examination rooms lacked adjustable examination tables, thus making it difficult for clients to get onto them (Figure 3). As a result, women reported that it was either painful or physically impossible to position themselves appropriately on basic medical equipment which they found there, and yet it is necessary for a basic pelvic assessment for cervical cancer. Similar reports were noted in a study where women with disabilities had never seen or used an adjustable examination table [18]. In order to ease accessibility,



Figure 1: A crowded corridor at a named health center.



Figure 2: A step at the entrance to the cervical cancer screening center.



Figure 3: A fixed examination table named health facility.

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 resulted into loss of privacy due to the need for the service provider to request assistance from a third party so as to lift clients onto the examination table.

Inability to access IEC materials

Further findings of this study revealed that most women with disabilities had little information about cervical cancer due to limited access to IEC materials. A similar study that 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 [19]. Without adequate information about cervical cancer and its screening services, a woman is likely to access the service. However, this study revealed that there is no distinction in information on cervical cancer for women with disabilities, information produced in print and digital media is generally designed for an able bodied audience. The health service providers reported that their health promotion messages did not cater for any particular group of people but the public in general, as a result these women did not benefit as they ought to. There had been no deliberate efforts to make information inclusive to everybody through Braille transcription or sign language interpretation by any of the cervical screening centers for example.

Limited confidentiality

Additional findings showed 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 does not appear in the literature which was accessed for review

in this study. Ultimately, the type and severity of the disabilities which women had, determined the level of confidentiality that they could receive. Compromized confidentiality during an examination normally occurs when there is need for the presence of a third person to assist in dressing or undressing the client and also when assistance in communication through sign language is sought. Breach of confidentiality was reported during the screening. The screening procedure was noted to be a very uncomfortable one for women with disabilities who were reluctant to share certain information when people other than the medical personnel who were present, this was more so due to the fact that cervical cancer screening requires a sexual history to be taken.

Limited skills of service providers

When cervical cancer screening service providers are equipped with adequate skills to handle women with disabilities during screening, this may minimize the need to have third parties, especially family members present due to the sensitivity of the nature of the pelvic examination. Past studies show a trend in the inability of service providers to provide a satisfactory service due to difficulties in care coordination for women with disabilities. Similar studies also revealed that difficulties interacting with service providers were encountered due to inability to communicate effectively with clients at appropriate comprehension level thus causing medical personnel to often display impatience during examinations [18]. The inadequate skills which the service providers had, limited the quality of screening for their clients. Ideally, coordinated care for persons with disabilities ought to be included in the curriculum for all medical related programs in order to ease contact with persons with disabilities. Without this, persons with disabilities will continue to feel misunderstood and medical personnel frustrated because they do not understand their clients' needs.

LIMITATIONS

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 Language. In addition, some terms in spoken English lacked direct translation into Zambian Language.

In spite of the identified limitations, the study had its 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.

IMPLICATIONS FOR POLICY AND PRACTICE

The Zambian PWD Act gives general guidelines on accessibility of health services, however, there is also need for specific reference to persons with disabilities in national health policies. The current health policies are rather vague because they are generalized to the entire population. Where necessary, new national health policies ought to be formulated to target Zambian people living with disabilities. When relevant policies have been put in place, there would be need to ensure that they are implemented and then closely monitored to check on outcomes and successes.

A multidisciplinary approach would be ideal in handling women with disabilities. This would especially be helpful in addressing concerns of those with communication challenges. For instance, professional sign language interpreters could be stationed at all health facilities to avoid involving non-professionals who may disclose private information about clients. In addition, there ought to be increased awareness of barriers to cervical cancer screening, through health promotion activities. Such campaigns could help curb discriminatory attitudes towards persons with disabilities in health centres. Furthermore, curriculum for training of health personnel ought to include necessary information on how to handle the special needs of persons with disabilities so that health personnel are more accommodating. Continuous professional development workshops could also accommodate such aspects.

Future research in Zambia could aim to include persons with disabilities as participants or respondents where necessary in order to allow comparisons with other populations. In addition, there would be need to determine how best to implement inclusive practices in the health sector. The extent to which current practices

benefit persons with disabilities by exploring their perceptions and experiences would also be helpful in determining future programs

CONCLUSION

Current cervical cancer screening programs are generally designed to cater for the entire population without taking into consideration special needs of minority populations such as women with disabilities. Many of these factors which hinder accessibility are avoidable and can be tackled by applying reasonable adjustments from all stakeholders. There is need for comprehensive policies at national level which recognize that persons with disabilities are a distinct population whose needs cannot be met by mainstream ideas. Having comprehensive policies in place will ensure that the needs of persons with disabilities are budgeted for in the health sector. Where possible, adjustments can be made to infrastructure and ideal screening equipment can be purchased in phases to handle a few health centers at a time. Continuous in-service training and workshops would be ideal to improve skills and attitude of health workers so as to improve relations between clients and themselves.

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Author Contributions

Mazuba Hachipola – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Oliver Mweemba – Substantial contributions to conception and design, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Doreen Sitali – Substantial contributions to conception and design, Revising it critically for important intellectual content, Final approval of the version to be published

Guarantor

The corresponding author is the guarantor of submission.

Conflict of Interest

Authors declare no conflict of interest.

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