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Article

Experiences of Women with Disabilities in Accessing Maternal Healthcare Services: A South African Case Study

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Abstract: Access to maternal healthcare services is a challenge in most low and middle-income countries. South Africa is one of the countries striving to improve the accessibility of maternal healthcare services. Although South Africa has put some interventions to improve the accessibility of maternal healthcare services, vulnerable women including women with disabilities are still facing numerous challenges when trying to access maternal healthcare services. The aim of the study was to explore the experiences of women with disabilities in the province of KwaZulu-Natal in South Africa in accessing public maternal healthcare services. Twelve women with disabilities (four with physical impairments, four with hearing impairments and four with visual impairments) were interviewed for this study. Data were transcribed verbatim and analysed utilising the Framework of Assessing Access to Maternal Healthcare Services by Peters *et al*. 2008. The study found that narrow passages and information in inaccessible formats were a challenge for women with visual impairments. The women with hearing impairments had challenges in communication as most facilities did not have sign language interpreters, negative attitudes of health care workers and being ignored when they asked for help. The women with physical impairments encountered inaccessible buildings, narrow passages, small consultation rooms and equipment which is not adjustable such as beds and scales.

Keywords: disability; maternal health; maternal health care services; pregnancy; access

1. Introduction

Disability is an important public health issue in low, middle and high-income countries [1]. Evidence shows that the healthcare needs of people with disabilities are generally not adequately met due to structural, financial and attitudinal barriers to access [2,3]. Although people with disabilities face challenges in accessing healthcare services, women with disabilities (WWDs) have more challenges compared to their male counterparts. This has been attributed to the fact that WWDs are more likely to be poor, have low education levels and are paid less as compared to men with disabilities ([4]. When it comes to access to maternal healthcare services, WWDs are worse off due to the prevalence of the dominant misconception that they are asexual and thus do not require reproductive healthcare services. Pregnancy and motherhood are considered taboo amongst this population [5]. Despite the fact that most people with disabilities reside in low and middle-income countries, research on the experiences of WWDs when accessing maternal healthcare services is growing in high-income countries and not in low and middle-income countries [6].

The government of South Africa enshrined equality in Section 9 of the Bill of Rights [7,8]. Article 3 of Section 9 states that "the state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth" [8].

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Non-discrimination of people with disabilities is further emphasised by the South Africa White Paper on the Rights of Persons with Disabilities [9]which has its vision as, "South Africa: A free and just society inclusive of all persons with disabilities as equal citizens". Furthermore, Section 27 of the South African Constitution recognises access to health as a human right [8].

Although there is strong political commitment on the part of the South African government to address inequalities and discrimination faced by people with disabilities, there is still a gap between policies and their implementation [10]. For instance, the government introduced the free healthcare policy for pregnant women and children under the age of six in 2002 [11], which was then extended to people with disabilities in 2004 [10]. However, a considerable proportion of the exempted groups still pay to utilise services [12]. This has resulted in access to healthcare services being a challenge to the larger portion of the population from disadvantaged groups in South Africa. Because a significant proportion of the population of disadvantaged groups have challenges in access to healthcare service, [13] conclude that the South African health system "falls short in provision of equitable access to needed, effective healthcare". Although access barriers are prevalent in South Africa, they are not well understood [14]. Furthermore, the increased public awareness of disability issues and rights, is not translating into more research in terms of access to healthcare for people with disabilities especially maternal healthcare services for WWDs.

Findings from a few studies available indicate that people with disabilities face numerous challenges in accessing healthcare services [15]. The plight of WWDs is worse off than that of men with disabilities. Public maternal healthcare services are not adequately prepared to cater for WWDs [16]. "While the factors that militate against access to such services for women, in general, are well-documented in South Africa, there is little research that documents the factors that inhibit or enhance access to maternal healthcare services for WWDs" [17,18]. This study therefore, aims to explore the experiences of WWDs in the province of KwaZulu-Natal (KZN) in South Africa in accessing public maternal healthcare services.

2. Methods

The qualitative research design employing the case study approach was utilised with the underpinning of an interpretive paradigm. The qualitative case study research design enabled the researcher to generate in-depth information on the experiences of WWDs. The case study research design was utilised because, " it is a form of empirical inquiry that enables the in-depth examination of a particular phenomenon, issue or object in real life situations" [19]. With respect to this study, there were no experimental groups. Furthermore, research indicates that case studies are useful in less well-developed research particularly where examination of context and the dynamics of the situation are important [19]. The context of the study was maternal healthcare services. The issue under discussion which is access to maternal healthcare service and the context which is maternal healthcare services could not be separated. As a result, the case study was the most suitable design as it allowed the context and the phenomenon to be explored in depth. The study utilised the interpretive paradigm which allowed the researcher to explore the accessibility of maternal healthcare services through the perspectives of the WWDs. "Interpretive methodology is directed at understanding phenomenon from an individual's perspective, investigating interaction among individuals as well as the historical and cultural contexts which people inhabit" [20].

This research was conducted in KZN, which is one of the nine provinces in South Africa located in the southeast of the country([21]. The province of KZN has the second largest population after Gauteng province [22]. The Statistics South Africa Report based on Census 2011 data, also indicates that the KZN Provincial disability prevalence is 8.4% [22]. To ensure that WWDs share their experiences in a comfortable environment, they were interviewed in their homes or in the organisations. In all the instances, the environment chosen would ensure confidentiality

Sampling can be defined as the process through which research participants or data sources from which data to address the objectives will be obtained are selected [23]. While there are two broad categories of probabilistic and non-probabilistic, this study utilised the non-probabilistic sampling.

 doi:10.20944/preprints202309.0867.v1

The target population for this study was WWDs who are currently pregnant or had been pregnant in the previous five years.

The researcher requested the KZN Department of Social Development (DSD) to provide a list and address of WWDs residing in eThekwini district. The KZN DSD provided the researcher with a list of organisations that have WWDs. These women were at second trimester of their pregnancy or were pregnant in the past five years. As this is a qualitative study, the non-probability sampling was used where the researcher purposively selected information rich cases from which to collect data for the study (Patton 1990: 169). In the current study, the criterion sampling was utilised to select women with visual, hearing, and physical impairments and who were at second semester of pregnancy or were pregnant in the past five years [24,25].

A minimum of 12 WWDs were selected. Of these 12, four were women who were visually impaired, four with hearing impairments and four who were physically impaired. However, data collection continued until a point when no new information could be obtained from the WWDs. This sampling strategy enabled the researcher to account for the impact of the different impairments on access to maternal health services. In addition, this sampling strategy enabled the researcher to include WWDs who are currently pregnant and those who have been pregnant in the past five years. The researcher visited these women at their homes to request them to participate in the study. Necessary provisions for communicating with women with different impairments were put in place. For instance, in cases of women with hearing impairments, the researcher engaged a sign language interpreter.

Inclusion and exclusion criteria define who can be included and who is excluded in the study. "While the inclusion criteria identify the study population in a consistent, reliable, uniform, and objective manner, the exclusion criteria include factors or characteristics that make the recruited population ineligible for the study" [26]. In this study, the inclusion criteria was, WWDs (that is women with a physical or mobility impairment, sensory impairment such as impaired vision and impaired hearing) who sought public maternal healthcare services (antenatal, perinatal and immediate postpartum), WWDs who were pregnant in their first and second trimester, WWDs who had a child in the past five years, WWDs residing in KZN and women in the age group between 18 and 45 as this is the reproductive age group. The exclusion criteria included, Women with cognitive impairments as they would not be able to give consent to participate in the study, WWDs who had never been pregnant, WWDs who were pregnant but are in their third trimester, WWDs who had never had a child more than five years and WWDs who were below 18 years and those who are 45 years and above.

An interview is defined as "extendable conversation between partners that aims at having in-depth information about a certain topic or subject and through which the phenomena could be interpreted" [27]. In-depth interviews were used to gather information on the experiences of WWDs in accessing maternal healthcare services. They provided in-depth understanding of the phenomena under study as they offered an opportunity for clarification of ambiguous responses; they explored more deeply individuals' perceptions on issues under discussion [27].

Since the researcher is not fluent in isiZulu, interviews were conducted by the researcher with the help of a research assistant who was a Masters student who understands research methodology and is fluent in both English and isiZulu. The interview guide contained questions addressing the main research questions. However, the interview guide was not used as a rigid structure. Where necessary, the interviewer asked follow-up questions for clarification even if they are not included in the interview guide. If issues that are not addressed in the interview guide kept coming up repeatedly during the interviews, the interview was amended to include questions around these issues. The interviews were undertaken until data saturation was reached. Data saturation is whereby no new information is obtained from the interviews [28]. Interviews were conducted in the homes of the WWDs.

Permission was sought from the participants to voice record the interview discussions. Each interview session took between approximately 45 minutes and one hour to allow for a detailed discussion of the issues. The researcher took some notes during each interview to act as back up in

 doi:10.20944/preprints202309.0867.v1

case the taping did not work. After each interview, the researcher compiled some notes on accessibility issues that were raised and how they can be incorporated in a practice framework that I would develop. After interviewing all the WWDs, the interviews were transcribed verbatim. However, the names of the participants were not included in the transcriptions to ensure confidentiality. Interviews that were undertaken in isiZulu were transcribed into the language used during the interview. These transcriptions were then given to a professional translator to translate them into English. The data was then analysed usinng the framework analysis. A framework analysis was utilised to analyse qualitative data. "The frame work analysis involves five steps which are familiarisation, identifying a thematic framework, indexing, charting and mapping interpretation" [29,30].

3. Results

The researcher employed the criterion sampling strategy to sample 12 participants from WWDs. Of the 12 WWDs, 4 had a physical impairment, one had both physical and visual impairments. The participants also included 4 women with hearing impairments. Four of the participants had a visual impairment. Of the 4 women with a visual impairment, 1 woman also had albinism. The women were aged from 18 to 48 years. Six were aged between 28 and 38 years, 4 between 38 and 48 years, and 2 women between 18 and 28 years. All the women were African and not employed. One of the women was enrolled as an IT student at the eDeaf Association in Durban. Amongst the women, 4 were married while the other 8 were not married. In terms of education, 1 woman did not have any formal education, 1 had primary education, 6 had secondary education and 4 had tertiary education.

The WWDs explained that they experienced numerous challenges when accessing maternal healthcare services. These challenges can be classified into three categories, which are a) systemic factors, b) structural factors and c) personal factors. Some of the experiences varied depending on the type of imairment the WWDs had.

The women with hearing impairments mainly had challenges in communicating with the healthcare workers. The two categories that emerged were a) lack of training in sign language, b) lack of sign language interpreters and c) lack of assistive communicative devices.

The excerpts below indicate that lack of training in sign language amongst the healthcare workers makes access to maternal services frustrating:

> *"Healthcare workers need to be able to communicate with the deaf because it's very difficult to communicate with them because it's very tiring to always arrive and have to communicate using a pen and paper. In government hospitals maybe if they can train nurses in South African Sign Language that would ease the communication problem".* (WWD 2: 24 years).

> *"They need to teach nurses sign language, or we can teach them sign language maybe the basics such as "hello".* (WWD3. 33 years).

The participants also indicated that a lack of sign language interpreters acts as a barrier to access to maternal services. The sign language interpreters would make communication easier between the healthcare workers and the women with hearing impairments. This is explained in the excerpts below:

> *"We cannot communicate with the deaf, you must come with the person…maybe your boyfriend or your sister so that they could interpret for you…that is what the nurses said*". (WWD3: 33 years).

> *"Please, please, please, we need interpreters…there're no interpreters and also in clinics there're no interpreters there…but hoping that everything will be improved."* (WWD2: 24 years).

The lack of sign language interpreters impacted negatively on WWDs in accessing antenatalcare as illustrated in the excerpt below:

> *"I went to the antenatal classes once and there was no interpreter. I could not hear anything, so I decided not to go as I did not gain anything from the classes."* (WWD3: 33 years).

Table 1. Demographic profile of women with disabilities.

Participant No.	Age (years)			Race	Marital Status		Educational level				Employment status	Type of impairment		
	18-28	28-38	38-48		Y	N	None	P	S	T		Visual	Physical	Hearing
WWD.1		X		African		X	x				Not employed		X	
WWD.2	X			African		X				X	Student			X
WWD.3			X	African	x					X	Not employed			X
WWD.4		X		African	x					X	Student			X
WWD.5		X		African	x				X		Not employed			X
WWD.6		X		African	x				X		Employed		X	
WWD.7			X	African		X			X		Not Employed	X		
WWD.8		X		African		X			X		Not employed	X	X	
WWD.9			X	African		X				X	Employed	X		
WWD.10		X		African		X			X		Not Employed	X		
WWD.11	X			African		X			X		Not employed		X	
WWD.12			X					x			Not Employed		X	

WWD= Woman with disability; Y = Yes, N = No; P= Primary; S = Secondary; T = Tertiary.

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The challenges in communication were even more during labour. The women indicated that they had just to follow the signs that the healthcare workers improvised and look at the facial expressions of health care workers.

However, women with hearing impairments indicated that communication with healthcare workers was much better if they were able to read and write and when they had family and friends to interpret for them. This is confirmed in the following excerpts:

"There was a communication barrier, but I was able to communicate with a doctor using a pen and paper." (WWD2: 24 years).

"The communication with the nurses was really difficult and I asked my sister to come with [me] to the clinic…" (WWD3: 33 years).

The women with visual impairments had challenges navigating through the facility and information in accessible formats. Some of the facilities had narrow passages and also had stairs as indicated in the excerpt below:

"The hospital has so many stairs and it is difficult for me as I am visually impaired. My sister helped me to move from one place to another." (WWD6: 35 years).

In addition, some of he information provided to the women with visual impairments was not in accessible fomats. This is illustrated by the excerpt below:

"At the antenatal class, they had pictures and used actions to explain to us how we breastfeed our kids. I could not see anything. It did not make sense for me to attend further." (WWD9: 38 years).

Women with physical impairments had contend with infrastructure which was not designed to suit their needs. This included; narrow passages, lack of wramps, narrow dorrs. Bathrooms that do not have rails, unadjustable beds and scales:

"Because I have one leg, it was difficult for me to climb onto the bed. I had to be assisted by the nurses… they had to physically carry me." (WWD8: 34 years).

"They did not weigh me. They would do the other check-ups but because I could not stand on the scale, I was never weighed." (WWD11: 27 years).

"Bathing was a problem for me especially because I have one leg and I cannot see. I needed something to hold onto but there was nothing. I relied on the nurses to assist me." (WWD8: 34 years).

"My partner had to assist the hospital sister to carry me onto the examination bed. It was difficult for me to get onto the bed on my own." (WWD11: 27 years).

"I had a problem. Um my wheelchair, it could not fit into the consultation room. The nurse had to come and see me in the passage, and I was then told to go to hospital X for my next visit." (WWD11: 35 years).

Some of the challenges were experienced across the women with the physical, visual and hearing impairments. These challenges included; staff attitudes towards WWDs quality maternal health care services and cost of services.

Negative staff attitudes were cited as having a negative impact on access to maternal healthcare services. This is outlined in the excerpts below:

"Because at Hospital X I felt that they did not understand that I too can have babies and kept on asking that and mocking me about it, I then decided to go to Hospital Y for my second baby. However, at Hospital Y still, there were nurses who were saying I love men too much that is why I keep getting pregnant" (WWD11: 42 years).

"In hospital where I delivered my baby, they ignored me and said you will deliver on your own and keep on crying like that" and finally I had to have an operation because I had felt severe labour pains and the baby was tired ….Because my first born almost lost his life at hospital A because of their negligence; I then decided to change the address in order for me to deliver at X". (WWD 5: 35years).

"It was a very difficult time; some of the hospital nurses would just ignore. I felt the nurses were ignoring me maybe because I'm deaf and they were attending the hearing patients…They gave the

hearing women fair treatment, but they were ignoring me because of my deafness." (WWD3: 33 years).

Most of the WWDs require someone to accompany them during hospital visits, The woen with hearing impairments require someone who would interprete for the, the ones with visual impairments would require someone to assist them with the navigation of the facility and the oes with physical impairments require someone who will assist them carrying the babies and navigating the facility. The need for a companion increases the cost of servicess illustrated in the excerpt below;

"They said "we cannot communicate with the deaf, you must come with the person…maybe your boyfriend or your sister so that they could interpret for you--that was the nurses." (WWD2: 24 years).

In the excerpt below, one woman explains how she has additional costs as they need to always have someone to assist them during a hospital visit:

"As I am blind and have one leg, when I need to go to the clinic for post-natal care, I need someone to accompany me to carry the baby for me. This means I need transport fees for two people." (WWD7: 38 years).

In addition, WWDs are more likely to be referred to higher levels of care as illustrated in the excerpt below:

"The nurses from the clinic said I should go to hospital X because they do not know what caused me to stroke even though the stroke happened when I was 5 years old." (WWD1: 29 years).

Furthermore, some WWDs explained that they had to contend with health care workers who did no understand their needs. The lack of understanding of WWDs needs by healthcare workers is indicated in the excerpts below.

"It surprises the healthcare workers that we get pregnant. It's like we do not have functional reproductive systems. They need to be educated that we too have functional reproductive systems, and it is normal for us to be pregnant as we are women too." (WWD9: 38 years).

"The healthcare workers need to be sensitised on how to be disability-inclusive in the provision of maternal healthcare services… They should be provided with regular training because if the training is once-off they forget." (WWD.7: 46 years).

4. Discussion

Sign language interpreters are important in ensuring that communication between healthcare workers and women with hearing impairment can interact effectively. The study found out that the facilities did not have sign language interpreters. The lack of sign language interpreters led to women with hearing impairments relying on their relatives to interpret their sign language for the healthcare workers. The lack of sign language interpreters and the issue of relying on relatives to be interpreters is also reported in other studies [31,32]. The lack of effective interaction between women with hearing impairments and the healthcare workers may result in adverse outcomes which could be avoided [33].

The study revealed that the availability of a companion during the health service visit was a facilitator of access to maternal health services. The companion would assist with sign language interpretation for women with visual impairments, navigating the facility for women with physical and visual impairments and carrying the women with physical impairments onto and off the high fixed beds. The findings are consistent with those from other studies which also found that family members assist with interpreting sign language and navigating the health facility [16,31,34]. However, a study by [31] found that the companion was only restricted to outpatient services and during visiting hours, and the women with hearing impairments would stay with no interpreter all the other time. This caused challenges in communication between healthcare workers and women with hearing impairments.

 doi:10.20944/preprints202309.0867.v1

Some of the WWDs reported being treated with disrespect by healthcare workers. The WWDs noted that not all healthcare workers were disrespectful. The disrespect was displayed in form of yelling and ignoring the calls by WWDs. Such kinds of abuse have also been documented amongst studies for women without disabilities [35]. Such abuse dissuades WWDs from visiting the health facilities early. Although disrespectful treatment has been recorded in studies for women without disabilities, it is important to note that disability worsens the situation. The negative attitudes may be due to lack of training and knowledge amongst the healthcare workers as well as assumptions on what WWDs can and cannot do. These findings are consistent with other studies conducted in South Africa [16,31,36] as well as other parts of the world [5,37]. These studies report that the social beliefs of healthcare workers, which perceive WWDs as asexual and are not capable of mothering babies lead to WWDs feeling disrespected.

The study findings revealed that most of the WWDs are not employed. However, these WWDs are regarded as high risk and hence are referred to higher levels of care. In most instances, their referrals happen when they are not emergency cases and hence, they are required to transport themselves to the higher levels of care that are not within their locality. This increases the distance travelled from home to seek health services which in turn increases the transport cost. The transport cost is worsened by the fact that the WWDs would need to be accompanied by a family member or partner to the facility. This makes the transport costs more expensive than what it is for pregnant women without disabilities. Other studies also reported that WWDs incur additional transport costs as they have to be accompanied and are also referred to higher levels of care [34,36,38].

In this study, some pregnant WWDs were referred to higher levels of care due to their pregnancy even if they were not ill. Consequently, they had to get their own transport to the higher levels of care. This is an additional burden to WWDs in terms of transport costs. Even though the facilities are accessible with public transport, in some areas, the WWDs have difficulties in accessing public transport as it is found a bit far from their homes. In their study which examined access to sexual reproductive health services for people with disabilities, [16] also found out that the referral of WWDs to higher levels of care increases the distance between the WWDs and the facility where they have to access the services from. Another challenge noted was the unavailability of ambulances all the time. In this study, healthcare workers highlighted that there were some delays in transfers due to delays in ambulances.

5. Conclusion

A few of the WWDs perceived the maternal healthcare services to be of good quality. The visually impaired raised the concern of narrow passages which are difficult to navigate and also information that is not accessible in braille. Women with hearing impairments raised concerns of challenges in communication and negative attitudes, rudeness and being ignored when asking for help. Physically impaired women raised issues regarding inaccessible buildings, narrow passages and small consultation rooms as well as beds that are not adjustable. The research on WWDs access to maternal healthcare services is still very scarce. There is a need for more extensive research on WWDs' access to maternal healthcare services understanding the factors that impact access for pregnant WWDs in order to develop disability-friendly maternal healthcare services. Considering the low numbers of pregnant WWDs that visit the facilities, having all the maternal healthcare facilities adequately equipped for pregnant WWDs may be a challenge. There may be a need to have selected maternal healthcare facilities that are designed to meet the needs of WWDs, have adequate resources and equipment including sign language interpreters and an interdisciplinary team. These facilities will be well known and all pregnant WWDs can be referred to those facilities. The WWDs can be provided with vouchers to reimburse them for the transport cost as they may have to travel to areas that are not within their communities. In addition, the access to maternal healthcare services could be improved by including pregnant WWDs to be part of the outreach programme. The outreach teams will then include a team of healthcare workers who provide maternal healthcare services and are sensitive to the needs of pregnant WWDs.

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Data Availability Statement: The data presented in this study are available upon request from the corresponding author. The data are not publicly available due to privacy restrictions.

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