

Lived Experiences of Women with Disabilities in Accessing Sexual and Reproductive Health Services in Lira District, Northern Uganda

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ABSTRACT

Purpose: *The study aimed at exploring the lived experiences of women with disabilities in accessing sexual and reproductive health services in Lira district, Northern Uganda.*

Method: *This study utilised a phenomenological study design. Ten women, aged 15 - 49 years, were purposively selected from Lira District Union of Persons with Disabilities. They were accessing sexual and reproductive health services across the district. Data was collected using an in-depth interview guide, and thereafter thematic analysis was done.*

Results: *More than half (60%) of the participants were 40-50 years old and had more than 2 children. Half of them (50%) were married; the majority (70%) resided in the rural area and had a physical disability. They related their positive and negative experiences. On the positive side, they indicated the existence of supportive stakeholders, availability of services, and being served with no discrimination in some health facilities. Negatively, they experienced difficulty in navigating the physical environment in health facilities, lack of transport, negative healthcare provider attitudes, long waiting time, side effects of family planning methods, lack of privacy and unhygienic sanitary environments in health facilities.*

Conclusion and Recommendations: *Women with disabilities in Lira district had both positive and negative experiences in accessing sexual and reproductive*

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health services. Recommendations of this study include counselling women with disabilities about side effects of hormonal family planning methods, incorporating disability studies in curricula for health workers, on-the-job training for health workers on care for persons with disabilities, and enforcing policies that favour access to sexual and reproductive health services for women with disabilities. The government should empower the local leadership to supervise every new health facility that is being constructed, and ensure that accessibility standards for women with disabilities are met.

Key words: *women with disabilities, sexual and reproductive health, lived experiences*

INTRODUCTION

Persons with disabilities still represent a group of people who do not always have equal access to public health programmes and services, despite all the gains made in improving their health status as stated in previous studies (Krahn, Walker & Correa-De-Araujo, 2015). Globally, 15 percent of the world's population lives with some form of disability and women represent more than half of all persons with disabilities (WHO, 2011). Disability is defined as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO, 2011). It is estimated that 80 percent of people with disabilities are living in low-and middle income countries (LMICs) (Rugoho & Maphosa, 2017). The high prevalence of disabilities in LMICs is partly a result of birth defects, chronic illnesses, accidents, violence and people living longer than before (ACPF, 2014). Women with disabilities constitute a minority group in every society and are more likely to face health, social and economic disparities compared to their counterparts who do not have any form of disability (WHO, 2011). Studies in Sub-Saharan Africa have established that women with disabilities have unequal access to sexual and reproductive health services (Ganle, Baatiema, Quansah & Danso-Appiah, 2020), with 61.3 percent of women with disabilities not able to afford a visit to the health facility (Ganle et al, 2016). Sexual and reproductive health services include maternal and new-born healthcare, family planning services, prevention of unsafe abortion, post-abortion care, management of reproductive tract infections including HIV/AIDS, and the promotion of sexual health (Fathalla & Fathalla, 2014). Women with disabilities face a multitude of

challenges when trying to access such services, including negative perceptions of health personnel, disability-unfriendly infrastructures at health facilities and the absence of trained personnel to provide targeted care to people with disabilities (Rugoho & Maphosa, 2017). Other difficulties include the communication gap, especially when communicating with women who are aphasic, blind or deaf (Masereka, Naturinda, Tumusiime & Munguiko, 2020). This is compounded by the inability of many women with disabilities to protect themselves, the isolation in which they may live, and dependency on others as compared to their counterparts without any form of disability (Spratt, 2013). In addition, false beliefs that women with disabilities are asexual, unsuitable for marriage and unable to manage their fertility or raise children exacerbates the failure of women with disabilities to access sexual and reproductive health services (Spratt, 2013).

In Uganda, despite the availability of sexual and reproductive health services at all levels of healthcare provision, women with disabilities may not have access and those who may have access face challenges such as negative attitudes of service providers, long queues at health facilities, distant health facilities, high costs of services involved, inaccessible physical structures and the general perception in the population that these women are asexual (Ahumuza, Matovu, Ddamulira & Muhanguzi, 2014).

Whereas many studies have explored the challenges faced by women with disabilities in accessing sexual and reproductive health services, few studies have documented their lived experiences.

Objective

This study aimed to explore the lived experiences of women with disabilities in accessing sexual and reproductive health services in Lira district of Northern Uganda.

METHOD

Study Setting

The research was carried out in Lira district, Northern Uganda. The study included women from the Lira District Union of Persons with Disabilities who were availing of sexual and reproductive health services from various health facilities around the district.

Study Design

A phenomenological study design was used. Women with disabilities were asked to recall their past or lived experiences pertaining to accessing sexual and reproductive health services at the various healthcare settings in Lira district.

Study Sample

Women with disabilities were purposively selected and interviewed one after the other until saturation of information was realized when the tenth participant was reached. The study utilised the Washington Group short set of assessment questions on disability to screen, identify and recruit participants (Sloman & Margaretha, 2018). This tool comprises a set of assessment questions from the six core domains of seeing, hearing, walking, cognition, self-care and communication that most often result in activity limitation and participation restriction among individuals. Women who were in the reproductive age group of 15 - 49 years, accessed sexual and reproductive health services earlier and fulfilled the Washington Group short set of assessment questions on disability criterion were included in the study.

Data Collection

Face-to-face interviews were conducted, using an in-depth interview guide that consisted of open-ended questions. The interview guide was translated from English into Lango, which is the local language in Lira district, for better understanding. This was then transcribed verbatim and back-translated into English. The researchers posed questions on the experiences of accessing and utilising sexual and reproductive health services. After asking a question, the participant was allowed to give her opinion on the matter in detail, without interruption; however, prompts to obtain more information were introduced in the discussion. Probes were used, such as silence, urging phrases and non-verbal attending skills. Interviews continued until there was saturation of information. Participants' narratives were tape recorded as well as jotted down in note books. Tape recorded information and written narratives were kept securely in a lockable office cupboard before analysis.

Data Analysis

Transcribed data was analysed manually using thematic analysis. Data was organised into manageable narratives; this was followed by a search for key

concepts and patterns in the narratives. The generated patterns were transformed into themes.

Ethical Considerations

Ethical clearance was obtained from the local Research Ethics Committee at the Uganda Martyrs University. Verbal and written consent was sought from all the study participants.

RESULTS

Socio-demographic Characteristics of Participants

More than half (60%) of the participants were 40-50 years old and had more than 2 children. Half of them (50%) were married, and the majority (70%) resided in the rural area and had a physical disability (see Table 1).

Table 1: Socio-demographic Characteristics of Participants

Characteristics (N=10)	Frequency	Percentage (%)
Age group		
<40 years	4	40
40-50 years	6	60
Marital status		
Married	5	50
Single	5	50
Number of children		
<2 children	4	40
2-5 children	6	60
Residence		
Rural	7	70
Urban	3	30
Type of disability		
Clubfoot	1	10
Amputated upper limb	1	10
Paralysed lower limb	4	40
Hunchback	1	10
Visually impaired	3	30

Lived Experiences of accessing Sexual and Reproductive Health Services

The experiences of women with disabilities were both positive and negative.

The following positive experiences in accessing sexual and reproductive health services were mentioned:

the existence of supportive stakeholders, the availability of services, and being served without discrimination in some facilities. Some participants reported that they received sexual and reproductive health services through Non-Governmental Organisations (NGOs) operating in their areas.

“Sexual and reproductive health information reached me when there were outreaches supported by organisations in our community and I was advised to go to a health facility” (Participant-U).

“On a quarterly basis, Action Aid (an organisation) brought cultural and religious leaders together to speak about gender-based violence and reproductive health in our community. At the end, we got solutions to many reproductive health challenges” (Participant-T).

Participants narrated that they were able to find and utilise sexual and reproductive health services at existing health facilities.

“...When I got to the health facility, there was a health education session going on where I got to know about the various services I could access at the facility” (Participant-U).

“I was able to do cervical cancer screening which otherwise I would not have accessed” (Participant -U).

Being served without discrimination in some facilities was another positive experience mentioned by one participant in particular.

“When I went to deliver my baby, I was served on a first come, first served basis through all the phases involved from registration to discharge” (Participant -J).

“...at the labour room, the nurses were very nice and easy to get along with” (Participant -J).

Negative lived experiences of accessing sexual and reproductive health services related to side effects of family planning methods, navigating the physical environment in health facilities, the lack of transport, negative healthcare provider attitudes, long waiting time, lack of privacy and unhygienic sanitary environments in health facilities.

Participants mentioned side effects such as headaches and vaginal bleeding from using hormonal methods.

"...I used this method where a tiny thin rod the size of a match stick was inserted in my arm after which I started bleeding heavily and also developed headache. This affected me so much since I didn't have any time where I was free from blood-stained panties...." (Participant -X).

Women with disabilities who experienced negative attitudes of the service providers reported that they were not respected in some health facilities. This was evident in the negative attitude of health staff who attended to them.

".... you know, it is like women with disabilities should not conceive at all. When I went for pregnancy check-ups, the way midwives looked at me, was like I have done something wrong! At times they were too rude to me but I learnt to ignore them and just aim at getting someone to check the condition of my baby. We do not like the way society and healthcare providers treat us....." (Participant -Z).

".....when I inquired about an HIV test, the nurse laughed and asked me why I needed it. I felt so embarrassed and only had an HIV test during an antenatal visit. It was like I was immune to getting HIV yet I was in a relationship. I now try not to ask questions as long as they give me the treatment I need when I am sick" (Participant -T).

Participants reported queuing with the rest of the mothers, which made it a much longer wait for services, and they were already experiencing pain from sitting too long. In addition they have to travel back home which takes a long time, especially if they have a limp, or have to crawl home or push themselves in a wheelchair.

"...at the health facility, there can be many patients but very few staff. This particular staff is the one that is giving people medical forms, writing their names and then sending them to the doctor for consultation. There would definitely be a delay....." (Participant -W).

"...at times when I would go for antenatal services, I would line up for a long time and sometimes I would get so tired and give up...." (Participant -Q).

"...our hip bones are not strong enough to stand for a long time and when we are pregnant we tend to feel weak and tired most of the time" (Participant -Q).

Lack of privacy for women with disabilities when visiting health facilities was also mentioned as a deterrent. The respondents felt that their privacy was often violated by health staff.

“When you are blind, they don’t care about privacy. When I was pregnant, I would be examined with even my guide around. This made it difficult for me to talk about my problems with the nurse. When I was examined and I had an infection, I felt embarrassed because even my guide knew about it” (Participant -C).

Most of the health facilities had considerable barriers, both outdoors and indoors, for women using wheelchairs and those with limited walking abilities. This was due to the absence of ramps, rails and multi-storey buildings without elevators.

“...the health facility did not have ramps to help those on wheelchairs like me. One day I went there and I had challenges negotiating my way around the buildings. The nurses who could have helped me also had lots of other patients to manage, which left me frustrated “ (Participant – P).

The absence of adjustable delivery beds made it difficult for women with disabilities to receive good quality maternity services and take full control of their birthing process.

“I found difficulty getting onto the bed at the hospital when I went to deliver. My attendant helped me up and down the bed which made me feel like a burden to her” (Participant –J).

Women narrated that sanitary facilities in the health facilities were completely inappropriate, inaccessible and unhygienic. There were no latrines designated for women with disabilities. This affected their hygiene since not everyone is very conscious about keeping sanitary facilities clean.

“... I face a lot of problems when it comes to using the toilets and latrines. For some of us, who crawl, the toilet floors are very dirty and it is difficult for us to squat on the toilets and latrines without sitting pans...” (Participant –W).

Movement to and from the health facility was reported to be challenging for women with disabilities. Major concerns related to transport, including the lack of support to make use of transport, the difficulty in finding transport and the high costs involved.

"...I had to pay the person to accompany me to the health facility and also pay for my own to travel to the health facility. Considering that I don't have a meaningful job, it is difficult" (Participant-O).

"...I sat behind a truck with no proper support for me while travelling from home to town to access the health facility, which was not very comfortable for me" (Participant-O).

".....I needed somebody to push me, especially with our bad roads..." (Participant -J).

DISCUSSION

This study identified a number of positive and negative experiences of women with disabilities in accessing sexual and reproductive health services. Among the positive experiences were:

1. The availability of supportive stakeholders who contribute financial aid to support social mobilisation campaigns, as well as outreaches to bring services closer to women with disabilities. (Nxumalo, Goudge & Thomas, 2013).
2. The existence of sexual and reproductive health services in various health facilities reduces demoralisation for women with disabilities. It builds trust in the facility and increases chances that women will come back to utilise the service when next required.
3. Being attended to without discrimination improves service attendance by women with disabilities (Ganle et al, 2020).

Women with disabilities had negative perceptions about family planning services, especially the hormonal methods that were being offered. The negative perceptions resulted from the adverse side effects experienced after taking contraceptives, including headaches, heavy bleeding and abnormally long and short menstrual cycles. This finding is consistent with a similar study carried out in Mexico (Dansereau et al, 2017) where women feared long-term infertility impacts, such as fears of harming the baby or difficulty conceiving. Being afraid that the uterus and ovaries could be harmed or altered after use of contraceptives was mentioned in the Mexican study as well (Dansereau et al, 2017).

The reported negative attitudes of health workers towards the provision of sexual and reproductive health services to women with disabilities can contribute

to the impression that health workers do not value these women equally, like other clients, during provision of services. This alters the perceived quality of sexual and reproductive health services provided to them (Tunçalp, et al, 2015). Similarly, studies conducted in Kenya and Uganda have shown that women with disabilities felt disrespected by service providers and this is seen as an indication that members of the community view women with disabilities as not having sexual feelings; as not being able to get pregnant, and as women who should not get married (Apolot et al, 2019). These perceptions held within many communities paint a picture of how women with disabilities are viewed when they seek sexual and reproductive health services. Studies carried out in Nepal and Uganda found that health workers not only have a negative attitude towards women with disabilities, but are also not trained to appropriately handle special needs of women with disabilities (Morrison et al, 2014; Lee et al, 2015).

In this study it became clear that women felt their privacy was compromised when making use of sexual and reproductive health services at health facilities. The finding that women with disabilities would be examined in the presence of their assistants or helpers is similar to a study in Zimbabwe which found that health workers did not know how to relate to women with disabilities, especially in the presence of their helpers (Papp et al, 2014; Rugoho & Maphosa, 2017). In such cases, women with disabilities would feel disrespected, which is a serious hindrance in providing quality healthcare. As such, women with disabilities may feel dissatisfied, thus reducing the chances of seeking sexual and reproductive health services again.

The opinions expressed by women with disabilities in the current study indicate the range of difficulties they encountered in navigating the environment and routes at health facilities, being unable to climb on to delivery beds and being unable to squat on the available toilets at the health facilities. The most notable barriers for women with disabilities in accessing health facilities were the lack of ramps for wheelchairs, high stairs and the lack of personnel to assist them in climbing stairs, narrow doorways, and inaccessible toilets. Similar findings have been reported in other studies (Ahumuza et al, 2014;). Findings from this study suggest that though much has been done to improve access to sexual and reproductive health services for women with disabilities, a lot still needs to be done to mitigate challenges and the aforementioned barriers to access such services. Improvements that are needed to create disability-inclusive services require a multi-sectoral and multi-disciplinary approach, due to the different types of barriers that prevail.

In this study, challenges related to transportation include the lack of suitable means of transport, lack of support to access transport, difficulty in finding transport and the high cost of transport. Similar results can be found in other studies (Sakellariou & Rotarou, 2017; Dassah, Aldersey, McColl & Davison, 2018; Apolot et al, 2019). The problems related to transport seem to be aggravated because many women with disabilities are poor (Pinilla-Roncancio, 2015; Naami, 2015).

CONCLUSION and RECOMMENDATIONS

Women with disabilities have both positive and negative experiences in accessing sexual and reproductive health services. On the positive side, women mentioned the existence of supportive stakeholders, availability of services, and being served without discrimination in some health facilities. Negatively, participants elucidated challenges related to side effects of family planning methods, difficulty in navigating the physical environment in health facilities, lack of transport, negative healthcare provider attitudes, long waiting times, lack of privacy and unhygienic sanitary environments in health facilities.

It is recommended that providers of sexual and reproductive health services address the side effects resulting from the use of hormonal family planning methods through appropriate information, education and management. The researchers propose also that healthcare personnel have relevant competences to work with women with disabilities; that curricula of health workers pay sufficient attention to the life and needs of women with disabilities; and that the current workforce of healthcare personnel be given on-the-job training in providing appropriate care for persons with disabilities in order to improve their attitudes towards women with disabilities. For every new healthcare facility being constructed, the government should ensure that accessibility standards for women with disabilities are being met. Favourable policies that ensure access to sexual and reproductive health services for women with disabilities should be developed, and necessary actions to ensure their implementation should be put in place.

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