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Photovoice Analysis of Healthcare Access Challenges among Women Living with Disability's in Nairobi's Informal Settlement during the COVID-19 Pandemic

Mercy Wairimu Kihiu[1]; Inviolata Njeri Njoroge[1]; Bernard Nyauchi[1]

[1]LVCT Health, Kenya, mercy.kihiu@lvcthealth.org; Njoroge@lvcthealth.org; Bernard.Nyauchi@lvcthealth.org

PHOTOVOICE ANALYSIS OF HEALTHCARE ACCESS CHALLENGES AMONG WOMEN LIVING WITH DISABILITY'S IN NAIROBI'S INFORMAL SETTLEMENT DURING THE COVID-19 PANDEMIC

Abstract: The COVID-19 pandemic exposed greatly existing health care inequalities experienced by persons living with disabilities. Many persons living with disabilities in Kenya's informal areas experienced numerous inequalities during the COVID-19 pandemic, and this was exhibited in their difficulty accessing employment as a result of mass layoffs, education, and health services. This qualitative study explored the health and well-being of women living with disabilities in informal settlements in Nairobi during the COVID-19 pandemic. The photovoice technique was used to collect data from six purposively sampled participants that represented the vulnerable persons with disabilities living in the informal settlements of Korogocho and Viwandani in Nairobi. Additionally, in-depth interviews (IDIs) were conducted to further highlight how common the experiences described by the Photovoice participants were. Recordings were transcribed verbatim, translated to English, and coded using NVivo. Through thematic analysis of the transcripts, three main barriers were identified: challenges with access and affordability of health services for women living with disability; social and self-stigma as a contributing factor in access to health services for women living with disability; and the built and physical environment as a challenge in access to healthcare services for women living with disability. Attitudinal factors were explored, and unfavorable health-seeking behavior was found to be a barrier to access to healthcare for some participants during the pandemic.

Keywords: COVID-19 pandemic, women living with disability, informal settlements, photovoice, access to healthcare

Introduction

COVID-19 exposed the vulnerabilities and limitations of the healthcare system on a global level (Lebrasseur *et al*., 2021). Globally, countries affected by the pandemic found their healthcare stretched to its limits, increasing the already worse situation. COVID-19 exposed the inequities in our world, and individuals living with *disabilities* were greatly impacted (Lewis *et al.*, 2022). Health care practitioners were compelled to confront unfamiliar situations that required critical care. The demand for COVID-19 care overwhelmed available resources; this decision related to equitable access to testing, shortages of protective equipment, and rationing of medical supplies (Lebrasseur *et al.,* 2021).

In the context of developing countries, sub-Saharan cities were experiencing rapid urbanization, leading to an increase in urban population and the rapid growth of informal settlements (Tsinda *et al*., 2013). These informal settlements exhibited challenges including constrained access to water and sanitation, tenure insecurity, inaccessibility, poor lighting, extensive flooding, weak institutional capacity, and a lack of policy frameworks and guidelines at the county and urban level (The World Bank, 2020). Urbanization in developing countries led to an increase in the number of people with disabilities living in informal settlements. According to the CDC (2013), the most common and functional disabilities in informal settlements were mobility limitations, disabilities in memory or thinking, self-care, vision, and independent living (Ngacha, 2016). In Kenya's capital, Nairobi, it is estimated that over 70% of the population lives in informal settlements (World Bank, 2020). Many residents in Nairobi's informal settlements disproportionately experienced ill-health and socio-economic burdens during the pandemic,

yet routine government data rarely cover informal settlements (Kenya Health Policy, 2014–2030). Vulnerabilities and inequities are often invisible in urban planning, health, and socio-economic indicators.

Evidence from several countries, operating a various healthcare systems, indicated that people with disability experience worse access to healthcare compared to the general population (AIHW, 2015, Gudlavalleti *et.al.,* 2014). Women living with disability in informal settlements encountered barriers in accessing healthcare services and reported less satisfaction with their medical care (McKinney& Mckinney, 2021) with problems including lack of transport, inaccessible buildings in hospitals, inadequate healthcare workers, their needs not being understood and feeling of low priority due to pre-existing conditions (Gibson & O'Connor, 2010). Such inequalities were be further compounded by the systematic exclusion that people with disability in informal settlements often face, exemplified by lower employment rates, lower income levels, and higher levels of poverty than the general population (McKinney& Mckinney, 2021). In Nairobi the situation was more pronounced as residents of urban informal settlements facing disproportionate socio-economic, health, and wellbeing burdens and experience grave inequities while accessing public health services (Lewis *et al.,* 2022).

This study examined the health and well-being of vulnerable people, specifically women living with disabilities, in informal settlements in Nairobi, with a focus on their access to healthcare services. The term disability was used in reference to the social model, which highlights a disadvantage that stems from a lack of fit between a body and its social environment' (Goering, 2015). In this paper, we use the term 'disability' to refer more broadly to the barriers and their implications because this is where we find that societal factors are causing the impairment to become a disability (Josephine *et a*l., 2020).

Methodology

Design

This study implemented community-based participatory research (CPBR) approaches, collecting data from women living with disabilities identified and prioritized by residents of Korogocho and Viwandani informal settlements between the years 2020 and 2022. To explore the health and well-being of women living with disabilities in regards to their access to healthcare services, the study used the photovoice technique, in-depth interviews, and focus group discussions.

Data collection

Data was collected using community profiling, the photovoice technique, in-depth interviews (IDIs), and focus group discussions (FGD). Women living with disabilities were accessed through community profiling techniques in both the Korogocho and Viwandani areas.

a) Community Profiling

Community profiling is a comprehensive analysis of a community. It includes an analysis of geographical context, demographic realities, statistical indicators, socio-economic indicators, resources, facilities, and infrastructure; the needs, aspirations, and conditions of the community (Wald, 2019). Having community background knowledge before conducting the study aided in increasing rapport, community engagement, and reducing anxiety for all parties. The community profiling in this study aimed at understanding basic

information for the settlement, land tenure system, historical background, access to basic services, and livelihoods in the study sites.

b) Photovoice and In-depth Interviews

A photovoice approach was implemented with six purposively sampled participants that represented the vulnerable persons with disabilities from Korogocho and Viwandani. Photovoice enabled the study to record and reflect on the day-to-day lived experiences of marginalization that affect the health and wellbeing of women with disabilities. About 18 in-depth interviews (IDIs) were conducted with study participants to ascertain how common the experiences described by the Photovoice participants could have been.

Table 1 below provides background characteristics of the women living with disabilities who participated in the study.

Table 1: Summary of some study participants

Type of disability	Gender	Type of Participant	Axis of vulnerability
PWD – Deaf	Female	Photovoice	PWD (deaf), low social economic status, no source of income, older person, lives with a husband who is also deaf and with no source of income.
Female PWD – Physical	Female	Community IDI	PWD – (physical disability) – moves with crutches, low social economic status, failing business, and lives by herself
Female PWD – physical	Female	Community IDI	PWD – (physical), low social economic status, no regular source of income and the caretaker of two of her children.

Data Analysis

Recordings were transcribed verbatim and translated into English. Thematic framework analysis was carried out, and coding was done using Nvivo to identify common as well as divergent experiences and opinions. The open coding approach that was adopted allowed for all new and perhaps unexpected themes to be identified, as well as those anticipated in advance based on the literature review.

Results

Profiles of Livelihoods and Basic Amenities

a) Livelihoods

Women living with disabilities in informal areas earn income from informal ventures, mainly working as maidservants or through garment work. It was established that there were many savings and credit societies that women with disabilities used, and many of the users were youth and women. During the COVID-19 outbreak, many women living with disabilities lost their sources of livelihood and were mainly relying on well-wishers for their basic needs.

Basic Amenities

According to this study, access to water was marked by significant disparities. Women living with disabilities faced difficulties in accessing water, particularly in Viwandani. During COVID-19, the problem compounded as they relied on charitable individuals who would pay water vendors to deliver water. Another significant challenge was waste disposal in Viwandani due to a reduced workforce due to lockdowns, quarantines, and social distancing measures. This led to delays in waste collection and processing, which resulted in waste piles. This created challenges in accessing social amenities such as markets and hospitals among women living with disabilities. The improper handling of waste created physical barriers, making it difficult for individuals with disabilities to navigate these spaces. Poorly maintained pathways and the presence of waste hinder wheelchair accessibility or impede the use of assistive devices.

Figure 1: Pauline PWD in Viwandani (Informal Settlement in Kenya): delays in waste collection and processing resulted in waste piles, creating barriers to accessing health facilities.

Challenges with Access to and Affordability of Healthcare Services among Women Living with Disability

The vulnerability and experience of women living with disabilities in accessing healthcare centers around challenges with access to and affordability of healthcare services and experiences of discrimination and social stigma. These acted together, impacting negatively on their health and well-being.

This study established that the vulnerability and experience of women living with disabilities in accessing healthcare were shaped by the nature of the disability. For instance, the deaf person's experience of marginalization is mostly centered around unintentional exclusion from healthcare and other services due to a lack of sign language interpreters. COVID-19 stretched the capacity of health care workers (Lebrasseur *et al*., 2021). Government health facilities did not have sign language interpreters; thus, deaf patients felt excluded from healthcare services, opting to seek help from informal service providers or chemists. The consequence was that diseases that required urgent medical care did not get early detection, thus resulting in deaths. Deaf people can opt to look for care in inclusive medical centers, though constraints in finances as a result of mass layoffs have heightened the need to seek informal medical services.

"*When we also talk about children who are disabled, looking for services here in Mareba, it is true as what the rest are saying. They will go and health service providers will prescribe drugs regardless of whether the person is disabled. They will be told to buy drugs in a chemist yet they do not have money. They are forced to stay with that disease and later the disease overwhelms them.*" *FGD with Nyumba Kumi*

"*One time as we were doing HTC (HIV Testing and Counseling) a person came and they were tested and turned out that they were positive, we tried to enquire about where she lives but she couldn't or we couldn't understand her. Tried to ask about medication and she said he only use chest medication so for us it was a challenge and we decided not to do another test with a deaf person without a translator because in the end we were not able to do any follow up but luckily, we found her where she has her business and we tried to get someone who can explain to us and we found someone who we could ask questions and whether she is adhering to her medication. So, it is a big challenge because even when she gets sick, she may not be able to express what she is ailing from" (FGD participant – Korogocho).*

The COVID-19 pandemic introduced limitations and restrictions to public transportation, causing Public Service Vehicles (PSVs) to operate at reduced frequencies in adherence to COVID-19 measures. This reduction in service frequency consequently constrained transportation choices for individuals, particularly women living with disabilities, who experienced extended waiting periods and increased customer competition due to the limited operating hours of PSVs. As a consequence, some of these women feared accessing health services and alternatively turned to other informal methods of transportation, including traditional medicine or over-the-counter drugs.

"Yes. While at the bus stations, when you want to board, you find many hawkers there trying to enter the vehicle. In the event of trying to board, they can push you and make you fall and you might lose what you were carrying because they are congested at one place and you might lose what you were carrying because they are congested at one place and you wonder how you are going to pass so as to enter" Theme 2. V-003-SP-PWD-Physical (Female, 32 years)

Figure 2 Photo Credit: Photo taken by Female PWD Pauline in Viwandani (Informal Settlement in Kenya)

Accessing health services has proven to be particularly challenging, especially for women living with disabilities. This significant barrier was highlighted by one of the respondents, who reported that during COVID-19 they were excluded from economic activities because of the perception that she was unable to satisfactorily carry out the manual jobs that she had sought. Disability (physical) intersected with gender-increased marginalization due to social stigma directed at the respondent, and this affected the respondent as it pushed the respondent into alcoholism as a coping mechanism. Perceived limited capacities and financial constraints on the part of persons living with disabilities impacted greatly on their health. Even though poor health is a burden in informal areas, accessing or seeking medical services was not common among the populations. Women living with disabilities perceived health poverty as normal, as they had lived with it for a long time because it was expensive to access medical services. Also, health facilities did not prioritize the needs of women living with disabilities, as their problems are not equivalent to those of the general public.

"*I stopped trying to get work in companies…Because I may go there and get caught in the commotion but at the end of the day I will not be picked. I preferred to just do the job I have. When they see me, they feel I cannot do the work yet when taught I can work like all the other human beings. They should give people a chance"* –PWD – Physical

Social and Self-stigma Contributing Factors in Access to Health Services for Women Living with Disability

The impact of the COVID-19 pandemic heightened the challenges faced by women living with disabilities. One respondent shared that the pandemic's effects on societal attitudes further intensified the negative perceptions surrounding disability. The pandemic's isolation measures led to increased feelings of low self-esteem and, in some cases, even suicidal thoughts. Women with disabilities, especially those resulting from permanent injuries, found it difficult to come to terms with their conditions during this period. The situation was further made worse in cases where families neglected their responsibilities towards these women. Such neglect often led to the emergence of mental health issues, a concern that was already prevalent within informal settlements. As a result of self-stigma, individuals with disabilities hesitated to seek out much-needed medical services. This reluctance pushed others to extremes, like suicide or turning to alcohol and drugs as a means of coping with their challenging circumstances.

Society played a role in reducing access to healthcare services for women with disabilities, as they were subjected to stigmatization even at home. This lowered their self-esteem to the point where, when urgent medical attention was needed, some opted to stay at home or seek help from relatives or informal service providers. Women living with disabilities shared that getting employment opportunities also hindered their access to health services. One participant with mobility impairments recounted her struggles with discriminatory practices while seeking employment. Poverty and a lack of income among women living with disabilities contributed to poor access to health services. The financial constraints and mass layoffs during the pandemic increased reliance on food assistance from neighbors or government aid. The COVID-19 pandemic showed the urgent need for support and reforms to address the connection between disability, poverty, and health disparities.

"*Yes. That has happened to me. I once came with my child who had chest problems. I was told to sit and wait because apparently the disabled people are treated differently. I did not understand why my treatment had to be different I did not feel good about it because it looked like they found me worthless and did not respect the fact that I also have a patient*" Theme 1. V-003-SP-PWD-Physical (Female, 32 yrs)

"… in the community we have local shops that sell pain killers, they go to those shops and buy pain killers, just to manage the pain but they have not received treatment. It's a short-term solution. They know if they go to the public hospital, they won't receive any medication" Youth and women leaders FGD

Built and Physical Environment: A Challenge in Accessing Healthcare Services for Women Living with Disabilities

Women living with disabilities reflected how their built and physical environment were key hindrances to accessing healthcare services. They reported that poor drainage, road infrastructure, and solid waste disposal affected people with disabilities' access to health services. According to them, the blind and those experiencing difficulty walking found it difficult to access health services due to poor drainage and

infrastructure. COVID-19 greatly affected the collection of waste due to the fear of contracting the virus in the early stages.

Figure 3 Photo credit: photo taken by female PWD Miriam in Korogocho (an informal settlement in Kenya). The built physical environment and walking paths made it difficult for women living with disabilities to access healthcare facilities.

They also stated a lack of physical structures that were more inclusive; for example, Mareba Hospital in Viwandani has structures that are not favorable to women living with disabilities. For example, a visually impaired person would not easily access medical services as there are no human guides due to social distancing regulations. Also, some public health facilities had structures that also inhibited the accessibility of services for visually and mobility-impaired persons, such as staircases. The built and physical environment created dependency on family, friends, and the community, leading to a social barrier to timely and adequate healthcare, with some participants losing their source of support and others remaining at the mercy of their care-givers. Dependency mostly presented itself as a theme in discussions about financial support, transport and distance to a health facility, and, in other cases, communication, especially for those respondents with hearing impairments, thus widening the health disparity compared to the general population.

": *Are the hospitals accessible of people walk from far? People do walk from far, for instance, for us we had to walk far to get here. It is an issue because you have to look for someone today to bring you tomorrow and you explain to him/her that I need you to take me this and this place. If that person is not available, it becomes stressful to you and it brings problem"* Viwa - 9. CM-PWID-Female

"This vehicle first, like this one I came with, I saw that there is a problem there, the blind do not know where the stairs are and how they will step. Yes, the one who is blind, the way they will step up to the seats, that is a

problem if they don't have someone to lead them. When you go back, like this without a friend, you find it's a problem because, on boarding the vehicle, the vehicle starts to move, before you reach the seat, the vehicle is moving. So that's a problem. FGD Co-researcher

Discussion

Challenges with Access and Affordability of Health Services for Women Living with Disability

Kenya has demonstrated its intent to extend health coverage for poor and vulnerable populations. Since 2013, the Government of Kenya has introduced health reforms, which have included the provision of free maternity services in public health facilities in an effort to reduce high maternal mortality and the associated healthcare costs. This is because cost was identified as a key barrier to access to health services as a way of improving access and utilization of health services (Kabia *et al.*, 2019). Secondly, the health insurance program for the poor and vulnerable (HISP) was piloted in 2014 and was fully scaled up from 2016 with the aim of increasing access to health services and reducing out-of-pocket (OOP) limits, thus improving the health outcomes of poor and vulnerable groups. Through HISP, the poorest and most vulnerable groups' health costs are fully subsidized by the government and donor support. HISP beneficiaries are able to access outpatient and inpatient care at NHIF in accredited public and low-cost private health facilities (Macharia, 2015).

While these are important developments, evidence shows that payments for healthcare with prepayment mechanisms do not guarantee access to care for the poor since subsidized costs for care only account for a small part of the total financial costs, especially at government health facilities (World Health Organization, 2021). In this study, women living with disabilities reported that access to and utilization of healthcare services were inhibited due to a lack of finances. This is true, as Cotlear *et al.* (2015) state that the poor and vulnerable populations, especially women living with disabilities, are more predisposed to healthcare spending that is catastrophic, which pushes them deeper into poverty. Almost half of women living with disabilities in Kenya are unemployed, and 67%, compared to 52% of non-disabled people, reported living below the poverty line (Mitra and Posarac, 2013). This contributes to a lack of or poor access to and utilization of healthcare services.

Respondents in this study stated a lack of prioritization by healthcare providers. The government, through the HISP program, enabled beneficiaries to access health services at no cost. However, following the subsidization of health costs for vulnerable populations, patients reported neglect and verbal harassment, which were common to women living with disabilities and women of low economic status (Kabia *et al.*, 2019). Additionally, a lack of awareness about service entitlements has led to some healthcare providers taking advantage of beneficiaries and charging them additional fees (Kabia *et al.*, 2019). Accredited NHIF facilities where beneficiaries such as women living with disabilities can access them are located mainly in urban areas, which has led to high transport costs, further excluding them from accessing health services (Macharia, 2015).

Social and Self-Stigma Contributing Factors in Access to Health Services for Women Living with Disability

Basic healthcare services are defined as healthcare needed to maintain health and protect against diseases (Adugna *et al*., 2020). Access to healthcare services exists when enough health services are available and there is an opportunity to receive them. Barriers in access to healthcare services arise when there are financial, social, or cultural strains within the community (Adugna *et al*., 2020). In many sub-Saharan African countries, healthcare services for women living with disabilities are limited to urban areas, if available at all (African Child Policy Forum, 2014). Disability persists and is continuously affected by the socio-economic, political, and cultural situation of a given community.

According to a study conducted by Miftah *et al.* (2017), high levels of stigma are considered a barrier to accessing healthcare, preventing women living with disabilities from accessing proper medical treatment. Caregivers of women living with disabilities in some parts of sub-Saharan Africa expressed concerns about being treated poorly by others; thus, they seek to conceal their children's conditions instead of seeking proper treatment. Women living with disabilities claim to face stigma right from their homes; this lowers their esteem, and they carry that burden even in health facilities. This is in congruence with Miftah *et al.* (2017), who asserted that women living with disabilities were worried about being treated differently, feeling ashamed or embarrassed about their health conditions, thereby making them seek other sources of treatment, which consequently worsened their conditions and, in the worst cases, led to deaths.

Respondents to this study reported that negative attitudes affected access to healthcare for women living with disabilities. Negative attitudes from family, caregivers, society, and health professionals hinder access to healthcare services, and this view is in agreement with the proposition from Miftah *et al.* (2017) in their study conducted in Ethiopia, which established that negative attitudes about disability from healthcare providers, family, and the community led to reduced motivation for seeking healthcare. In other instances, healthcare providers usually deny women living with disabilities health services such as HIV-related services due to misconceptions about them not being sexually active. Despite the challenges and barriers that prevented access to healthcare services, a positive attitude among healthcare workers, family, and community members can encourage women living with disabilities to seek treatment (Adugna *et al*., 2020).

Built and Physical Environment: A Challenge in Accessing Healthcare Services for Women Living with Disabilities

Women living with disabilities usually navigate their day-to-day activities with physical help or assistive technology. For instance, people with mobility impairments use wheelchairs, while the visually impaired use white canes to navigate around. Wheelchairs are usually provided by governmental organizations, charitable organizations, and other international organizations (Barbareschi *et al.*, 2020). However, many wheelchairs provided are donated by countries in the Global North and are designed for temporary use in hospitals or other institutional settings. They do not meet the WHO guidelines or the durability requirements of limited-infrastructure environments, inaccessible infrastructure, and informal road systems (Barbareschi *et al.*, 2020). Women living with disabilities reported that accessing health services was a challenge due to poor drainage, road infrastructure, and solid waste disposal. This problem is even worse during rainy seasons when informal areas have poor drainage systems, inadequate road

infrastructure, and inefficient solid waste disposal. These issues may limit the accessibility of healthcare facilities to women with mobility problems. This is in agreement with Vergunst *et al.* (2015), who noted that women living with disabilities in informal areas were not able to push themselves when trying to access formal healthcare services on account of geographical barriers such as mud, uneven roads, and open drainage.

Built structures in public hospitals were also considered a barrier to access and utilization of health services. However, these findings are not in agreement with the findings from the study undertaken by Vergunst *et al.* (2015), as they state that infrastructure is a relational subject that is part of human organization. Infrastructure is highly subjective, as one man's infrastructure is another person's problem. For instance, the staircase can be seen as a means of accessing a building for a person, but on the other hand, it remains an impediment to movement for a person with a disability. Despite this view, the development of infrastructural facilities should strive to meet the demands of all members of the population, including those perceived as marginalized; forgetting their needs often means system failure.

Conclusion and recommendations

Women living with disabilities in informal settlements have resorted to alternative means of acquiring healthcare services. For instance, women living with disabilities usually opt to seek health services from other informal health providers for fear of ridicule and stigma. In several instances, formal healthcare services lack systems that are inclusive for persons living with disabilities. Chronic illness can be addressed earlier if women living with disabilities greatly seek services from skilled health providers.

This study highlighted the lived experiences of women living with disabilities. There is a need for the full dissemination and implementation of Kenya's Persons with Disabilities Act of 2003 (NCPWD, 2003) as a measure to reduce social stigma against women living with disabilities, increase their participation in economic activities, and fully realize their rights, especially their right to participate in decision-making. Moreover, urban planning, inclusive of hospital infrastructure, needs to be cognizant of the needs of persons with disabilities, such as the construction of disability-friendly roads with restricted pedestrian paths and health facilities. Because of inadequate disability-friendly facilities, many women with disabilities, especially those born with disabilities, have faced multiple forms of discrimination and subsequent denial of health services and other opportunities, compounding their marginalization and vulnerability.

Lastly, this study notes that closely interconnected financial, practical, and social barriers hinder healthcare access for people with disabilities in Kenya. There is a clear requirement for policymakers to consider the challenges identified here and in similar studies and to address them through improved social security systems and health system infrastructure, including outreach services, in a drive for equitable healthcare access and provision.

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