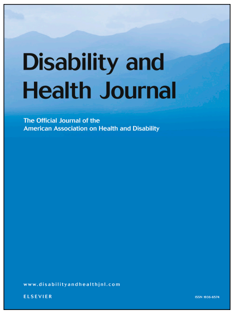

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Health System Access Challenges of People with Disabilities Increased During Covid-19 Pandemic

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Health System Access Challenges of People with Disabilities Increased During Covid-19 Pandemic

Background: People with disabilities (PWDs) have unequal access to health services compared with the general population and this disparity is worsening during COVID-19 pandemic. Evidence supports the importance of policy development and legislation for addressing the unmet health needs of PWDs, but little is known about the impact of these efforts in Ghana.

Objective: This study examined health system experiences of PWDs in Ghana within the context of existing disability legislation and related policies prior to and during the Covid-19 pandemic.

Methods: Narrative analysis of data from qualitative research approaches of focus group discussions, semi-structured interviews, and participant observations were used to examine the experiences of fifty-five PWDs, four staff of department of social welfare and six leaders of disability-focused non-governmental organisations in Ghana.

Results: Structural and system barriers hinder PWDs access to health services. Bureaucratic bottlenecks hinder PWDs access to Ghana’s free health insurance policy and health workers’ disability stigma impedes accessibility of health services.

Conclusions: Access barriers and disability stigma increased accessibility challenges for PWDs in Ghana’s health system during the Covid-19 pandemic. My findings support the need for increased efforts toward making Ghana’s health system more accessible to address health disparities experienced by PWDs.

Keywords: Covid-19, access, stigma, people with disability, health equity.

Introduction

PWDs encounter a range of barriers when they attempt to access health services resulting in unequal opportunities for meeting their health needs.[1-4] The unmet need for health services by PWDs worsened during the Covid-19 pandemic. [5-15]Ghana confirmed its first case of covid-19 on March 11, 2020, and cases increased from that time. To protect public health, the government introduced partial lockdowns, contact tracing, isolations, quarantine, social distancing, and border closures. By the peak of the pandemic in April 2020, there were partial lockdowns, and all businesses and schools were closed with only essential services remaining opened nationwide. [15,16] Studies confirmed that these Covid-19 containment measures had more adverse impact on PWDs compared to their non-disabled counterparts across the economy, education, social support, and health service access. [13,16]

Evidence suggests, the achievement of equity in health depends largely on a country's commitment to appropriate legislation, policies, and adequate funding for implementation.[1,5] Section 31-35 of Ghana's Disability law, Persons with Disability Act 715 has provisions for improving health services for PWDs,.[17] Specifically, the disability law passed in 2007, promised free medical care for people with total disability and the National Health Insurance law, (Act 650) passed in 2003 has a legislative instrument (LI 1809), Regulation 58 (Section 1) that promises free health insurance enrollment for PWDs. [13]

Previous studies identified physical barriers, out-of-pocket costs, financial disincentives for providers, organizational gatekeeping and negative attitudes toward disability as impediments for PWD's health service access.[1-4,18] Attitudinal, physical, and system level barriers such as lack of access to information, reduced clinician–patient communication, discrimination, lack of reasonable accommodations, and rationing of medical goods worsened health service accessibility of PWDs during the Covid-19 pandemic.[9,13,16,19] This study examined health access experiences of PWDs in Ghana within the context of existing disability legislation and policies before and during the Covid-19 pandemic.

The recognition of unmet health needs of PWDs underscore the need for work that examines their health system accessibility. However, work on the topic has been difficult due to variations in definitions of access.[18] Access has been defined as the use of health services and the ability of populations to seek and obtain health services.[18] A comprehensive concept of access proffered by Levesque, Harris, and Russell considered five dimensions of accessibility (Approachability, Acceptability, Availability/Accommodation, Affordability and Appropriateness) and 5 related abilities of populations (ability to perceive, seek, reach, pay for and engage with health services).[18] The 5 dimensions of accessibility have to interact with 5 related abilities of populations to generate access in conjunction with multilevel (individual, household, community, population) factors related to providers, organizations, institutions, and health systems.[18] PWDs may be at a disadvantage for access because of hampered ability to perceive, seek, reach, pay for and engage with health systems. The reduction or lack of PWDs opportunity to identify health needs and the opportunity to seek health services compromises the opportunity to reach, to obtain service and fulfill health needs.

Methods

Study Design and Data Collection

This qualitative study used ethnographic research methods of focus group discussions, semi-structured interviews, and participant observations for data collection. Data was collected in 6 communities in Ghana between January 2018 to October 2020. I conducted a total of 15 focus group discussions. These focus group discussions interrogated PWDs' health system access prior to and during the Covid-19 pandemic. From a positionality perspective, I had both insider and outsider statuses during various stages of the research. I grew up in Ghana and this prior experience facilitated my research but my identity as a person without disability who lived outside the country required me to negotiate my access to PWDs.

I conducted 43 semi-structured interviews which further examined topics covered in the focus groups with individual PWDs. The focus group discussions and interviews lasted for approximately 2 hours each. I recorded audiotapes of the focus group discussions and interviews and took field notes during participant observations. I conducted multiple follow up interviews for member checking and validation of results. During the pandemic, my IRB made accommodations for remote data collection, and this facilitated the conduct of interviews via phone and video call platforms for completion of the study. Confidentiality was assured through storage of data on password protected servers and hard drives, and deidentification of the data as required by IRB regulations.

Participants

A purposive convenience sampling was used to select the participants including PWDs (physically impaired; hearing impaired; visually impaired), staff of Department of Social Welfare, and leaders of disability-focused non-governmental organizations were included in the research. Institutional review board (IRB) approval was granted for this research and a PWD who is a local disability expert served as a cultural consultant. Consent was secured from all research participants. Sign language interpreters facilitated the collection of data from people with hearing impairments. People with cognitive impairments were not included in this study.

Data Analysis

Audio recordings of interviews and focus group discussions were transcribed prior to data analysis. Transcripts and field notes were reviewed and coded by grouping participants' narratives and responses into similar categories of emerging themes. The coded narratives and field notes were examined to understand research participants' experiences with Ghana's health system. Adopted themes were further examined and reviewed to arrive at conclusions from the data. I also used feedback loop processes of triangulation and member checking to refine analysis drawn from emerging themes. A local disability consultant reviewed the data, themes and interpretations and provided useful feedback.

Results

Data was collected from 65 people made up of 55 PWDs (Physically impaired=48; Hearing impaired=3; Visually impaired=4), 4 staff of Department of Social Welfare, and 6 leaders of NGOs. Respondents' ages ranged between 20 and 70 years. The results are reported together under thematic areas and not as different groups of respondents because same topics were covered for PWDs, staff of Department of Social Welfare, and leaders of NGOs in focus groups and interviews. I aggregated the findings for the limited scope of this analysis because I did not find significant differences in responses between male or females nor between people with different impairment types

The results were grouped into 3 separate themes of factors that negatively impacted PWDs access to health system. One theme focused on structural and systems barriers in Ghana's health system that hindered PWDs access prior to and during the Covid-19 pandemic. Another theme focused on the role of bureaucratic bottlenecks in PWDs access to free health insurance and the final theme delineates how health workers' disability stigma negatively impacted accessibility of health system prior to and during the Covid-19 pandemic.

Structural and System Barriers Hinder PWDs Access to Health Services

During focus group discussions and interviews, PWDs detailed structural and system barriers that hindered their access to health services. These barriers included but were not limited to inability to pay for health services, afford transportation, lack of specialists' services and inaccessible health facilities. PWDs also had worse poverty indicators compared to their non-disabled counterparts. A disability group leader buttressed this point by stating:

> …we the disabled have worsening health conditions due to our poverty levels and inability to pay for or access services. The cost of travel and the dangers associated with inaccessible transport and built structures make it difficult for us to seek health services. Our members rely on family support, social networks, and disability self-help group participation to mitigate some of the challenges associated with seeking health services.

A research participant recounted how his family was unable to afford rehabilitation services for his paralysis although he was making significant progress in physical therapy. He quit the rehabilitation because his parents could not afford the physical therapy and cost of transportation from his village to the hospital. This respondent's situation was not peculiar. Several PWDs could not afford to make their physical therapy appointments due to cost of the service and cost of transportation.

Inaccessible roads and means of transportation to hospitals also created barriers for access to health services, sometimes forcing PWDs to resort to alternative (indigenous) medicine which was readily available to them in their rural areas. A physically disabled woman who uses wheelchair described her experience thus:

> …anytime I have an appointment at the hospital, I would be in my wheelchair at the bus stop for several hours and none of the buses or taxis would stop to pick me up because I looked like an extra burden for them. Since these vehicles are not disability accessible, even when drivers stopped to pick me up, boarding of the vehicle was very stressful and the least said about the ride, the better. The roads are so bad that I experienced a lot of discomfort, and this sometimes discourages me from going for my clinic appointments.

These reports of inaccessible transportation to health centres and inability to pay for services increased during peak periods of the Covid-19 pandemic. PWDs reported reduced opportunities to access public transportation because of lockdowns around the country.

During the pandemic, PWDs also reported dwindling family members' and friends' support for healthcare costs. Research participants contended that the difficult prevailing economic situation in the country, loss of jobs and reduced income, adversely affected sources of support for PWDs toward mitigating poverty and healthcare costs during the pandemic.

Bureaucratic Bottlenecks Hinder PWDs Access to Free Health Insurance Policy

The free enrolment of PWDs in Ghana's National Health Insurance Scheme was intended to make health services accessible to this group but, results from this study suggest PWDs face barriers when they attempt to enrol or renew enrolments. PWDs described their experiences with the implementation of the health insurance policy as cumbersome because of bureaucratic bottlenecks in the process. A disability self-help group leader said:

> Even as a disability group leader, when I went to renew my health insurance, I was asked to pay for the service. I confronted the NHIS officers about provisions for us to register without paying. The insurance officer said that previously, disabled people were supposed to take an introductory letter from the Social Welfare Officer at the District Assembly to the NHIS Office for free registration or renewal. He said the new government introduced changes which required disabled people to leave their expired cards with the Social Welfare Officer who will then forward them to Ho

> [regional administrative capital], then to Accra [nation's capital] for approval and subsequently returned to the Social Welfare Officer at the District Assembly who will then add an introductory letter to it before a disabled person can take it to the insurance office for free registration. Some expired insurance cards have been sent to the Social Welfare Officer since September 2017, and to date we have not heard back so we cannot access services for free.

Another PWD, described her experience with the health insurance challenges thus:

Previously, we only sent our NHIS cards to the social welfare office for introductory letters, but this has changed. We are suffering a lot because these things are not being done well. In fact, if you have some time, I will take you to the hospital for you to see one of our members [disability self-help group member] who is stranded there and not being discharged because he has not paid his hospital bills. So, the NHIS is a big problem for us...these programs sound nice on paper, but the implementation becomes a problem, and we are not enjoying them.

To further understand the free health insurance challenges, I ran these reports of bureaucratic bottlenecks and delays by a government official in the department of social welfare who confirmed the reports and explained thus:

> The issue is, for those who are existing beneficiaries, an eligibility list is brought from Accra [nation's capital] to the various NHIS district officers for renewal of enrolments. But recent additions to the list are yet to be released. So, if some people with disabilities are having challenges, they are probably part of the new enrolling groups. When we are successful at registering them and their cards expire, we have a community representative who is the focal person within the community. The arrangement is that the community representative will collect all the expired cards and send them to social welfare officers who forward them to the health insurance office for renewal. There are challenges in these processes, but we are dealing with them.

At the peak of the pandemic in 2020, there were reported increases in challenges PWDs encountered in enrolling in the insurance scheme. PWDs reported worsened delays in processing of enrolment applications due to Covid-19-related shutdowns. Disability-focused non-profits and self-help groups that offered health insurance enrolment support to PWDs prior to the pandemic reported lack of funding and human resources to continue offering such support. Other non-profits shifted their attention to providing food and basic livelihood needs during the pandemic. One leader of a disability-focused non-profit described the situation thus:

> …my brother, as for COVID, it has really affected our support for the health of PWDs because funding is non-existent during the period, we need it most. We have channelled the little funds we have in our coffers into providing food and other necessities to our PWDs. The focus has now shifted to survival. So, yes, we know there are worse issues with the health insurance and other health challenges, but all our focus is on just supporting them with food until things return to normal.

Results from the interviews, focus group discussions, and observations in the communities studied suggest that Ghana's free health insurance policy for PWDs was fraught with challenges that emanate from bureaucratic bottlenecks associated with the policy prior to Covid-19 pandemic and the situation worsened during the pandemic. Making claims to benefits in the insurance policy involves layers of negotiations that regulate access and shape the healthcare experiences of PWDs prior to the covid-19 pandemic and during the pandemic in Ghana.

Health Workers' Disability Stigma Impedes Accessibility of Health Services

Several PWDs in this study narrated incidents of negative attitudes from health workers which they interpreted as disability stigma primarily from. PWDs interviewed expressed concerns about probability of these negative attitudes resulting in patients with disabilities receiving inadequate intervention. For example, a focus group participant who uses axillary crutches because of paraplegia from post-poliomyelitis narrated how he overhead his physical therapists discussing his condition and making derogatory remarks about his prognosis. He said:

> While I was waiting in the treatment room, I overhead my therapist telling one of her colleagues that she wondered why I keep coming for therapy for back pain even though I am already Alanta [local language derogatory term for lower limb deformity]. This made me wonder how much effort the physical therapist would put in to help me recover from my back pain even though the referring doctor recommended that recovery from this episode of chronic backpain would help improve my mobility. The remarks from the therapist made me lose confidence in the care I would receive

During the Covid-19 pandemic, similar reports of incidents PWDs considered as stigmatization by health workers were reported. PWDs believed stigma associated with their disability identity and stigma associated with the emerging Covid-19 pandemic worked together to worsen their plight. For example, I interviewed a PWD who recounted a tragic incident of how a chronic Asthmatic patient with disability who regularly received care at a local hospital died after reporting to the hospital with signs that mimicked Covid-19 amid hesitancy of hospital staff to provide prompt care. Reports indicated that she did not have Covid-19. The research participant lamented thus.

> …I strongly believe that if this woman wasn't disabled, the health workers would have been more willing to help. Even before Covid, these incidents happened lots of the time. Covid only worsened it…

The PWD wondered if the Asthmatic patient died from convergence of factors related to the stigma associated with the woman's disability, her chronic Asthmatic condition, and the Covid-19 stigma at a time when Covid-19 symptoms were not well understood, and health workers were reluctant to attend to suspected cases. He argued that the stigma associated with both conditions might have worked together to put the Asthmatic patient with disability at a higher risk.

The data collected during the pandemic did not support widespread increase in disability stigma during the pandemic but PWDs had reduced interest in use of health services during the pandemic for fear of being a burden at a time the health systems was under stress from the ongoing pandemic. During interviews, PWDs drew parallels between their experiences with disability stigma and the Covid-19 stigma, the general population experienced from health workers. PWDs also expressed concerns about potential increased health worker stigma they would have had to deal with if they attempted to use health services during the peak of the pandemic.

Discussion

I have examined health system access experiences of PWDs within the context of existing disability legislation. I identified multiple barriers for PWDs access to health services prior to and during the Covid-19 pandemic. Structural and system barriers hinder PWDs access to health services. Bureaucratic bottlenecks hinder PWDs access to free health insurance and health workers' disability stigma impedes accessibility of health systems. A wide range of factors determine PWDs health status including but not limited to existing health condition, impairment, type of disability, livelihood, socioeconomic status, cultural and environmental conditions, and access to health services. [1-14] This paper's examination of access to health system in deconstructs how factors associated with disability increase PWDs' vulnerability to negative health system experiences.

Drawing from Levesque, Harris, and Russell, PWDs health system access was impeded by factors related to organizational, institutional and health systems interacting with household, community and population level influences including social structuring, community health beliefs, culture, religion, family resources, community resources, health policy, cost of health services, transportation accessibility, and health insurance challenges.[18] The types of impairments PWDs have, gender, personal socioeconomic status, personal health belief, personal health characteristics and clinically evaluated needs were individual level influences that interacted with both the provider and the health institution to impede access in the health system. Covid-19 negatively impacted economic situation of communities and sources of support for PWDs mitigation of health care inaccessibility. Previous studies predicted Covid-19 could negatively impact support that PWDs receive from families and friends.[13] Access is produced through people or populations' abilities to perceive, seek, reach, pay for and engage with health systems.[18] Unfortunately, PWDs' agency is compromised by various material and structural challenges that hinder developing required abilities for generating access.

Prior to Covid-19, PWD experienced dearth of opportunities for identifying health needs and seeking health services compared to their non-disabled counterparts. The limitations in these determinants of access resulted in reduction of opportunities for PWDs to reach, obtain or fulfill their need for health services. This preexisting dynamic between determinants of access was worsened during Covid-19 pandemic.

Promise of free health insurance for PWDs is a product of disability legislation but does not guarantee the automatic access to benefits. While disability status is a prerequisite for enrolment, this condition is not enough for receipt of benefits. Further conditions must be met by PWDs through leveraging agency and social networks such as membership of disability self-help groups. Processes of application, eligibility determination and enrollment for free health insurance involve PWDs negotiating with various stakeholders associated with the program. These negotiations involve tensions and play key roles in PWDs access to health services.

The discourses around health insurance for PWDs in Ghana prior to and during the covid-19 pandemic suggest eligibility determinations and procedures for accessing the free health insurance are shaped by existing socioeconomic conditions, political influences, government gatekeepers and bureaucratic challenges. The worsened insurance enrolment challenges during the peak of the pandemic were due to administrative delays from lockdowns and the loss of systems that supported PWDs insurance applications including disability non-profit staff and self-help groups. This finding agrees with earlier work which concluded that challenges with PWDs health insurance participation could affect their health-seeking behaviors during the Covid-19 pandemic.[13] The free health insurance enrolment for PWDs was intended to mitigate the challenges associated with affordability as a dimension of access, with ability to pay being the requirement for individuals and populations to be granted access. However, bureaucratic barriers associated with enrolment work with individual, community and population level factors to reduce PWDs opportunity to identify health needs and to seek care.

Disability stigma hinders ability of populations to engage (a required ability for Appropriateness dimension of Accessibility) and predisposes PWDs to health system inaccessibility. Disability stigma produced feelings of embarrassment for the stigmatized with negative implications for the health and wellbeing of PWDs.[20,21] Disability stigma experienced by PWDs before and during the Covid-19 pandemic was either externally imposed by some health service providers or self-perceived and internalized by PWDs.[22,23] Evidence suggests mental health challenges, obesity, and poor health outcomes have increased among stigmatized populations.[21,24-28]

Disability stigma by health service providers is an important determinant of health because it is peculiar to PWDs experience in the health system unlike other access barriers which also affect the general nondisabled population. The negative attitudes of health service providers toward PWDs are not always overtly hostile, but they affect the quality of care PWDs receive. Goffman's work explains how stigma shapes health services for PWDs.[23-25] For some health workers, the long-term existing conditions and permanent impairment of PWDs represent a departure from the able-bodied patient expectations of recovery from ill health. This expectation results in poorer prognosis determinations for patients with disability compared to patients without disability and affects the quality of care provided.

The parallels drawn between disability stigma and Covid-19 stigma exhibited by health workers is useful for health system access discourse because both types of stigmatizations negatively impact ability to engage with health services. It is imperative to recognize that disability stigmatization has adverse effect on health outcomes even when affordability and availability dimensions of access are met. This was demonstrated by PWDs who had the ability to afford available services but were discouraged from utilizing them because of assumptions of increased discrimination from combination of disability stigma and covid-related stigma. Previous studies agree with concerns about PWDs suffering from separate or combined effects of stigma as a Covid-19 patient and disability stigma by health providers. [13]

I have examined the health system access experiences of PWDs prior to and during the Covid-19 pandemic. My study demonstrates how PWDs health system access barriers worsened during the Covid-19 pandemic. My positionality of insider, outsider status was a source of strength for the research. The limited scope of analysis conducted without disaggregation of data is a limitation for the research. Efforts need to be directed at making the health system more inclusive because evidence shows unmet needs for accessibility of health systems still exist. Further research on mitigation of health providers' disability stigma through health professions training curriculum and continuing education can provide useful information for making changes.

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