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Qualitative Exploration of the Experiences and Coping Strategies of People with Disabilities at Some Selected Healthcare Facilities in the Bosomtwe District of Ghana

Enoch Acheampo,[1] Anthony Kwaku Edusei,[2] Peter Agyei-Baffuor,[3] Reindolf Anokye,[4] and Godfred Atta-Osei[5]

[1, 2, 3, 5] Kwame Nkrumah University of Science and Technology-Kumasi, Ghana
[4] Edith Cowan University Joondalup, Australia

Abstract

Discrimination in healthcare may exclude or deter people with disabilities from seeking health services for fear of stigma and discrimination. The purpose of the study was to explore the experiences of people with disabilities at healthcare facilities in the Bosomtwe District of Ghana. A case study design with qualitative approach was adopted in which data was collected from 30 people with disabilities using purposive sampling through face-to-face interview and focus group discussions and data were audio-and video-recorded, transcribed, and categorized into themes. The study found that people with disabilities experienced communication difficulties with healthcare providers, neglect and nepotism, abuse and insults by healthcare providers. It is recommended that the heads of the various hospitals should establish a unit in each hospital to attend to the healthcare needs of people with disabilities who visit their facilities so that the stress people with disabilities go through whenever they visit their facilities could be reduced.

Keywords: heathcare, access, Bosomtwe District of Ghana

The Sustainable Development Goal 3 and subsection 3.8 talk about achieving universal health coverage, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines for all (United Nations, 2015). People with disabilities have health needs arising from their primary impairment as well as their general health needs (Shakespeare, 2012). Yet evidence shows that these health needs are not adequately met, due to financial access and attitudinal barriers as shown in the World Health Survey that people with disabilities were twice as likely to find health care provider skills and equipment inadequate to meet their needs; three times as likely to be denied care; and four times as likely to be treated badly by health care providers (WHO, 2011).

Accordingly, in many developing countries around the world, people with disabilities may feel reluctant to access health services although they may have significant concerns that require health care (Shaikh & Hatcher, 2007). Patients' ability to accept and utilize services has a relationship with service providers' attitudes (Shaikh & Hatcher, 2007, d'Ambruoso et al., 2005, Jones et al., 2008). It has been established in previous studies that attitudes and behavior of primary health care providers were barriers for people with disabilities as they seek health care (Jones et al., 2008, Badu et al., 2016). Discrimination in health-care settings is often driven by stigma—negative beliefs, feelings and attitudes towards people with disabilities. Such individuals and groups also experience intersecting or compounding forms of discrimination on the basis of their age, sex, race or ethnicity, physical or mental health status, disability or vulnerability to ill-health (United Nations, 2006). Negative attitudes of providers may discourage the use of services by the users with disabilities, and negative attitudes may foster low expectations, encourage discriminatory behaviors and marginalization of people with disabilities among health providers themselves (WHO, 2011, Kleintjes et al., 2013).

Similarly, other writers have highlighted the importance of fairness, respect, equality, dignity and autonomy in healthcare delivery. If human rights are to have any meaning or force, the authors suggest, then they are particularly relevant to vulnerable groups and marginalized minorities (Fish & Bewley, 2010). The way people with disabilities are received and treated at health care facilities can serve as either a barrier or a facilitator to accessing health care services. Past experiences of negative health worker attitude discourage the use of health services in the future. Several studies suggest healthcare providers show negative attitudes towards people with disabilities (Barratt & Penn, 2009, Ravim & Handicap International, 2010, Coomer, 2012, Munthali et al., 2013). In most instances, healthcare providers fail to acknowledge the fact that different lived experiences impact access to care when designing services (McColl, 2005). Healthcare providers appear to be somewhat insensitive, whether on purpose or because of a lack of knowledge about the needs of people with disabilities (Gainhre, 2016, Kritzinger, 2014). Verbal, physical and mental abuses characterize the negative attitudes experienced by people with disabilities at healthcare facilities. Other studies have also reported of instances where healthcare providers have refused to either shake hands with or treat a person affected Hansen's disease (leprosy) (Dadun et al., 2016). Again, it is reported that people who are blind are ridiculed by health workers for requesting HIV/AIDS testing (Mulumba et al., 2014). The negative attitude of healthcare providers towards people with disabilities is heightened when it comes to women with disabilities (Mulumba et al., 2014).

Further intensifying these concerns, many societies in sub-Saharan Africa have historically linked the appearance of physical, intellectual, sensory or mental health disabilities with witchcraft, sin, or have seen such as evidence of retribution for some action or wrong committed by the individual or a family member (Batterbee, 2010, Byrne, 2011, Cimpric, 2012 Groce et al., 2011, McGeown, 2012). Consequently, people with disabilities and their families have often suffered social isolation, discrimination and, in the most extreme cases, violence and death as a result of such widely held folk beliefs (Batterbee, 2010, UNICEF, 2005). Such underlying beliefs have resulted in many with disabilities being denied access to modern healthcare because their conditions are viewed as not requiring modern healthcare services but instead needing traditional and spiritual forms of treatment.

Consistent with this, in Ghana, where there is strong belief in myths and the existence of supernatural powers, it is not uncommon to associate the cause of disability with spiritual factors such witchcraft, sorcery and magic (Avoke, 1997). Article 25 of the United Nations Convention on the Rights of People with disabilities enjoins member states to undertake to adopt immediate, effective and appropriate measures to ensure the right of people with disabilities to equally enjoy “the highest attainable standard of health without discrimination on the basis of disability.” Furthermore, states are to provide free or affordable general and specialist health services to those with disabilities.

Aligned with this, the mission of the Ghana Health Service (GHS) is to contribute to socio-economic development by promoting health and vitality through access to quality health for all people living in Ghana using well-motivated personnel (Ministry-of-Health, 2014). The significant inequalities in healthcare in Ghana have persisted for years (Ministry-of-Health, 2014). Health status of those with disabilities is improving much more slowly than that of the rest of the country’s populace (Eyob et al., 2012; Frimpong, 2013). The Ministry of Health through the Ghana Health Service launched the Ghana Health Policy to help promote the health of Ghanaians. However, this policy does not have any specific aspect which is dedicated to the health needs of people with disabilities. The assumption, therefore, is that people with disabilities have the same health needs as non-people with disabilities. In 2006, Ghana's Parliament passed the People with Disabilities Law in an attempt to help improve the general living conditions of people with disabilities in the country. In section 31 of this law, it states "The Ministry of Health in formulating health policies shall provide for a free general and specialist medical care, rehabilitative operation treatment and appropriate assistive devices for persons with total disability." This provision on healthcare in the act is problematic because the act failed to indicate precisely who 'a person with a total disability’ is. It is therefore important to note that people with disabilities will find it difficult to access healthcare because there is no clear definition of who has 'total disability'. It is against this background that this study to explore the experiences of people with disabilities at selected healthcare facilities in the Bosomtwe District of Ghana was conducted.

Methods

The Bosomtwe District is in the central part of the Ashanti Region of Ghana in West Africa and lies within Latitudes 6° 24' South and 6° 43' North and Longitudes 1° 15' East and 1° 46' West. The population according to the 2010 Population and Housing Census is 93,910, representing 2.0 percent of the region's total population. About 2.9% of this population has some form of disability. The proportion of females with a disability is slightly higher (3.2%) than males (2.7%) (Ghana Statistical Service, 2010). The health delivery system in the district is made up of sixteen (16) public and private health institutions which include 3 hospitals, 3 health centers, 7 clinics, 5 maternity homes, 4 Community Health Planning Service (CHPS) Compound and 1 Midwifery Training Institution. The district also has 52 outreach points where reproductive and child services are rendered (Ghana Statistical Service, 2012).

The design of this study was a case study. A case here referred to a single community, institution, group or organization (Quinn, 2002). The Bosomtwe district of Ghana was used as a case for the purpose of doing an extensive study to find out how disability stigma has affected people with disabilities' access to healthcare. A qualitative study approach was employed because it explains the culture and behavior of humans and their groups from the viewpoint of those being studied and does so in a natural real-life setting (Quinn, 2002).

The purpose of the study was to explore the nature and extent of the effects of stigma on people with disabilities' access to healthcare services. The target population were all people with disabilities registered by the Department of Social Welfare within the District, and also registered members of recognized Disability Organizations in the District. There were 502 people with disabilities who had been registered and certified by the Department of Social Welfare (Department of Social Welfare Disability List, 2019). The study employed purposive sampling in selecting the respondents for the study (people with disabilities). Purposive sampling helped in getting individuals directly linked to the issues under consideration. The set of inclusion and exclusion criteria associated with purposive sampling helps researchers to get rich information and helps prevent the possibility of recruiting participants who may not have any idea or may not be affected by the research problem.

Furthermore, purposive sampling helps to recruit 'qualified participants'. First, the list of all registered people with disabilities within the district was taken from the Department of Social Welfare. This list served as the sampling frame from which participants were selected. The inclusion criteria for people with disabilities were: (1) the person must have been certified and registered by the department of social welfare as disabled; (2) they must have had the condition not less than one year; (3) they must be 18 years and above; (4) and they reside within the district at the time of data collection. Individuals with all forms of disability were considered as potential participants. A total of 30 participants were selected based on the principle of saturation, the point at which responses received were being repeated and no new information was being given (Quinn, 2002).

Specifically, the study employed in-depth face-to-face interview and Focus Group Discussion to collect data from participants. Semi-structured interview guides with open questions were used for the in-depth face-to-face interviews. The focus group discussions were conducted in addition to the in-depth interviews. Focus group discussion was employed because they provided the opportunity to study ways in which individuals collectively make sense of a phenomenon and construct meaning around it. An empathetic stance in interviewing was adopted to avoid being judgmental and to allow neutrality during data collection by showing openness, sensitivity, respect, awareness and responsiveness throughout the interaction (Quinn, 2002). Two research assistants who were Postgraduate students at the University who were also knowledgeable in sign language helped in the data collection exercise. The research assistants were given a two-week training in qualitative research data gathering with special focus on interviewing and focus group discussions skills and techniques (Quinn, 2002). The interviewers had no familial relationship with participants and did not know any of the participants prior to data collection.

Regarding format, the interviews were conducted at the home of each disabled participant. Each interview session lasted for an average of 45 minutes per participant over a period of three (3) months. The choice of these venues was to help participants feel at home so the research could take place in the natural settings of participants, this being a strength of qualitative research (Quinn, 2002). Regarding focus group discussions, they took place in a rented community center with an enclosed room. There were five (5) different focus group discussions with the following composition: (a) 3 disability specific groups (as none of the participants had multiple disabilities); (b) an all-male group; and (c) an all-female group). These compositions helped in obtaining rich information from each group as participants were more comfortable in giving out information as all members in a group had similar characteristics in terms of disability and gender. Non-participants were not present during data collection to avoid possibility of influencing responses with their presence. Data was audio-and video-recorded. For the hearing impaired, data collection sessions (interview and focus group discussions) were video-recorded.

Additionally, an inductive analysis approach was used (Quinn, 2002). The strategy was to allow the analysis dimensions to emerge from patterns found in the cases under study without presupposing in advance what the important dimensions would be (Quinn, 2002). This approach helped in understanding the multiple interrelationships among dimensions that emerged from the data. This is without making prior assumptions or specifying hypotheses about relationships (the linear or correlative) among defined variables. Data-led analytical principles such as categorization, exploration and confirmation were employed to establish creative synthesis through themes (Quinn, 2002). The audio data was transcribed from Twi to English verbatim with a professional language translator from the department of modern languages at the Kwame Nkrumah University of Science and Technology-Kumasi. The video data was transcribed by the sign language interpreters who doubled as the research assistants. Cross-case analysis was done on transcribed data to establish patterns and themes that cut across individual experiences in terms of the various groups under study and how those experiences are related to disability stigma and access to healthcare (Quinn, 2002). The cross-case analysis was done by three research assistants under the guidelines of the principal investigator, with each analyst blind to the work of the other and later converged to compare notes and transcripts to correct discrepancies. (Quotes have been used when necessary to support the analysis).

Ethical issues

Ethical approval was obtained from the Committee on Human Research, Publication and Ethics of the Kwame Nkrumah University of Science and Technology-Kumasi, Ghana. Other ethical issues that were considered included the following: the purpose of the study was explained, and verbal consent was also obtained from every participant to tape record the discussions. The respondents were assured of confidentiality and anonymity and were informed that the information retrieved was for academic purposes. To ensure this, identifiers such as names, street, position, contact numbers of participants were not taken during interactions. Participation in the research was solely on a volunteer basis. No form of inducement was used to entice participants to partake in the study. Data collected were transferred to the personal computer of the researcher and kept under security password to prevent unauthorized access. After the completion of the research, data was moved to the research repository of the Department of Health Promotion and Disability Studies at Kwame Nkrumah University of Science and Technology-Kumasi, Ghana.

Results

Demographic characteristics of participants

Table 1

Demographic Characteristics of Participants

Variables	**Frequency(f) N=30**	**Percentage (%) 100**
Age group		
Below 20 years	3	10.00
20-29 years	6	20.00
30-39 years	11	37.00

40 years and above	10	33.00
Gender		
Male	14	46.40
female	16	53.60
Religion		
Christianity	25	83.40
Islam	5	16.60
Disability type		
Hearing impaired	10	33.30
Physically impaired	10	33.30
Visually impaired	10	33.30
Employment status		
Employed	13	44.00
Unemployed	17	56.00
Educational background		
Tertiary	5	16.60
Senior High School	4	13.40
Junior High School	6	20.00
No formal education	15	50.00

Source: Field Data (2019)

The demographic characteristics of participants can be seen in Table 1. From Table 1, it can be observed:

1. 50% of the participants have had some form of formal education ranging from tertiary, senior high and junior high schools, while
2. the remaining 50% have not had any form of formal education,
3. 56% were unemployed,
4. the following disabilities were distributed evenly, 33.3% each: hearing impaired, physically impaired and visually impaired.
5. In terms of gender, 53.60% were females and 46.40% were males;
6. With respect to age, 33% were either 40 or more, whereas the remaining participants, 67%, were below 40.

People with disabilities' experiences at the hospital

The organization-level experiences which affect access to healthcare as revealed by people with disabilities who took part in the study have been presented here as the main findings. They include: neglect and nepotism (with people who are friends and relatives given unfair advantage), insults and verbal abuse, lack of prescribed medicines, long hours of waiting, inaccessible healthcare facilities, and communication challenges.

Neglect and nepotism shown by healthcare providers

At the organizational level, one negative factor found affecting people with disabilities' access to healthcare was neglect and nepotism shown by healthcare providers. Most people with disabilities indicated frequent neglect by healthcare providers. The healthcare providers appeared to give preferential attention to friends and cronies, even when they arrive later than others.

> *"…Their attitude is not good, because me as a disabled person when I visit the hospital, they [are] supposed to attend to me [quickly] but sometimes someone will come late and they say protocol and send the person in while you are sitting outside"* (A 33-year-old hearing impaired female participant, individual interview)

> *"…While some of us will join the queue, they will be taking others in as protocol (their friends and cronies). This their attitude is not good"* (A 23-year-old physically impaired male participant, individual interview)

Insults and verbal abuse by healthcare providers

The study again found that healthcare providers frequently insulted and verbally abused people with disabilities. According to the people with disabilities, without provocation, healthcare providers shout at them and insult them. This is especially true if one's name is read aloud off of a folder are one does not respond immediately or appropriately. Many participants felt this treatment made them less likely to seek care at facilities even when they needed them.

> *"…I had stomach ache, and my daughter took me to the hospital, and because of the pains I was going through, I screamed, and one of the nurses came to me to [shouted] at me that I was disturbing their peace because I am not the first person to have such a condition so I should stop the drama."* (A 45-year-old visually impaired male participant, individual interview)

> *"…Instead of attending to the patients, some will pick their phones, and for them to put the phone down and attend to you is an issue. The one even asking you where is*

> *paining you, has the phone at the other side conversing with it."* (A 56-year-old hearing impaired female participant, individual interview)

Lack of availability of prescribed medicines in hospitals

Most participants lamented the frequent lack of availability of prescribed medicines. In most cases, they were asked to buy prescribed medicines outside the hospital premises because the hospitals did not have the necessary medicines in their pharmacies. This was not aligned with their expectations that once they visited the hospital with their National Health Insurance Card that all medicines would be readily available at the hospital. Some felt this lack of availability of medicine was intentionally done to discourage visits. Nonetheless, the challenge posed by seeking medication elsewhere is a significant barrier to equitable heath care.

> *"…I do not know what the problem is in some of the hospitals in this district…Always they will tell you we do not have the medicine here so go and buy it in town. I think is deliberate that they ask us to buy the drugs from town because sometimes they mention the name of specific shops we will get the drugs from of which I suspect they own..."* (A 59-year-old hearing impaired male participant, individual interview).

Relatively long hours of waiting at the hospital

The study found that people with disabilities generally spend several hours at the hospitals in an attempt to access healthcare at the Out Patient Department (OPD). Upon arrival at the hospital, 3 to 4 hours can pass before they finally see the doctor for examination and diagnosis. It takes another 1 hour before to finally get their drugs from the pharmacy. This long wait appears consistent with a lack of concern also attitude shown by healthcare providers as well as frequent neglect and nepotism. Many participants viewed the long wait they experienced as evidence that providers were neither concerned nor focused on attending to their needs. Participants felt that rather than attending to them, many healthcare providers were pre-occupied with their phones and casual conversation between themselves, all while people with disabilities waited in queue. At the same time participants felt this indifference also frequently occured throughout the country and in other countries as well. Regardless, this perception of indifference discouraged people with disabilities from seeking care.

> *"………Whenever, I am going to the hospital, I make up my mind that I will not have any other activity for the day because I know it will take very long time before I return. Too much time is wasted at the hospital and still you are told to go and buy the medicine from outside"* (A 25-year-old hearing impaired female participant, individual interview)

Inaccessible healthcare facilities

These significant delays are compounded by additional challenges as well. Due to the lack of accessible buildings, many have to endure the shame of having to be carried by others to receive healthcare in the first place. According to the many of the disabled participants, these situations effectively disclose participants' health conditions to their assistants. At times this can be a significant break of privacy if they do not wish to or elect to share specifics of their particular impairments.

> *"…My wheelchair cannot move freely around the hospital because there are no ramps or elevators to help me move freely. If you do not get people to lift you up, sometimes it is hell before you can get to the pharmacy to collect your medicine."* (A 20-year-old physically impaired participant, male individual interview)

> *"…The hospital buildings are not accessible at all, especially the eye clinic… you*

> *have to climb two different stairs before you get there and considering my age and condition, it is very difficult anytime I come for review"* (A 34-year-old visually impaired participant, individual interview)

Communication barrier between healthcare providers and people with disabilities

The study found widespread challenges in participants' communication with healthcare providers, something found particularly true for those Deaf or hearing impaired participants. Language barriers in exchanges with providers can serve as another major impediment to access to healthcare access.

> *"…You go to the hospital and there is no one there who understands your language and you too could not hear whatever is being said. I find it difficult to tell them rightly my problem because I am hearing impaired and cannot hear what they say."* (A 22-year-old hearing impaired male participant, individual interview)

Coping strategies adopted by people with disabilities to manage their experiences

Refusal to use the facility in the future

Many participants appeared to choose refusal to use a particular medical facility as a coping strategy. A negative experience receiving healthcare led to participants visiting a different hospital, not visiting any at all, or choosing instead to use other unconventional means, including self-medication.

> *"…I have vowed not to use one hospital in this district again because of the difficulties I went through at the hands of some small girl who was a nurse…She*

> *shouted at me and insulted me with my condition. I will never go there again, and I have informed my children that they should never send me to that hospital again."* (A 41-year-old visually impaired male participant, individual interview)

> *"…I do not think if I am disrespected in a particular hospital I will go there again even if they can provide the best treatment for my condition."* (A 50-year-old hearing impaired female participant, individual interview)

Confronting healthcare providers when they try to abuse them

Another coping strategy of some participants was confrontation. Here they attempt to challenge and confront healthcare providers who tried to abuse them or neglect them because of their conditions. Sometimes exchange of words and insults are inevitable.

> *"… Sometimes when you stand up and talk, they attend to you and treat you well so I think for me, I use confrontation to cope with any difficulty that comes my way at any of the hospitals that I have visited in the past."* (A 30-year-old hearing impaired male participant, individual interview)

Report to hospital authorities over challenges they face

Some participants reported problems with healthcare access to the hospital authorities. However, they could not ascertain whether their reported cases were dealt with by the authorities.

> *"…I will report them to the leaders, maybe the District Chief Executive. I can also say it on radio that this is what this particularly hospital is doing. That, because I am disabled, they don't openly attend to me, so that they can also speak for me and ask*

> *whether it is right for them to treat me like because I am disabled.* (A 26-year-old physically impaired female participant, individual interview).

Patience and endurance

The study also found that patience and endurance were strategies adopted by people with disabilities to manage problems encountered. Participants believed that when a person needs treatment, it is important to ignore possibilities of ill treatment and instead focus on the reason why one needs to visit the hospital.

> *"...I am the one who is sick so I have to remain calm and get treatment…. I do not think that I have to say anything because if I get healed, I will not come to the hospital again for them to disrespect me so for me the strategy is just simple, keep quiet and get treat and go home."* (A 40-year-old hearing impaired female participant, individual interview)

"...I keep quiet and get my treatment so I can peacefully go home…. If I talk and they refuse to attend to me, what will I do? I have nowhere to go so I do not think it is important to do anything apart from ignoring them." (A 21-year-old physically impaired male participant, individual interview)

Discussion

The examples of barriers encountered in accessing medical care stand in contrast to Sustainable Development Goal 3 Subsection 3.8. This talks about achieving universal health coverage, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines for all (United Nations, 2015). People have health needs arising from their primary impairment as well as from their ability to access care

(Shakespeare, 2012). This is especially true for those who lack influence. This is consistent with United Nation findings that discrimination in health-care settings is often directed towards marginalized and stigmatized populations (United Nations, 2015).

These and other inequities found in this study mirror those found elsewhere globally. A 2017 study conducted in Nepal in 2017 found that poor care and rude staff affected women with disabilities' access to maternal healthcare services (Devkota, 2017). Another study suggests providers' discomfort working with people with disabilities and lack of disability-specific knowledge are important interrelated factors hindering access to quality health care (Lam et al., 2010). Moreover, experiences of people with disabilities in the Bosomtwe District of Ghana regarding lack of availability of prescribed medicine are consistent with experiences by both disabled and non-people with disabilities at various healthcare facilities depending on the geographical settings (Mannava et al., 2015, Nair et al., 2014). Problems with excessive waiting times to receive care at facilities are also reported elsewhere. Relevant findings indicated that people with disabilities continue to experience discrimination from National Health Service staff who fail to treat them with dignity and respect and appear to devalue the lives of people with disabilities in general (Mencap, 2012). Another study also addresses similar communication barriers with providers found in this one (Devkota et al., 2017). Finally, these experiences of barriers to care are also consistent with other findings that such concerns are particularly relevant to vulnerable groups and marginalized minorities (Fish & Bewley, 2010). As such, the findings provide further evidence for the need to address these barriers.

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