

Barriers affecting access to health information and health care services among the Deaf Community in Namibia

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ABSTRACT

Health is a crucial aspect in an individual's life as it enables people to enjoy their potential as human beings. Consequently there has been an enormous emphasis on equity in access to health care. Just like anybody else, Deaf people have a right to access health information and services and should not be discriminated against in any way. Unfortunately Deaf people are usually marginalised within society and as such their experiences with health care systems across the world are not readily understood (Scheer, Kroll, Neri & Beatty, 2003). For example, it is assumed that everyone who seeks health service hears and can communicate in a spoken language to receive a standard quality of health care. This study explored the barriers experienced by the Deaf community when accessing health information and health care services in Namibia. The study applied a qualitative approach, and conducted semi-structured interviews with Deaf learners, teachers and other employees in purposefully selected special schools

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(now known as Resource schools, [MoE, 2013]) and centres for people with disabilities in Namibia. The results indicate that the implementation of regulatory and policy frameworks surrounding disability are still hindered by structural inequalities, social prejudices and stigmatisation of the Deaf community. Therefore, the study recommends changes in the broader structural and social arrangement beyond the health sector if Deaf people are to receive equitable health care.

Keywords: *barriers, Deaf community, health, Namibia*

Health is one of the most crucial aspects in an individual's life as it enables people to enjoy their potential as human beings. Consequently there has been a huge emphasis on equity in access to health care. For Example, the Namibian Constitution (GRN, 1990, article 3 & 95) asserts that every citizen has the right to health care and should be free from discrimination. Equally, Namibia's long term plan, Vision 2030, emphasises this as it states that "all people in Namibia will have equitable access to high quality and affordable health care services; [and] the health infrastructure is strong, equitably distributed, and is being supported by adequate human, material and financial resources" [Government of the Republic of Namibia (GRN), 2004, p. 58].

In both Vision 2030 and the short term Harambee Prosperity Plan, the Namibian government echoes its ability to deliver high-quality and equitable services (GRN, 2004, 2016). The same values of quality and equitable services are adopted by the National Health

Policy; towards achieving health and social wellbeing for all Namibians (Ministry of Health and Social Services [MOHSS], 2010). These frameworks aim to achieve equitable, accessible, affordable and sustainable healthcare for all Namibians through the five year national development plans [NDPs] (Kuwana, 2014).

These policies are informed by the United Nations (UN) Universal Declaration of Human Rights (1948), the UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and the UNDP Millennium Development Goals (MDGs) and the subsequent Sustainable Development Goals (SDG, 2015) where universal access to health care is underscored as paramount to inclusive development. As an international human rights treaty, the UNCRPD, (2006) in particular aims to protect the rights and dignity of persons with disabilities (PWD).

In addition, it also intends to promote and protect the full enjoyment of human rights by PWD; and ensure that they enjoy full equality under the law. During the 1994 International Conference on Population and Development (ICPD), PWD were identified as particularly vulnerable, with a need for recognition of their reproductive health needs and elimination of discrimination with regard to their reproductive rights. Thus similar to anybody else, PWD including the Deaf have a right to access health information and services and should not be discriminated against.

Unfortunately PWD are usually marginalised and, as such, this impacts their experiences with the health care systems across the world (Scheer et al., 2003). As a social group, PWD generally present a multiple complex of medical and non-medical needs, yet very often receive below par health care (Hwang et al., 2009). For example a

study by Kritzinger, (2011, p. 1) found that people with disabilities receive less of certain preventative services or different preventative services from the general population; they also experience poorer access to needed services and report a greater degree of dissatisfaction with services that they do receive. PWD were also found to less likely utilise primary preventative services even though they are at higher risk for secondary conditions; and similar to the general population are also likely to partake in risky health behaviour (Kroll, Jone, Kehn & Neri, 2006). The Deaf population is among the most affected by inadequate health services as they suffer discrimination and exclusion due to their unique language.

The problem of inequity in accessing health care services among Deaf people usually arises as an intersection between their hearing impairment and the social environment factors such as inflexible policies, social arrangements, cultural values, and language that exclude, discriminate and stigmatise PWD. For example, it is assumed that everyone who seeks health service hears and can communicate in a spoken language to receive a standard quality of health care. However, in many countries around the world Deaf people have no access to proper education and there are no sign language interpreters in public services (Oladottir, 2014). These limitations, combined with negative cultural attitudes, hinder the Deaf to live fulfilled and prosperous lives guaranteed under the United Nations (UN) Universal Declaration of Human Rights and the UN Convention on the Rights of Persons with Disabilities (Oladottir, 2014).

Since Deaf individuals rely on sign language as their primary means of communication, overheard conversations and mass media

(radio and television) are generally inaccessible to them (Barnett & Franks, 2002; Groce, Yousafzai & Van der Maas, 2007). These obviously deny them access to health information with regards to prevalent diseases such as Malaria, cancer, TB, HIV/AIDS etc. (Zazove, Meador, Reed, Sen & Gorenflo, 2009). Consequently, the Deaf and hard-of-hearing people were found to be more likely to avoid health care providers because of lack of information and poor communication among other factors (Tamaskar et al. 2000).

Inaccessibility to health care services appears to be a general problem in Namibia. Many people especially those in the rural areas are still facing challenges of long distances, shortage of health professionals, long waiting hours in health facilities, out of pocket expenditure towards travelling and accommodation, loss of production and risk of losing their employment through absenteeism, especially in the rural areas (Van Rooy et al., 2012). The situation is worse for persons with disabilities and persons with hearing impairments are not spared humiliation and exclusion in health services.

In this article we argue that the consequences of these challenges are probably more pronounced among the Deaf community as they are among the poorest of the poor, and usually do not have equal opportunities and access to employment, health, education, land, housing and other basic necessities to lead fulfilling lives. Moreover, people with disabilities require services which are specific to their impairments such as health-related rehabilitation and appropriate specialist care (Scheer, Kroll, Neri & Beatty, 2003 cited in Kritzngr, 2011, p.1). Consequently, it is imperative to understand the barriers that are unique to the Deaf community if we are to achieve

the WHO (1978) Alma Atta declaration of “health for all by the year 2000 and beyond”. This paper investigates the experiences of the Deaf community in Namibia with regard to barriers to access health information and health care services. The paper may create awareness and understanding of the needs of the Deaf community amidst the hearing culture that dominates Namibia’s society, including its health facilities. The findings in this paper may also inform the implementation of the National Policy on Disability (1997) and UNCRPD (2006) which ultimately aims to create an inclusive “society for all” which recognizes and values individual differences.

PURPOSE AND OBJECTIVES OF THE STUDY

The purpose of this study was to explore Deaf people’s perceptions and lived experiences and barriers when accessing health information and health care services in Namibia. The specific objective was:

- To describe the Deaf learners and teachers’ perceptions and experiences of structural and process barriers related to seeking health information and health care services in Namibia.

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Disability and Legislative Frameworks

The World Health Organisation [WHO] (2011) and World Bank's [WB] (2011) World Disability Report state that about one billion (15%) people worldwide live with some form of disability. About 80% of these people are within the low income bracket in developing countries (World Disability Report, 2013). Poverty, poor educational systems and limited access to health services are some of the contributing factors to higher incidences of disability and impairments reported in developing countries than in other parts of the world.

According to Namibia's Disability Report (2011), about 98,413 (4.7%) of the population reported some kind of disability during the census. This report disaggregated the different types of disability conditions as: 35% blind; 24% physical disability affecting legs; 21% Deaf; 13% physical disability affecting hands; 11% speech and 5% mental impairments. The rate of disability was higher in rural areas (5.7% of people with disabilities) than in urban areas (3.3% of people with disabilities). There was no significant difference in the rate of disability between men and women with disabilities (4.8% male and 4.6% female). About 9% of people with disabilities in Namibia indicated that they were affected by two types of disability and close to 2% of people with disabilities reported three types of disabilities (Namibia Statistics Agency, 2011, p. 1).

According to Oladottir (2014), there is little statistical data about Deaf people and their specific situation. This could be an

indication of underreporting due to communication barriers during the data collection process. The lack of data affects planning and subsequently makes Deaf education problematic. The 2011 Namibia Population and Housing Census estimated the total number of Deaf people at 6257 (3196 female and 3061 male). People experiencing hearing difficulties were 9440 (5218 female and 4222 male) (Namibia Statistics Agency, 2011, p. 54). People with mild hearing impairment who relate to being relatively to profoundly deaf were 1 out of 15600. The Census (2011) also counted a number of people that are referred as Mute/Dumb (5908) and a number of people with speech impairment (6056). It can be added that the reference “dumb” is seen as an old, inaccurate and offensive concept within the disability fraternity in Namibia and is not accepted by the Deaf community. As these terms are not explained further so those individuals might also have a hearing impairment making the total number of Deaf people in Namibia inaccurate (Bjarnason, Stefánsdóttir & Beukes, 2012).

According to WHO (2010), the United Nations General Assembly (UNGA) adopted the World Programme of Action Concerning Disabled Persons at its 37th regular session in 1982. The purpose of the programme was to promote measures for prevention of disabilities, rehabilitation and realisation of goals, “full participation” of disabled persons in social life, development and “equality” (UN, 1983, p.1). Subsequently the UNCRPD was adopted by the UNGA on 13 December 2006 and came into force on 3 May 2008. Many countries around the world including Namibia ratified the UNCRPD and adopted legislations and policies on disability. The National Disability Policy of 1997 was introduced in Namibia and it states that the government’s vision is to create a ‘Society for All’ based

on the principles of participation, integration and the equalization of opportunities (Ministry of Lands, Resettlement and Rehabilitation, 1997, p. v). The government further strengthened its commitment by passing the Disability Council Act in 2004 (Act 26 of 2004). This act makes provision for the formulation of a disability council which is tasked with among others; ensuring implementation of the disability policy; identification of any hindrances existing in the current legislation which limit the implementation of the disability policy; initiating reformulations of the disability policy so that it is in line with changing circumstances; and taking the required steps to improve the lives of PWD (Lang 2008, cited in Kuwana, 2014, p. 22). Despite the presence of the policy and act in Namibia, the situation of PWD has not greatly improved since then. Their numbers are actually increasing and they are among the most marginalised groups in any society (Namibia Statistics Agency, 2011, pp. 1&11).

Health Care Service in Namibia

Health care in Namibia has been impacted by colonialism and the “apartheid” system. The system of “apartheid” not only created a gap in access to health care between rural and urban but also between the rich and the poor. Due to a strong political commitment after independence to upgrade the primary healthcare system, there has been a slow improvement in access to healthcare facilities in the last two decades. Nevertheless, the gap between the different social groups is still prominent (Gustafsson-Wright et al., 2011).

A majority of the Namibia population relies on public health care services as they do not have health insurance. The main reason

many individuals lack health insurance in Namibia can be related to the inability to pay health insurance premiums. The premiums are often too expensive for many to afford despite the existence of a spectrum of insurance/medical aid schemes. Majority of those who are insured are either in the highest income quintiles or are middle-income and receiving an employer subsidy such as those workers covered by PSEMAS, which insures civil servants (Gustafsson-Wright et al., 2011).

As Namibia is within the top tier of African countries with respect to government health expenditure, one should expect that the beneficial role of public health care would be particularly visible in the country (Gustafsson-Wright et al., 2011). For instance, all recipients of state social grants which include pensioners, PWD, orphans and vulnerable children are exempted from paying fees in all government health facilities. The initiative to provide free medical care is another effort of the government to ensure that the most vulnerable people in the society are not excluded from health care services (Van Rooy, Mufune & Amadhila, 2015). Yet due to the absence of sign language interpreters at public health facilities some Deaf people still end up paying the required fees (findings from the current study). Despite government's concerted efforts to provide an equitable health care service, there are reports of critical shortage of health professionals, long distance to health care facilities especially in rural areas and long waiting times at public health facilities (Van Rooy et al, 2012).

The Concept of Disability

Disability is complex, dynamic, multidimensional, and contested. The concept has evolved throughout the years and changed significantly from one community to another (Munyi, 2012). For instance Thomas (1957) quoted by Munyi (2012) points out that in the 16th century, Christian religious leaders such as Luther and John indicated that the mentally retarded and other PWD were possessed by evil spirits. Similarly, Bjorn (1990) cited in Munyi (2012) observed that in communities such as Kenya and Zimbabwe, a person with a disability is regarded as a curse within the family, therefore he or she will experience rejection from both the family and community. Consequently, these persons will fail to develop to their full potential as they get less attention, are less motivated and possess little or no education. Hence, from a cultural point of view, there are many specific historic circumstances that have influenced people's attitude towards PWD as well as their living conditions. History shows that ignorance, neglect, superstitions and fear are some of the factors that have worsened the exclusion of PWD from many aspects of life (Bjorn, 1990 cited in Munyi, 2012). The Disability Service Act (1993) defines disability as meaning 'disability' which is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairments or a combination of those impairments. Conversely, the World Health Organisation (2011) defines disability as an umbrella term, covering impairments, activity limitations and participation restrictions.

Throughout history PWD have been treated differently from those who conform to “societal norms”. Disability has been viewed as a medical problem or disease needing intervention or cure by means of medical help or medicine (World Health Organization [WHO] & World Bank [WB], 2011). This perspective has caused PWD with disabilities to suffer beyond their actual physical, physiological or medical condition.

The old definition of disability was too focused on the individual and the impairment he/she has. It was also the foundation of the development of the poor perceptions and stigma surrounding PWD, which the social and phenomenological models of disability are fighting to deconstruct today. The social model argues that PWD should not be seen as sick; disability is not a health issue but rather a social one. Society sometimes determines a person’s disability by what s/he cannot do rather than looking at how s/he can be assisted to ensure that they are able to live like everybody else. The social model of disability introduces disability as a result of barriers and limitations in the environment that hinder PWD from full participation in society (D’Alessio, 2011). D’Alessio (2011) elaborates that on the basis of the model, it is society which disables people with impairments therefore if there is any meaningful solutions intended to help PWD; it should come from society not from the individual or rehabilitation. Thus, the core dimension of this model is that disability is a socially constructed phenomenon. PWD are one of the most marginalized minority groups in any society but the Deaf which form part of a minority within this category face greater marginalization (Namibia Statistics Agency, 2011). Perhaps because being Deaf is not

visible, these people find themselves to be one of the most neglected groups of PWD.

In the literature of deafness and Deaf culture, a common distinction is made between “deaf” and “Deaf” (Heap & Morgans, 2006; Reagan, 2008). The audiological condition, resulting in lack of hearing is commonly referred to as being deaf (denoted with a small cap ‘d’); this definition is closely linked to the medical model’s definition which includes a person having a hearing impairment when compared to ‘normal’ peers (Chong-Hee Lieu, Sadler, Fullerton, & Stohlmann, 2007; Steinberg et al., 2006; Williams & Abeles, 2004). Deaf, denoted with a capital letter, on the other hand refers specifically to a distinct cultural group which uses the local sign language in their daily lives and is more in line with the social model’s definition which considers deafness as a problem located within society and not the individual. For many people, with no exposure to the Deaf culture, the definition of deafness is straightforward and within the medical model as defined above; it is seen as a hearing loss which is easily classified as a disability (Williams & Abeles, 2004). With the distinction made, this study focuses on ‘Deaf’ with a capital D, because it refers more to the culture of the ‘deaf’ people as a group of people that share a language, experiences and with a specific cultural identity. Thus, the study mainly focuses on those that cannot hear nor speak (including the hard-of-hearing who prefer sign language over speech) and thus use sign language as a means of communication, hence belonging to the ‘Deaf’ community.

Sign Language in Namibia

According to Schembri and Adam (1998) as cited in Rodriguez (2007, p. 46), sign language has its own structure. It consists of phonology (sounds/hands faces, body and space), morphology (words and signs), syntax (sentences), discourse (conversations, letters, speeches etc.) and semantics (meaning). However, within the wider society, there is still a general lack of understanding of sign language. Subsequently, society prefers speech to signs as the correct form of communication whereas sign language and a visual mode of communication are perceived as deviation from the norm (Ladd, 2003). Conversely, sign language became a symbol of unity for the community of the Deaf and according to Jankowski (1997) it represents how a symbol of oppression can be turned into a positive tool in the fight for equality.

According to Ashipala et al., (1994) cited in Oladottir (2014), it is believed that the Deaf in Namibia developed the Namibian Sign Language (NSL) in communicating between one another similar to other places in the world. For example, a former Deaf student at Engela in Ohangwena region explained that the children (learners) use the same signs as the teachers but the difference was that between themselves the language did not follow the word order of the spoken language as it did inside classrooms. The same was the situation for the Deaf adults who worked there – their sign language did not follow the word order of Oshiwambo (the vernacular in that region).

The first NSL dictionary was officially launched on 16 April 2008 in Windhoek. The dictionary was compiled by the Namibian National Association of the Deaf (NNAD) with Finnish and Icelandic funding (Embassy of Finland, Windhoek, 2008). The Sign language

project was started because it was evident that the lack of a dictionary hindered both organisational building and the promotion of deaf people's right in Namibia. Despite the compilation and launch of the NSL dictionary in 2008, many of the Deaf in the study by Oladottir (2014) in Namibia complained of not being understood by health care providers. The conversation between the hearing doctor and a Deaf patient was described as ineffective and open to misunderstanding. The respondents pointed out that an introduction of interpreting service at all public services is essential for full participation of the Deaf in society.

DATA AND METHODS

The data of the research reported in this paper were collected through a qualitative survey approach in selected special schools (now known as Resource schools, MoE, 2013) and centres for PWD in Khomas and Oshana regions of Namibia to describe and understand rather than to explain and predict access to health facilities. The research design was based and guided by the phenomenological approach as well as symbolic interactionist theory. The phenomenological approach involves an understanding of the essence of phenomena by examining the view of people who experience those phenomena; it is interested in the individual experience of the people (Barrow, 2017; Boyd, 2015). Semi-structured in-depth interviews were used to collect data from Deaf teachers, Deaf learners and other Deaf persons in special schools (Resource

Schools) and rehabilitation centres for PWD. Parahoo, (1997, p. 59) states that qualitative research focuses on the experiences of people and stresses the uniqueness of the individual. Additionally, Holloway and Wheeler (2002, p. 30) explain qualitative research as a form of social enquiry that focuses on the way people interpret and make sense of their experience and the world in which they live. Therefore, the approach was deemed the best methodology to achieve the research objective because it enabled the researchers to do an in-depth exploration of the Deaf people's experiences and feelings towards the barriers affecting their access to health information and health care. The study used a qualitative research methodology which usually involves long in-depth interviews with subjects (Boyd, 2015). Therefore this approach is highly relevant to understanding the world of the Deaf, because the Deaf people belong to a linguistic and cultural minority group and this approach enabled the researchers to understand the social world and the needs of the Deaf community from a collective point of view. Conversely, Symbolic Interactionist assume that facts are based on and directed by symbols and the foundation of this theory is meanings. Being a proponent of this theory George Herbert Mead, assumes that symbols develop the mind and they are used as means for thinking and communication (Aksan et al., 2009). Symbolic interaction theory acknowledges the principle of meaning as the centre of human behaviour. Language provides meaning to humans by means of symbols. Thus this theory is relevant to this paper because Deaf people communicate using symbols through sign language; it is their language and they attribute meaning to those symbols (Nelson, 1998 cited by Aksan et al., 2009).

Sample and Sites' selection

The respondents and the two regions in this study were chosen following a non-probability purposive sampling technique. The two regions were purposefully chosen out of the fourteen regions, on the basis of the following criteria: There are limited institutions catering for the Deaf around Namibia. The Khomas and Oshana regions host the most well-known schools for the Deaf namely Eluwa Special School in Ongwediva-Oshana region, the National Institution for Special Education (NISE) and the Centre for Communication and Deaf Studies (CCDS) in Windhoek-Khomas region. This eased the process of accessing and locating the Deaf population.

The data were collected by fourth year students of the Sociology Department of the University of Namibia as part of research projects for their Honours Degree in 2015. The data were collected under the guidance and direction of their supervisor, the author of this article. The students who chose the main topic of "Disability" were coached throughout the entire research process by the supervisor.

Research Procedure

All interviews were conducted using a semi-structured questionnaire with open-ended questions. Open-ended questions calls for free responses in the respondent's own words. The questionnaire was administered in English, but was interpreted to the participants in Namibian Sign Language (NSL). Interpreters were "hearing" teachers, school matrons at the schools and the co-ordinator of the CCDS.

At the beginning of 2015, a number of preliminary meetings were held with principals of the schools for deaf learners (Eluwa and

NISE) and the co-ordinator of the CCDS. The purpose of the meetings was to explore the feasibility of conducting the study as well as the appropriate procedures to be followed before interviewing the Deaf people in their schools and centres. During the preliminary meetings, the research team explored the possibility of getting NSL interpreters from the special schools (Resource Schools) and the centres to interpret during the process of data collection. Prior to fieldwork, permission was sought from the Department of Disability Affairs in the Office of the Vice-President. Thereafter permission letters were also obtained from the Ministry of Education, Arts and Culture and from Khomas and Oshana Regional Directorates of Education. Finally permission was also granted by the principals and coordinators of the selected schools and centres. Informed consent was explained in sign language and participants were made aware that the interviews will be voice recorded (voices of the sign language interpreters) and notes will be taken during the interview (the notes included the non-verbal communications such as the gestures, facial expressions and laughter of the Deaf people). The respondents were also informed (through the sign language interpreters) that they can withdraw at any stage if they are not comfortable with the questions. For ethical considerations, the learner-participants were only those who were 18 years and older.

DATA ANALYSIS

The audio recorded interviews (voices of the sign language interpreters who interpreted back and forth between the

respondents and the research team) were transcribed into English and the data was analysed using qualitative content analysis. Content analysis was done by formally identifying set of themes from the data collected (Crang & Cook, 2007). Related themes were then connected together to make sense of the data. These themes were used as codes to create sections of the main headings and are presented with illustrative comments in quotes for various themes under the findings' section.

FINDINGS

Demographic Characteristics of Respondents

A total number of 15 Deaf and hard-of-hearing respondents were interviewed for this study. In-depth interviews were conducted at Eluwa with four (4) Deaf people aged between 18-50 years and one (1) hard-of-hearing respondent who was 49 years old (using sign language). Three (3) of the respondents were females and two (2) were males. All were teachers, labourers, a hostel matron and a learner at Eluwa. Two (2) key informant interviews were conducted with hearing teachers (not deaf) at the same school, aged 38 and 42.

In the Khomas region nine (9) in-depth interviews were conducted in Windhoek with four (4) Deaf and five (5) hard-of-hearing respondents (using sign language). Key informants interviews were also conducted with the principal (school for the Deaf) at NISE and the coordinator at CCDS. Three (3) of the respondents were males and six (6) were females. Their ages ranged from 18 to 54 years. Two (2) of

the respondents were learners at NISE and the rest were employed at either CCDS or NISE. The income of employees at Eluwa, NISE and CCDS ranged between N\$ 1000- N\$19000. The level of education of the learners was between grade 6 and grade 10. All the Deaf and hard-of-hearing labourers interviewed at Eluwa have not attended any formal education. Only six (6) out of the fifteen respondents had tertiary education; a diploma in child development, a degree in education and three (3) have certificates in pre-primary education. The rest of the employed respondents who attended formal education did not go beyond junior secondary school; the highest went up to grade 10.

When the Deaf and hard-of-hearing respondents were asked about what caused their deafness, most of them indicated that it was caused by Meningitis; two (2) said it was caused by Malaria. Only one (1) respondent reported that she was born deaf and two (2) were not sure as to what caused their deafness. Two respondents identified themselves as partially deaf, eight as totally deaf and one as moderately deaf; yet all of them indicated that they prefer sign language over speech.

Disability Identity

Some of the Deaf respondents showed how proud they were about their Deaf culture. An instance was a 50-year-old female respondent at CCDS who corrected the information in our questionnaire by informing us that we should not use the concept “people living with disabilities” but “people with disabilities”:

First before we start, it is not people living with disabilities but people with disabilities. We don't want to be discriminated [against] or to have stigmatization attached to people with disabilities. The Deaf/disabled people can do all things; it's just the environment... that makes it difficult. For example you [as] a person [are] able to talk, you come in an environment with people only signing and when you can't sign, then you also become disabled that way."

Other respondents expressed similar sentiments: "...There was a woman from South Africa who taught us sign language and then I mastered sign language and now it's definitely my culture." (A 41 year-old, male respondent, Eluwa); "...I am happy to be a Deaf, I don't have any problem." (A 26 year-old, male respondent, Eluwa)

Structural–Environmental Barriers to Accessing Health Care Service

Kroll et al. (2006) cited in Kritzinger (2011) described structural-environmental barriers as those conditions in the physical, social and economic environment. These barriers include limitations due to facility design, equipment and inability to pay due to lack of cash and insurance coverage. Environmental barriers have been further described by the International Classification of Functioning, Disability and Health (ICF) as social attitudes, architectural design, transportation barriers, such as access to public transportation, publicly-funded ambulance system, and private transport etc. (WHO & WB, 2011).

The status of the Deaf in the Namibian society. Even though the Deaf people are proud to maintain their Deaf identity, a 42-year-old female key informant at Eluwa pointed out to us how people in the community perceive Deaf people:

Point number one, they are neglected in the community, point number two is lack of communication among the community, and three, due to ... [the] facts I mentioned, it cause them to lose self-confidence; now they even put themselves down because they do not have support. People in the community regard deaf people as “those people, those people”; they are not regarded as people like others in the world.

A similar sentiment was expressed by a 26-year-old, male respondent at Eluwa who said that “many people say or think Deaf people are mentally challenged (makes facial expression of disgust); they call us names and look at Deaf people as paper (meaning nothing).”

Distance and transportation to health care services.

The Namibian Demographic and Health Survey (GRN 2006) found that urban households are more likely to be nearest to a clinic than rural households. Similar to the rest of the society, the Deaf also experience the problem of travelling long distances to health care facilities. However, Deaf people do not only incur cost but are also face challenges in the use of public transport due to poor communication. According to a 50-year-old female respondent at Eluwa “Taxis are ... [our] mode of transport, but they [drivers] do not know sign language;

once they realise you are deaf they will force you out before your destination or they drop you off at a wrong place.”

Corroborating the mobility challenges, a 25-year-old male respondent at NISE said: “I always pay double transport fare. One for me and another for my interpreter, just because I am deaf; any movement I make, I need an interpreter.”

Socio-economic factors play a huge role in accessing quality health care service. Some of the teachers interviewed indicated that they have health insurance coverage that is subsidized by the government under PSEMAS scheme. These teachers indicated that they prefer private doctors over and above the public health care system. A 31-year-old female respondent at Eluwa articulated this preference:

Because private doctors are good. They give you medication that helps/heals quickly. When you ask questions, they will understand. They will show you a lot of things “nicely”, then you get well “soon”. It’s better than government [public hospitals], because sometimes they don’t explain anything.

The rest of the Deaf respondents do not have health insurance coverage but they were all aware that they are exempted from user fees at all public health facilities. However this arrangement is hampered by communication barriers. According to a 50-year-old female respondent at Eluwa:

We Deaf people we don't pay, it's free. Because their health passports don't have an identification [that states that they are deaf] so the nurse do not know. It has to be written 'Deaf'. Those others they don't know; there is no information, but they should not pay because all Deaf people in Namibia are given equal rights [of being disabled] that they shouldn't pay; the same applies to the elderly.

A 49-year-old, female respondent, CCDS put the blame on both parties:

The problem being experienced is that Deaf people at the village are suffering, unlike those in towns. They are not informed; they don't know that they do not pay [do not have to pay] at government hospital. The people there are zero, zero! [Meaning "know nothing" referring to the health care providers]. Information at rural hospital is zero, zero [poor].

Structural and environmental barriers experienced by the Deaf community can be linked to the general low status ascribed to people with disabilities in the society. People with disabilities including the Deaf are neglected and are at times regarded as physically and mentally unfit to be involved in social life. The Deaf people are even more excluded due to their unique sign language with symbols that are not understood by hearing people. Besides the transport costs, Deaf people also find it difficult to communicate their destination to taxi drivers. Sometimes they are rejected or dropped off at wrong and unsafe places.

Deaf people seem to be well informed about being exempted from the user fees at all public health facilities however, due to poor communication and lack of awareness from the side of the health care providers they still end up paying for the service.

Process Barriers to Accessing Health Care Service

Process barriers are difficulties inherent in the delivery of service. It includes provider knowledge, timeliness of service, communication between the provider and the user, receipt of preventative care and scheduling of appointments (Drainoni et al., 2006)

Communication with health care workers. Effective communication is information that is understood by both the health care worker and the service user. Barriers to access due to communication are a result of language and cultural differences which affect one's understanding and perception of words. The findings of this study show that lack of communication is the most common barrier affecting access to health care services among the Deaf community. On the question whether they (the Deaf community) access health care like any other person in their community, one respondent said:

No, I do not access health the same as the so-called hearing people, because I am deaf and I use sign language and nurses and doctors at hospitals do not know sign language so there is always a challenge when I write my English. My English is a little bit mixed up because we don't have the same way of structure

of English and sometimes when you sign, they misunderstand you and do not get the right information that I want to convey to them. (38-year-old Deaf male, CCDS).

However, a 31-year-old, female Deaf respondent at Eluwa indicated that he does not have a problem with communication: “I don’t need an interpreter. I write because I know English...privacy is 100% because I know English.” Another respondent raised the problem of local language barrier:

I speak Oshiwambo, the doctor speaks English; there is no communication and I don’t know English. If I speak Oshiwambo I can’t communicate to the doctor through writing because we won’t be able to communicate, so there has to be an interpreter” (A 49-year-old, female Deaf respondent, at Eluwa).

While the findings show a challenge of communication between the Deaf community and health care providers, it also denotes that deaf people are not homogeneous. For, example deaf people who have high levels of education (can write in English) can easily communicate with the health care providers than those with no/little education.

Consequences of miscommunication and queues dilemma.

Deaf respondents expressed frustration with the health facilities system in terms of handing in medical passports and having to sit in a queue waiting to be called. According to a 50-year-old female respondent at Eluwa:

At the hospital, you give your health passport. I cannot hear my name being called and the nurse removes it when I don't respond because she thinks I went [away] or something. So I sit there waiting to be called ... so you think your name has been called, but it hasn't been called. I don't even know how to spell, so I don't know when I am being called or not.

The same difficulty was expressed by a 41-year-old male Deaf respondent at NISE:

My card is marked "Deaf" but they do not look at the card so that they see this patient is deaf, he should go first. Sometimes the door is closed and they will call inside there while you cannot hear. So we have different culture there; I am deaf, I will sit and watch but people are calling names that I cannot hear.

The misunderstandings and dilemmas as narrated by the respondents seem to confirm the general perceptions that deaf people are excluded from full societal participation and public (probably also private) services, including health. Their narratives illustrate that it is assumed that everyone who seeks health care service hears and can communicate in a spoken language or is otherwise accompanied by a family member or any other person from their social support network. Consequently, no provision is made for assistive and support service at health care facilities.

Alternative forms of communication. When health care providers and Deaf patients have difficulty communicating in the health setting, they try alternative means of communication such as writing and lip reading. In an effort to guard their privacy some respondents specifically prefer to independently communicate with the health care providers through writing to express their symptoms while receiving the instructions on their treatments in the same way. A 25-year-old male respondent at NISE described the process: “I go alone...I use writing with doctors as a way of accessing health care service.”

However, the respondents also expressed their frustration when it comes to communication through writing. It is mostly difficult when they have to write in English and they also experience difficulties comprehending medical concepts. A 31-year-old female respondent at Eluwa said “when I am in deep pain, the English, sometimes we cannot understand each other with the doctor [the English does not come out easily]. Sometimes we can’t find words to describe the pain.” A 41-year-old male respondent at CCDS also emphasised the challenges: “...sometimes I go [go alone to the health care facility] but it is difficult because there are no interpreters. You keep on exchanging writing. I think we could have an interpreter because writing is difficult; sometimes you get stuck.”

Lip reading is also another form of communication that is used by some of the Deaf respondents to communicate with the health care providers. However, the respondents who are able to lip-read raised an interesting point that they find it easier to lip-read in

their mother tongues. A 38-year-old male respondent explained the contrasting scenarios:

The nurses were speaking Oshiwambo; yea, at least I lip-read to understand and I picked up something then I will say may be repeat and explain. That was good, for us who can lip-read, it is fine. But now, for Windhoek is English, you can't lip read... you ... lip read your mother tongue. There was no interpreter, I was just lip-reading for HIV test. They counselled me before and after and I was lip reading myself.

Challenges with prescriptions and medical instructions. Deaf patients do not get proper instructions on how to take medication. A 35-year-old female Deaf respondent at CCDS said that “they don't explain, they only say ‘morning; afternoon, and evening’; no explanation on how to use or dosage of the medication. It is just the medication package ... so they just show you.” Continuing, she noted that miscommunication can occur unintentionally:

It is very dangerous for the deaf to go for HIV test at the hospital. If I am deaf and I am positive, and the nurse shows that positive sign (+); I will jump, because I understand that I am fine. Because a positive sign is actually a good thing in sign language. So it is good for health workers to know the sign language so that they can explain well.

In addition, health information are usually conveyed through audible mode of communication i.e. health talk, radio and TV but the Deaf cannot access it. A 50-year-old, female Deaf respondent at Eluwa brings this challenge home poignantly:

I went for Pap smear; (when prompted on how she found out about Pap smear) she said: “no, I did not get it from the media; a person who works here explained to me through interpretation; I guess most Deaf people don’t know about it.

When she was prompted about contraceptives, she indicated that the situation is very worrying especially for young people.

The same difficulty in accessing health information was recounted by a 25-year-old male Deaf respondent at NISE: “I know my HIV status; I went for counseling and they did the HIV testing to know my status.” When asked where he got the information about HIV/AIDS, he stated: “I got it here at school.”

The respondents also raised a concern on the violation of their privacy when accessing health care. A respondent who went for HIV counselling and testing remarked:

It was more practical because I went with the interpreter and I should know before I go for testing; I must have all information on HIV so that I can cope with what I come out with. I was with the interpreter, but they said it is confidential (A 50-year-old female Deaf respondent, CCDS).

Challenges of lack of communication, prescriptions and procedures that are not explained to Deaf patients stem from the lack of inclusivity in the Namibian health sector. Whereas the principle of inclusive education has received considerable attention both at the national and international level (Batiste, Malachie and Struthers, 2013; Haihambo, 2010; MoE & UNICEF, 2018), this commitment seems to be lagging behind in the health sector. Under its principles and values, the Namibia Health Policy Framework 2010-2020 states that health and social services will be affordable and the principle of equity will apply while special attention will be given to the needs of vulnerable groups (Ministry of Health and Social Services, 2010).

However the experiences of the deaf people interviewed in this study signify that healthcare in Namibia is targeted to a broader population and therefore does not provide an equitable service. Zere et al. (2007) cited in van Rooy (2018) also argue that the Ministry of Health and Social Services does not have a clear definition of access nor does it take into account the different needs of people. Hence the significance of the findings of the current study which show that the service is not accessible neither acceptable to the Deaf community.

DISCUSSIONS AND CONCLUSION

This study applied the phenomenological method and the Symbolic Interactionist theory to explore the barriers experienced by the Deaf community and persons with severe to profound hearing impairment when accessing health information and health care

services. The primary aim of phenomenology is to understand the phenomena in question by grasping their meaning (Martiny, 2015). The study, in particular, focused on those who use NSL irrespective of whether they were completely Deaf or hard-of-hearing. The aim was to give direct descriptions of the Deaf community's experiences when accessing health information and health care in Namibia. The respondents narrated their stories about their lived experiences as Deaf persons when seeking health care services. Symbolic Interactionist theory, on the other hand, assists us to understand how the Deaf community make use of symbols in the NSL to make meaning of their social life.

The barriers were grouped into two categories; namely the structural-environmental and the process barriers. From these two broad categories emerged several themes under which the respondents' narratives were captured. An important remark made by a Deaf respondent at the very beginning of her interview after she read the informed consent; 'that we should not refer to them as people 'living' with disabilities, but people 'with' disabilities illustrates that the Deaf accept their disabilities but they do not embrace the discrimination attached to it. This finding is consistent with those from a study done in Namibia by Oladottir (2014). Their finding states that Deaf people wish, foremost, to live a "barrier-free" life but not to "fix their disability" to become hearing persons (Oladottir, p. 113). Similarly, the Deaf respondents in this study expressed the wish to live in a society where they are considered equal. At no point did the respondents express a wish to become hearing persons, instead they identified the lack of interpreters in the health setting as the main barrier to communication.

The findings of the current study indicate that despite regulatory and policy frameworks that are in place in Namibia, the Deaf community still continue to face significant barriers when accessing health care. Similar to other studies, we found that lack of communication is the most common barrier affecting the Deaf (Kritzinger, 2011, p.110). All respondents in this study (Deaf or hard-of-hearing key informants) pointed out that the main factor that affect the health-seeking behaviour of the deaf and hard-of-hearing people in Namibia is lack of knowledge on the cultural linguistic characteristics of the Deaf by the health care providers and the community at large. There was widespread concern that when health care providers do not understand the Deaf culture nor sign language, this leads to misunderstanding while it also deprives the Deaf and hard-of-hearing population of important curative and preventative information. Miscommunications in health setting lead to a feeling of being misunderstood as well as errors in diagnosis and prescriptions.

Deaf respondents also observed that sometimes nurses do not believe that they are genuinely deaf and they (nurses) rather ignore them. This is a clear indication of the lack knowledge of the health care providers on human rights as well as the lack of understanding of the Deaf 's linguistic culture and their needs.

The findings also show that Deaf people find it hard to communicate in English, because their first language is sign language and not English. Additionally, the proficiency of English among Deaf people is determined by their level of education. Our findings show that most of the respondents have not attended any formal education while those who attended did not go beyond junior secondary schools. High rate of illiteracy in the official language among the Deaf

community does not only hinder communication with the health care providers but it also makes it difficult for the Deaf people to access information from TV, newspapers, health posters and pamphlets.

This study concludes that the first step to accept the Deaf/deaf would be to acknowledge their culture, language and rights (UNCRP, 2006). Though this study is based on a small sample of Deaf people who are linked to some institutions, it highlights the inequality faced by the general Deaf community daily when accessing health care services and information. The problem of inequity is caused by the interaction between structural-environmental and process barriers that do not only exclude the Deaf from health care services but it also excludes them from accessing the mass media for health information. Consequently, we recommend changes in the broader structural and social arrangements beyond the health sector to promote the inclusion of the Deaf people in all aspects of life in Namibia.

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