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Barriers to Mental Health Access of Deaf Adults in Kenya: A Review

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Abstract

The Deaf (capitalized 'D') refer to those who ascribe to the Deaf community and culture. The majority of adults who are Deaf experience marked difficulties in accessing quality and affordable mental health care in Kenya. Factors that affect these access barriers require a review in order to inform interventions. Systematically, five key databases were searched and three specialized journals identified fourteen papers that met the inclusion criteria. Using an adapted checklist, methodological quality of the articles was assessed and consensus across studies was lacking. The three key factors found for Deaf mental health access challenges were: communication difficulties between mental health care providers and patients, Deaf adults' inaccess to health care in their preferred language and poor health-related information in sign languages. The first factor was overall positively associated with professional interactions and consequently mental well-being of the Deaf. Some studies also found that certain Deaf adults were more likely to have positive professional interactions. The majority of studies were cross-sectional. Some studies lacked appropriate control groups and did not recruit an appropriate range of informants. Several factors were associated with professional communications between Deaf persons and mental health providers, majority of who are Hearing. The role of communication showed the highest consensus across studies. Other factors were involved in further complex interactions such as Deaf cultural aspects. A Deaf-centric type of study on stigma is recommended to identify Deaf-friendly mental health care in Kenya.

Key Words: Deaf, Kenya, mental health access, communication

Introduction and background

There is marked awareness in the well-being of populations, especially cultural groups such as the Deaf population, who classify themselves as part of the Deaf community (Rogers et al., 2016). Health access barriers abound, which is a form of inequality and discrimination (Baumer, Simser & Hannan, 2013). Sign languages are not universal and in Kenya, Kenyan Sign Language

(KSL) is the first and preferred language of the Deaf community (Ndurumo, 2008). KSL is a visual-gestural language that is recognized as a true and complete language, and is, in fact an official and national language in Kenya (Ndurumo, Zanten, & Meereboer, 2009). The Deaf adults, with a capital 'D', signify those who ascribe to Deaf culture which includes sign language, values, behaviors and traditions of the Deaf. Deaf community members look at Deafness as a cultural difference rather than a disability (Rogers et al., 2016).

Deaf adults with psychological disorders usually face a double stigma in accessing mental health care: mental illness and Deafness. The Deaf are therefore a fragile population in terms of accessibility to psychiatric care (Cole & Cantero, 2015). The United Nations recommended provision of quality health care to Deaf and Hard of Hearing (DHH) populations by creating innovative strategies to reduce health disparity of communication barriers (UN, 2006). Kuenberg, Fellinger and Fellinger (2015) contend that the Deaf/Hard of Hearing (DHH) community is a severely under-represented and often unrecognized minority in the health sector. Whilst health care providers are obligated to provide reasonable accommodations for the Deaf according to existing legislations, the reality is that Deaf patients report concomitantly with decreased routine and eventual absenteeism on visits to medical facilities over time (Kuenberg, et al., 2015).

Deaf adults are at higher risk of physical and mental disorders than hearing-able people. A psychiatrist in the UK claims that Deaf patients who lose hearing often present with depression symptoms, while those born Deaf may not experience this deficit but rather the deficiency of public information and vital communication access, therefore are often agitated with anger and anxiety symptomatology (Denmark, 1969). Moreover, some Deaf patients may also present with co-morbid illnesses such as hallucinations (Kuenberg et al., 2015).

The mental illnesses are often not distinguished from ordinary conversations which should be construed as non-pathological experiences, leading to misunderstanding and misdiagnosis. This is in line with the Diagnostic and Statistical Manual, 5th Version (DSM-5), which states that, "In some cultures, visual or auditory hallucinations with a religious content (such as hearing God's voice) are a normal part of religious experience" (American Psychiatric Association, 2013, p. 103). For instance, Deaf adults may portray agitation by fast-paced signing about the

miscommunication difficulties experienced in a typical health care encounter, in line with systemic problems of Deaf cultural suppression by mainstream culture (Kuenberg et al, 2015).

The purpose of the study is to undertake a meta-analysis of the prevailing literature on mental health and Deaf adults in Kenya so as to inform on the scope of the problem of mental health care access.

This study sought to determine the communication difficulties between mental health care providers and Deaf patients, Deaf adults' access to mental health care in the preferred language, the relationship between mental health information and sign languages, correlations between access to mental health and Deaf adults' educational level, use of sign language, age at of Deafness onset and gender and suggest recommendations for stigma-informed Deaf mental health access in Kenya

The study examines in depth the specific areas that need to be addressed in mental health access of Deaf persons, namely: communication, preferred language of mental health care, information in signed languages and Deaf-centric formats, as well as demographic variables depicting the diversity of Deaf adults as disaggregated by education level, use of sign language, age of Deafness onset and gender (Hauser, O'Hearn, McKee, Steider, & Thew, 2010). A Deaf-friendly and stigma-informed care will also be proposed.

This study will inform best practices in inclusion of Deaf adults in mental health care, including advocacy for more Deaf providers. Access to health care services is usually discussed in terms of need, provision and utilization, therefore this study creates a theoretical framework for the attainment of the highest standards of mental health care for Deaf adults

The study also highlights the importance of Kenyan Sign Language and Deaf culture mainstreaming training to psychological treatment providers, most of whom are hearing-able. In addition, increased societal awareness and promotion of public information access including adaptation of contemporary digital technologies in mental health care is of paramount importance to achieve Deaf inclusion.

The research methodology has great ecological validity and may be representative, not only of the Deaf population in Kenya, but also the East Africa countries, which are similar in most social

and cultural aspects (EAC, 2012). To this end, the generalizability of the findings to other populations in the sub-Saharan region, such as the Deaf in Uganda and Tanzania, is possible. However, this study may not fully represent the situation in the resource-rich developed countries, whose infrastructure and legislative frameworks may be greatly developed as compared to the Low and Middle-Income Countries.

Methodology

The study was a review of literature whose significance was to conduct a meta-analysis method to deduce from various studies, both local and international, the challenges of mental health care access for Deaf adults in Kenya. Using document analysis as well as the Wilson method of concept analysis development, the barriers to mental well-being were analyzed from a Deaf cultural perspective (Pendergrass, Newman, Jones, & Jenkins, 2017). This is a descriptive, exploratory, quanti-qualitative study, justified by the fact that there is no approach that works only with either statistical techniques or testimonials. These data types are not exclusive and a reductionist posture in technical and operational terms is hence avoided by using both data types (Machado, Machado, Figueiredo, Tonini, Miranda, & Oliveira, 2013).

There were a number of steps involved in the methodology. From the 5 key databases and the 3 specific journals, the co-investigators identified a total of 14 scientific journal articles whose titles and abstracts were the closest match to the formulated topic of mental health access challenges of the Deaf in Kenya. Next, the issues using an adapted checklist of three paradigms were summarized, namely communication barriers, language barriers and information barriers as well as an additional two paradigms of demographical correlations and stigma. Finally, a systematic analysis was constructed from which emerged the grounded theory of stigma-informed Deaf mental health care access.

Results

From evidence-based data, it is clear that Deaf adults cannot get help for mental health problems when barriers restrict access to general health care (Kuenberg et al., 2015). This is well illustrated in a review article that advocates a reversal of the slogan “No health without mental health” (Fellinger, Holzinger & Pollard, 2012). With limited empirical evidence about global mental health issues of Deaf citizens, the World Federation of the Deaf (WFD), in conjunction

with Dr. Johannes Fellinger of Austria, conducted a survey of Presidents of National Associations of the Deaf and obtained from 44 countries, including Kenya (WFD, 2011).

World Federation of the Deaf Health Resources Initiative Global Survey indicated that 80% of Deaf leaders worldwide report about great problems in access to health care (WFD, 2011). The same survey indicated that two thirds of participants revealed that Deaf adults have more health problems than their hearing counterparts (WFD, 2011). This survey showed over 50% of respondents reported that mental health problems basically emotional disorders and depression were the t common health issues, Flaws in health care delivery compound such issues, with 32 countries indicating that Deaf adults face more difficulty when trying to access health care (WFD, 2011). limited information among health care professionals in the health systems creates a lack of basic health care, a principal cause of mental health issues among Deaf adults (WFD, 2017).

This meta-analysis identified communication difficulties as the most major concerns of Deaf adults' mental health access. This is closely followed by both language barriers and Deaf patients' low information access and literacy levels. Demographic variables such as education level, use of sign language, age and gender interplay to create dynamic correlations. Stigma is a systemic barrier discretely observed. The results of the mental health access challenges of the Deaf in Kenya from the 14 articles are discussed.

Discussion

Communication is arguably the most important factor that may hinder Deaf persons to obtain adequate, timely and relevant mental health services (Steinberg, Barnett, Meador, Wiggins & Zazove, 2006). Professionals may not understand how differently Deaf persons present mental illness unlike their hearing peers. For instance, it is typical in sign language to put together words based on structure rather than meaning, a linguistic phenomenon known as 'clanging' (Michell, 2014). Communication barriers between Deaf patients and health providers often lead to the Deaf patient not understanding the diagnosis, treatment, medication use or side effects (Sheppard, 2014).

Leftridge (2017) reports that Deaf patients may perceive healthcare providers as insensitive because of the lack of eye-to-eye contact. Also, in line with Deaf cultural norms, most Deaf adults in conversations with hearing people usually provide minimal responses including nodding or further questions to a question (Hoang, LaHousse, Nakaji, & Sadler, 2011). This may be misinterpreted by professionals who may not be aware of the socioeconomic and cultural-linguistic backgrounds of the Deaf; The Deaf often utter mono-syllabic responses as a reaction to the perceived power difference. Kuenberg et al. (2015) accurately refer to this as the 'Nodding syndrome' of Deaf adult in typical conversations with hearing professionals perceived to be more powerful, indicating cautious rejection owing to fear, mistrust and frustration by most Deaf persons towards the hearing.

Although barrier-free communication is a basic human right, sign language interpreters are often inadequate and expensive, with this communication support perceived as cumbersome and inconvenient rather than a fundamental necessity (Lowrie, 2015). Access devices such as hearing aids and cochlear implants for the Hard of Hearing are too expensive thus unaffordable (Crowe, 2016). Good lighting and the necessary technical set up is often missing. There are hardly any Deaf relay interpreters, an often necessary ingredient for the Deaf who have not attended schooling and hence the lack of any standardized sign language (Kuenberg et al., 2015).

Communication fluency in sign language even for trained professionals is often lacking, inadvertently leading to misdiagnosis, inaccurate treatment, hospitalization and aftercare (Funeka, 2015; Lieu, Sadler, Fullerton, & Stohlmann, 2007). In addition, ease of access is hampered greatly by lack of powerful and visually accessible signage in addition to the voice-over microphones or audio announcements in most clinical corridors (Kuenberg, 2015). Shackleton (2009) suggested that in Kenya, just as in the rest of the world; most Deaf born into hearing families are unfairly expected to lip-read verbal languages. Nantumbwe (2006) reported that in Uganda, disability, gender and poverty factors interplay to exacerbate communication barriers such that there is distrust by Deaf women, and inadequate interpreters for the 'talking' community to reach to the Deaf.

Shackleton (2009) interviewed 32 Deaf Kenyans whose three most common concerns on health access were: challenges in receiving essential treatment and particularly medicines (12),

communication barriers (10) and fear breached confidentiality as well as distrust of medical staff (4). The regularity of reporting difficulties in communicating and distrust of medical personnel may provide an indication of feeling Deaf persons have towards seeking medical help, owing to their anticipated difficulties eoncounted and fear compromised confidentiality (Shackleton, 2009).

Sign language interpreting is a fundamental means by which Deaf adults can gain access to education and employment opportunities, as well as medical, legal and social services. However, sign language interpreting training and accreditation is non-existent in many developing countries (WFD, 2011). Consequently, Deaf adults often lack access to basic services and opportunities. As with any other minority cultural-linguistic groups, the Deaf consider themselves a tribe with a shared legacy of historical oppression by the societal norm of audism, which refers to the arrangement of typical communication as inclusive of only those with the ability to hear (Bauman, Simser, & Hannan, 2013).

Sign language rights awareness is missing (Kuenberg, 2015). Sign language is the first and often only language of the Deaf, yet it is not widespread in the hearing community; with the Deaf population often sparsely distributed in any population. Socially, sign language is shrouded in taboo in most African societies, with four stigma factors of the Social Impact Scale arising as related to language barriers, namely: social rejection, financial insecurity, internalized shame, and social isolation (Funeka, 2015).

Deaf persons communicate in various ways such as Sign Language, lip reading, Cued Speech, Dialect Sign, and Signed Exact English (Mitchell, 2014). Shackleton (2009) explained that the majority of Deaf persons in Kenya rely on a combination of gestures, writing, speaking, lip-reading as well as 'Home Signs', unique family developed communication system, which makes it difficult to communicate with non-family members or communicate complex issues. Moreover, owing to language barrier as well as low expectations, Deaf persons lack parental and teachers' guidance hence they develop a lifestyle which may seem to permit free sexual interactions (Shackleton, 2009). The free sexual behaviors contribute to unsafe sexual practices which may lead to sexual infections as well as unsafe abortions.

It is interesting to find Deaf persons using body language and facial expression and preferring not to have interpreters, in order to protect confidentiality. Further, in a study on HIV care access in Uganda, Deaf persons were found to experience feelings of distrust and dissatisfaction towards the health care system and hence reluctance in seeking testing and treatment services particularly in regard to HIV (Nantumbwe, 2006). It was noted that excellent, high professional-standard, specialized mental health services by culturally competent staff is missing in most Kenyan mental health clinics (Kuenberg et al., 2015).

Public and private information on mental health care that is considered 'common sense' to hearing people is not so common in Deaf circles due to inaccessibility to informal and incidental knowledge, such as that automatically enjoyed by hearing persons from those around them and through radio and television soundtracks (Shackleton, 2009). This environmental access barrier leads to a generally low fund of information by the Deaf as compared to the hearing. There is general low health knowledge and inadequate uptake of communication technology such as online prevention programs in sign Languages such as Kenya Sign language video tutorials by the Deaf, which compounds quality mental health care access (Kuenberg, 2015; Kushalnagar, 2015; Lowrie, 2015).

Deaf adults struggle to get information in times of emergency due to natural disasters. Recent examples of such catastrophes are such as those in Nairobi, Kenya and Texas, USA, where there was an amateur sign language interpreter who misled Deaf audiences on the news broadcast and hurricane Irma respectively (Michael, 2013; Okumu, 2015). In Japan, a group of Deaf adults at the Deaf Club were affected by tsunami as a result of inability to see warnings to evacuate. Similarly, in Haiti, a number of deaf children in attempt to escape a collapsing classroom, landed in a location where accessing food or water for many days was difficult yet there were food distribution sites (WFD, 2017).

There is no protective policy in most countries for Deaf rights, and low general health information is the norm rather than the exception (Crowe, 2016). In a study in Uganda, discrimination of Deaf women seeking HIV help is in three levels: institutional, individual, and interactional. Service providers dictate info methods and channels for information delivery to deaf women and there are hardly any employable skills to reduce economic dependence with its

concomitant illiteracy (Nantumbwe, 2006). A pilot survey in Swaziland revealed that Deaf experienced difficulties in communicating with healthcare facility personnel which resulted in minimum utilization of HIV voluntary counseling and testing services (Nora, Aisha, Phindile, Sarah,, Shelia,. 2006).

Multidisciplinary team workers in mental health institutions do not inform important steps of the patient health care with the Deaf person, but rather prefer to inform the caregivers, which leads to the Deaf person feeling disrespected and undervalued (Ohre, 2012; Ohre, Tetzchner, & Falkum, 2011; Tiejo, 2016). In fact, the model of 'Social counseling' to increase information access and informal contacts' access is missing in most settings, as well as adapted informational leaflets in pictures and short notes (Kuenberg et al., 2015).

The close-knit Deaf community has a small degree of separation between its members, and this phenomenon is well known in typical Deaf studies as the 'grapevine' (Shackleton, 2009). While it exists for social control, however, it also ensures no confidentiality amongst Deaf persons of the health status of individuals. Deaf persons often have to navigate through creating and protecting their identity within the Deaf community as well as the hearing community, often with alliances and dalliances similar to a typical large family (Shackleton 2009).

Sensitization on Deaf culture is inadequate, with the obstacles that divide, oppress and exclude still existing instead of factors to unite, liberate and belong. Deafness is not a disability, but a diversely different culture (Funeka, 2015). As argued by Mitchell (2014), delivery of specialist care with trained professionals who can interact with the Deaf is hardly available, as well as screening tools which are Deaf-friendly in terms of language and information presentation.

Therefore, development of referrals and resources for the Deaf to get appropriate mental health treatment and assessments is recommended (Mitchell, 2014). Further, there is need to develop Culturally Affirmative Mental Health Specialist training for professionals who work with Deaf individuals which would include cross-cultural communication skills, skills working with interpreters, and skills in selecting and designing culturally responsive and reliable treatment interventions (Fileccia, 2011).

Most Deaf adults in Kenya have a basic education and some technical skills to assist in getting work (Shackleton, 2009). It is assumed that written language is fully understandable by Deaf

persons who have attended schooling, which ignores the fact that written language is based on the ability to hear. Most Deaf persons struggle with technical terms and the low educational outcomes from typical Deaf schools which lack resources for remedial teaching (Margellos-Anast, Estarziau, & Kaufman, 2006). In addition, most Kenyan Deaf are not familiar with Kiswahili because it is not taught in residential Deaf schools. English is not the first language for the Deaf adults, and Kiswahili is replaced with Kenyan Sign Language, yet English and Kiswahili are taught in regular schools (Shackleton, 2009).

Deaf low literacy in the majority verbal languages and their concomitant isolation in African communities is similar to that of most Asian communities which classifies Deaf persons as belonging to the lowest group of 'untouchables' in the caste system, exacerbating the problem of inadequate community support (Crowe, 2016). In Uganda, there is isolation, neglect and exclusion from recognition of the Deaf; illiteracy in sign language and inaccessible health care due to poverty (Nantumbwe, 2010). Language is the key to developing identities and understanding the world, which is often limited in this population (Leigh, 2009).

In a study on HIV perceptions in 32 Deaf Kenyans, speaking and lip reading (6; 18%) was the means most commonly used by the participants to communicate with their families (Shackleton, 2009). In the same study, a combination of speaking and lip reading and the local language (5; 16%) was common, with notable gestures (13%) and a combination of speaking and lip reading and some KSL (4; 13%) while KSL being the exclusive communication means of communicated (6%) was the least reported. . In the same study, participants with other Deaf family members reported the use of KSL, and lip reading as well as gestures (Shackleton, 2009).

Shackleton (2009) further reported that (13%) participants reported communicating at home using KSL combined with speaking and lip reading, local language as well as gestures. Additionally, 22%) participants relied on unique combination of gestures, writing, speaking and lip reading and 'Home Signs' (Shackleton, 2009). This implies that Deaf persons' families may not know KSL, hence not able to communicate complex messages with their children; with important implications because Deaf persons may miss out on the passing down of familial and socio-cultural values that are not communicated in a language they fully understand (Shackleton, 2009).

At a Health Center for the Deaf, Linz, Austria, as of 2011, 85% of the total 1,900 patients who had ever attended the center since it opened in 1991 were prelingually Deaf; and were evenly distributed throughout all age groups as shown below:

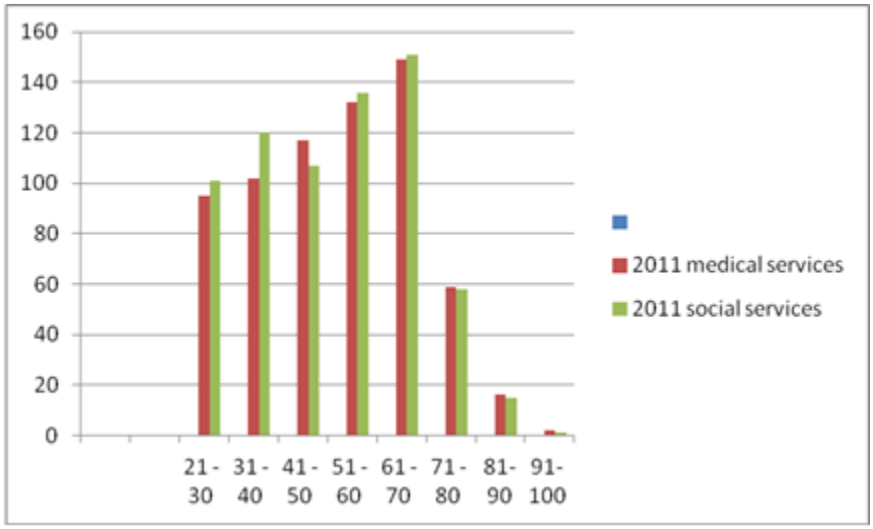

Figure 1: Age Distribution of Deaf Clients Seeking Medical and Social Services at the Health Centre for the Deaf Linz, Austria in 2011

Traditionally, Deaf women do not fully access mental health services; as a result, they are faced with issues such as access to essential self-knowledge on coping with psychological symptoms; inadequate communication, support and level of involvement with biological families; competing cultural demands; health concerns; and coping with chronic mental illness (Corbett, 2003). Health information and personal awareness are often generally lacking (Shackleton, 2009).

This preliminary study emphasizes the need for comprehensive examination of health and services for Deaf adults around the world. National Associations of the Deaf carry a responsibility, through the WFD Congress resolutions, to initiate national studies to determine the extent of the problem; the results of these reports can be submitted to the World Health Organization (WHO) (WFD, 2011). The grounded theory developed by the co-investigators rests on the four principles of access, namely affordability, availability, relevant and timely mental health services for the Deaf in Kenya.

Affordability is a major factor to ensure mental health access. Fellinger (2012) informed of Upper Austria's legislation that ensures that the government's social welfare covers the additional of up to 85% of the total costs, which are primarily incurred because of the extra time needed when providing medical and social services for the Deaf, with the Deaf legally entitled to demand-oriented services with direct or interpreted communication support. The majority of Kenyan Deaf adults cannot afford health insurance. The World Federation of the Deaf indicates that Deaf adults are early adopters of new technologies which have the potential to break down communication barriers (WFD, 2011).

Conclusion

This paper presented a compelling case of the challenges of limited access to mental health care of the Deaf in Kenya concomitant with the burden of health problems of Deaf adults (Kuenberg, et al., 2015). It therefore concludes that the communication, language and information barriers that Deaf adults may face include complex aspects that may interfere with the diagnosis and treatment of psychological disorders. Communication barriers are the major challenge that affects both the interaction between the Deaf, mental health providers as well as the other caregivers. The Deaf use Sign Language yet are expected to develop other skills like lip-reading, which are not universal. The ineffective communication may lead to misdiagnosis and intervention of various psychological disorders. Similarly, the Deaf do not easily and adequately access information.

Kuenberg et al., (2015) suggested various ways that can improve access to health care; they include provision of powerful and visually accessible communication through the use of sign language, implementation of communication technologies and cultural awareness trainings for health providers. Additionally, programs that raise health knowledge in Deaf communities and models of primary health care centers for Deaf adults are also presented. It is essential that published documents can be presented to the Deaf in relevant settings to help the Deaf realize their right to appreciate the highest attainable standard of health (Young, & Hunt, 2011). There is dire need to include the voice of the Deaf in mental health sector as a way of creating awareness on health care access as well as reducing the communication barriers between the Deaf, the hearing-able as well as mental health service providers.

The investigators suggest a Deaf-centric and Deaf-friendly model of getting healthcare in specialized mental health settings which emphasize a trustful relationship with barrier-free communication and respect for Deaf culture can be considered a basic right of Deaf adults (Kuenberg et al., 2015). For further study, a deeper investigation of the mental health care burden in the Deaf community is urgently needed so as to ease the suffering of the many Deaf Kenyans who cannot access affordable, accessible and adequate health care. Psychology assessments, therapies and other interventions adapted for Deaf populations need to be documented to create best practices and ensure improvement through monitoring and evaluation.

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