Methodological Considerations of Clinical Research with Adults who are Deaf in Kenya

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Abstract

Clinical research with adults who are Deaf in Kenya is nascent and with a loose array of methodological considerations detailed by various authors (Kakiri, 2019). Indeed, Deaf clinical research considerations are necessary for viable outcomes. A desk review of Deaf studies found that there are certain global sets of principles on ethical research and clinical practice considerations with Deaf populations. The document analysis method was used in this literature review, revealing the need for modifications to the standard protocol including the use of a visual-spatial language (Kenyan Sign Language) rather than a spoken language (English), as well as coding and procedural variations from the standardized protocol to fully accommodate Deaf culture. The use of Deaf research assistants or/and the researcher's reflexivity as a Hearing signing researcher are certain key component of field research considerations. Since the Deaf are a marginalized sub-set of the population, paradigmatic as well as methodological considerations are recommended for effective clinical research in Kenya.

Key words: Clinical research methodology; Deaf adults; Kenya

Overview of legal and demographic frameworks of Deaf clinical research in Kenya

Dr. Andrew Foster, largely considered the father of Deaf education in Africa, delineated that an individual who self-identifies as “Deaf” (with an initial capitalized letter “D”) belongs to the Deaf community; members who share: a complete (or partial) inability to hear; a signed language; similar education in specialized Deaf schools; and a shared cultural and social history (Foster, 2001). This is in contrast to the medical model that uses the terms ‘hearing disability’ or ‘hearing impaired’, which implies a lack or loss (Naik, et al. 2013). Contrariwise, an individual who is ‘deaf’, but does not self-identify as ‘Deaf’ will likely primarily, if not wholly, communicate using listening and spoken language, and may sometimes be referred to as oral deaf (Naik, et al. 2013).

Comprising a distinct minority of the population, Deaf individuals typically experience stereotyping and prejudice from the hearing people in society which may create severe social, political and economic disadvantages for this group (LaBelle, Booth-Butterfield, & Rittenour, 2013). The Deaf person manages both an individual and a collective identity in the Deaf community, which provides a sense of heritage and pride (Landsberger, et al. 2013). As a result of the tendency to be viewed by out-group members more negatively and homogenously, the Deaf receive those stereotypes held for the general realm of disability: incompetent, sick, unproductive, burdensome, unattractive, hypersensitive, bitter and not independent (LaBelle, et al. 2013).

The Deaf community culture, with its hallmark of sign language, seems to be a haven from the harsh reality of Deaf people navigating a largely hearing and speaking world (VanArkel, 2005). The Deaf community comprises all the individuals, organizations and entities that ascribe to the Deaf culture (Chatzopolou, 2014). Smit (2009) notes that the Deaf culture features, just like any minority group, can be identified as collectivism, loyalty, and a generally

suspicious and mistrustful attitude towards the majority hearing people. Furthermore, people who are Deaf have distinct and common ways of interrupting in conversations or gaining attention, such as touching people or gently moving their hands in front of them (Gill & Fox, 2011).

African countries fall far behind other nations in addressing disability issues; in fact, Yokoyama (2012) contends that the African Decade of People with Disabilities held by the African Union from the year 2000 to 2009 is now extended to 2019 since most African countries are still in the process of achieving full participation, equality, and empowerment of Africans with disabilities. Around 80% of the globally estimated 1 billion people with disabilities live in developing countries, and also tend to be the poorest and least socially mobile (WHO, 2012).

Nevertheless, the three East African countries sharing similar social and cultural backgrounds, namely Kenya, Uganda and Tanzania, have so far adopted the United Nations Convention on the Rights of People with Disabilities (UNCRPD) which is of great importance to foster universal human rights and inclusion of PWDs (EAC, 2012; UNCRPD, 2006). The UNCRPD definition of disability represents a hallmark shift from the medical to the social model of PWDs, who are now seen as people with full citizenship rights to exercise meaningful social change (UNCRPD, 2006).

The East African Community has also adopted a disability policy that explicitly mentions the need for adequate specialized psychosocial and counseling initiatives for social protection, care and support of PWDs (EAC, 2012). EAC has so far witnessed significant achievements, especially in the development of laws, collection of statistics and in allocation of funding, such as the Kenya's Disability Act of 2003 (KLHRC, 2015). The Kenyan Constitution 2010, Section

4 (b) states that people with disabilities are entitled to access institutions and facilities that are integrated into society to the extent compatible with the interests of the person (KLHRC, 2015).

Kenyan Sign Language is now a national language, as well as an official language of Kenya and used in Parliament; the recently launched Programming Code legislation has also increased media communication access of the Deaf, and inadvertently also raised visibility of Kenyan Sign Language in the national rhetoric (KLHRC, 2015). The Kenyan Deaf community is vibrant with its active lobbying for excellent standards, which are often missing, such as recently when an amateur sign language interpreter misled Deaf audiences on the news broadcast (Okumu, 2015).

Throughout Kenya, there are myriad registered associations of the Deaf in all major cities and many municipalities, and there are 41 registered schools for the Deaf within the country (Ingstad & Grut, 2006). However, those who are Deaf in the society are often hard-to-reach because there is often family shame. In addition, the dismal perception by most policy makers that Deafness is a low-incidence disability thus unimportant, therefore greatly hinders service quality to this highly marginalized group with wide regional dispersion (Shackleton, 2009).

Different sources vary in their estimates of the deaf in Kenya; this controversial issue seems to aggravate the problems of the already under-served and often under-represented Deaf community (Kuenberg, et al. 2015; Shackleton, 2009). For example, as stated by Wilson and Kakiri, *"exact figures are impossible to obtain because we do not keep accurate statistics in the country"* (2010, p. 279). Poor transport, inadequate telecommunication systems, and a tendency of families to sequester the deaf people in their homes place considerable barriers to obtaining adequate figures (Hochgesang, 2006; Kakiri, 2012).

Method

A review of the Sign Language Communities' Terms of Reference (SLCTR) principles developed by Harris (2009) was done in light of the primary investigator's desk review and field research with Deaf adults in Nairobi and Kajiado counties, Kenya. In line with qualitative methodology guidelines, the researcher's role is of paramount importance (Gill & Fox, 2011). The researcher, who is also a psychologist, is also responsible to do own self-work on how personal Hearing status, gender, ethnic background, and communication style impact the research relationship.

The investigator used a correlational, mixed method design to compare psychological symptoms of depression and access to social support of Deaf adults in Nairobi and Kajiado Counties of Kenya. A qualitative style of researcher-administered data collection was used, according to the Sign Language Community Terms of Reference Principles outlined by Wilson (2009). Reflection on the investigator's learning on the local Deaf community, its activities, and leadership as relates to the 'triple jeopardy' of being black, deaf and mentally ill as described by Corbett (2003).

The multistage proportionate stratified sampling method used in the study has great ecological validity and may be representative, not only of the Deaf population in Kenya, but also of those in other East African countries, which are similar in most social and cultural aspects (EAC, 2012). To this end, the generalizability of the findings to other populations in other regions may be possible such as to Deaf people in Uganda, Tanzania, as well as most other Deaf communities in Sub-Saharan Africa. However, this current study may not fully represent the situation in the resource-rich developed countries, whose Deaf infrastructure and legislative

frameworks may be greatly developed as compared to the Low and Middle-Income Countries (LMIC) of the majority world such as Kenya.

This limitation is mitigated by the Primary Investigator (PI) traveling to two different counties so as to glean the various perspectives of the Deaf adults in various Deaf communities in Kenya, which concurs with best practices to avail ambulatory mental health services as close as possible to the Deaf community (Fellinger, 2012). The sample is drawn from urban low & middle-income, urban informal settlement, rural-urban, and rural settings of the greater Nairobi region of Kenya.

Results

The Sign Language Communities' Terms of Reference (SLCTR) principles outlined by Wilson and Kakiri (2011), who delineated the best practices for collaborating with Deaf communities in developing countries, are the philosophical underpinnings of this review. According to the first principle by Harris (2009), Sign Language Communities' Terms of Reference (SLCTR), the authority for construction of meaning and knowledge lies with the sign language community by making it "by, for and with the Deaf". For instance, the visual element of sign language has an increased emotional impact in therapy because of the re-enactment style used more often than past narration (Gill & Fox, 2011).

Secondly, the sign language community values should be fully incorporated in all interactions. These include deference to the Deaf culture as defined by the indigenous Deaf community members themselves, as well as interactional values for instance always starting with specifics and ending with the general conclusions. Thirdly, the worldview of community members as they would like to be represented should be carefully considered in all negotiations

or dealings that impact community members; this also implies that research team members ascribe to norms of the Deaf community (Harris, 2009).

Fourthly, recognizing diversity in experiences, understandings and way of life in the Deaf community; this principle also concerns the close-knit nature of the community and implications for confidentiality and anonymity of research participants. The fifth principle states that Deaf sign language users are involved in every step of the research process and not just as consultants, including planning, data collection, coding, analysis and dissemination. Research evaluation and validation should be accessible and representative, including views and perceptions of the critical reference group.

The sixth principle is that decisions of research procedures: what, how and why, lie with the sign language community. In addition, the specific Deaf community research considerations will be followed, as per the Centres for Disease Control and Prevention (2006) recommendation for Community-Based Participatory Research (CBPR), whereby culture and community involvement is consciously considered in research methods.

Discussion

In this current study, the Deaf-specific ethical guidelines included survey translation and back-translation of the English items into Kenyan Sign Language, working with Deaf community partners to prioritize survey topics, adding Deaf-specific items to create context, developing a survey dictionary for identified technical psychological terms, and conducting in-depth individual cognitive interviews to evaluate the survey. Ndurumo (2008) alludes to the need for effective policy formulation for full inclusion of Deaf people.

Simple English was used to enhance readability of the Informed Consent form by participants, in line with cultural sensitivity to the educational level and English competency of

typical Deaf Kenyan adults (Shackleton, 2009). This is in line with Landsberger, et al. (2013) assertion that culturally-sensitive evaluation of individuals in Deaf populations involves a thorough assessment of language modality and language fluency, deafness/audiological history, and cultural identification.

In Deaf-centric research methodology development, ethical considerations of informed consent, confidentiality, standard of care, autonomy, participants' vulnerability, and procedures are not universal, especially when working with signed language communities (Hochgesang, 2015). 'Deaf grapevine' is a concept that means a network of personal communication by Deaf people that is often a rumor, secret or private message (Stiles, 2016). The idea of confidentiality is less cherished among Deaf and Hard of Hearing individuals than it is among the hearing; the Deaf grapevine acts as a social control by enhancing group cohesion, although it may also be susceptible to inaccurate information (Shackleton, 2009).

Other ethical considerations of the Deaf community include not transforming the setting with outside languages, values and artifacts; an example being the inadvertent tendency of a Hearing researcher to impose Hearing norms, which may be considered more superior to Deaf norms by the Deaf community members. Ndurumo (2008) alludes to the special place of language in interpreting KSL in African contexts. For instance, turn-taking in a typical hearing conversation may involve several speakers speaking at the same time, while in the Deaf community, there is strict visual turn-taking which is sequentially organized. Therefore, using Hearing norms imposed in conversations to the Deaf may be seen as very patronizing by the Deaf people.

The Deaf may suffer environmental barriers of low health literacy due to inferior education and language access barriers, therefore may not adequately appraise the research

benefits. This limitation was counteracted by the investigator's own clinical judgment from the observational data throughout the interview session, as well as corroboration through the research assistant team of Deaf and hearing mental health providers. This is in line with recommendations on counseling the Deaf, whereby communication is a key area requiring more clarification and a precise determination, while not dehumanizing the individuals who need the services (Connolly, et al. 2006).

In the approaches used to answer research questions, the analyses will inherently conflate the issues of treatment and clinical research – a key concern, according to Anderson (2016), associated with the ethical issue of therapeutic misconception. However, it is important to recognize here that clinical research is not analogous to treatment and that this important distinction, therefore, influences any sort of generalization to the research environment (Anderson, 2016). Therefore, assessments constituted first-stage interventions, with a pre-referral intake assessment aimed at pointing to further clinical psychology interventions if necessary (Aboge, et al. 2015).

The recruitment of Deaf research assistants on condition that they are trained is in line with the UN Convention on the Rights of People with Disabilities, which calls for equal rights in participation in political and social activities on all levels for people with disabilities (UN, 2006). Involving people with disabilities in the research process is comprehended as a question of empowering disabled people (being in a learning process and in a decision-making position) in line with the transformative paradigm of this current study. Moreover, framing good research questions, developing a good design and ensuring that results are communicated to, and will be of use to the people that the research concerns, is of ultimate importance (Ingstad & Grut, 2007).

Conclusions

This current study raises an important methodological contribution of research with the Kenyan Deaf. The Deaf community has recently outlined various terms of reference for engaging signed language communities. These ethical considerations are of paramount importance, since it is situated in the transformative paradigm which seeks to empower the current study's users. It also demarcates the role of the Primary Investigator (PI), to engage in reflexivity, as informed by principles of qualitative research (Ingstad & Grut, 2006). Inadequate recognition and marginalization of people with disabilities in Kenya, particularly the Deaf (capitalized letter 'D' denoting culturally Deaf) who use Kenya Sign Language (KSL), remain the biggest contributing factors to inequalities, stigma, discrimination and exclusion. Therefore, clinical research needs to be linked to adequate resources for clinical psychology support for research participants.

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