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Methodological and Ethical Issues in Research with Deaf Persons: Experiences from Uganda

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Abstract

This paper examines the key methodological and ethical issues on the appropriateness of applying research methods designed for the hearing population while conducting research on these individuals. Based on fieldwork conducted in Uganda in 2012 and 2013, this qualitative study was informed by the interpretive theoretical proposition, which provided an overall orienting lens through which the findings were discussed. A total of 42 DHH persons were interviewed while three Focus Group Discussions (FGDs) were held with selected individuals. The study shows that the design and application of the traditional research approaches and methods of data collection and analysis to studies involving DHH persons present a host of methodological and ethical dilemmas largely arising from its unique social and linguistic characteristics. The overall conclusion is that researchers on issues involving these 'silent' individuals should be as flexible and dynamic as possible while applying the universally used research methods and techniques.

Introduction

The plight of the Deaf and Hard of Hearing (DHH)[1] persons in developing countries is one of the least considered subjects by social scientists. Faced with a general paucity of information on the numerical strength of such persons in most Sub-Saharan African countries and the fact that such persons are often geographically located far apart from each other, this 'silent sub-population' also faces an ever increasing risk of becoming victims of varying forms of violence and neglect because of their disability (Ghobara, 2004). The threat posed by global warming and the emergence and, in some cases, the re-emergence of infectious diseases such as HIV and AIDS and *ebola* further

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worsens their woes and keeps them in their lower echelons of the socially vulnerable communities. The situation is exacerbated by the scholarly definition of DHH persons, with opinion heavily divided on the extent to which social researchers must take into account the intricacies of extrapolating the medical model of disability to encompass the social constructions of deafness (Albrecht, 2001; Lee, 2010; Agar-Jacobsen and Roberta; 2010; Miyako, 2010).

In Uganda, efforts to promote and protect the basic human rights of the deaf community were boosted when the country became the one of the first ones to ratify the 2006 United Nations Convention on the Rights of Persons with Disabilities (PWDs) in 2006 (UBOS, 2012). Earlier, the Uganda Constitution (1995) had been enacted to recognise the rights of Persons with Disabilities (PWDs). Specifically, section XXIV of the constitution compels the state to promote the development of a sign language for the deaf. The country is also one of those with a fully fledged ministry that deals with issues of PWDs. Other legislative frameworks that deal with issues relating to the DHH community in the country are contained in the Local Government Act (1997), the Communications Act (1997); the Universal Primary Education Act (1997); the Uganda National Institute of Special Education Act (1998); the Land Act (1998); the National Council for Disability Act (2003); Equal Opportunities Act, (2006) and the National Policy on Disability (2006).

Despite the above legislative framework however, the DHH sub-population remains one of the socially vulnerable communities who are yet to feature prominently on the social research agenda. Although government and civil society activists have over the past two decades or so, made commendable efforts to promote the interests of this community in the social, economic and political spheres of influence; there is little empirical evidence to suggest that academicians and other researchers have ventured into issues related to this 'forgotten tribe' (Murangira, 2005). In addition to the limited literature available on this subject, researchers face a multiplicity of conceptualisation and methodological dilemmas. The few studies conducted on the DHH community point to a host of such limitations as key that often stand in the way of conducting such social inquiries (Obasi, 2008; Cline & Mahon, 2010). In an assessment of the sexual and reproductive health needs of the DHH community in Ghana (Mprah 2013) presents a host of ethical concerns relating to protecting the privacy and confidentiality of participants and obtaining informed consent. The author also points to methodological challenges arising from misconceptions and the sensitive nature of Ghanaian culture. This paper[2] is therefore, aimed at examining the methodological and ethical issues that researchers face in designing, implementing and analysing studies involving this sub-population, focusing on the DHH persons living in central Uganda.

Methodological Issues

The theoretical positioning of the study of which this paper was written was drawn from the interpretive theoretical proposition that reality is not 'out there' but in the minds of people; reality is internally experienced, is socially constructed through interaction and interpreted through the actors, and is based on the definition people attach to it (Sarantakos, 2005). Specifically, the social identity theory (Stets & Burke, 2000) and the interpretive theories of social constructionism and symbolic interactionism (Blumer, 1969) were used for this work.

A phenomenological study design was adopted for this study with the view to focus not on the life of the individual subjects of inquiry but rather, on a concept or phenomenon (HIV and AIDS communication, in this study) as described by Creswell (2009). In line with Creswell's proposition, a phenomenological design helps the researcher understand the meaning of experiences of individuals about this phenomenon as opposed to focusing on the study subjects themselves (p.51). Accordingly, individuals who have experienced the phenomenon (the DHH persons) were selected and, through various techniques of inquiry, provided the raw data that was analysed into 'the essence of the experience' (Creswell 2009).

The study areas and respondents were purposively sampled (Sarantakos 1997), a procedure that enabled the researcher to use his judgment to purposively choose only those areas and respondents, who, in his opinion, were thought to be relevant to the research topic. The technique was also chosen to ensure maximum variation of study variables such as rural and urban settings, profession, age, marital status, level of education, additional forms of disabilities, values and beliefs, cause and age at which deafness occurred and family backgrounds until data saturation could be achieved. However, there were circumstances in some study sites where the researchers had to adopt snow ball sampling by relying on the knowledge of the insiders (within the deaf persons' community) to locate the target respondents. Overall, a total of 42 DHH persons were interviewed during the data gathering process. In addition, three Focus Group Discussions (FGDs) were also held. Although I had planned to interview 50 DHH respondents, I used my judgement to decide to stop the data collection process after realizing that the data being gathered was repeating and there were no new themes or essences that were emerging from further interviews.

Data collection

An interview guide in the form of a list of questions on the specific objectives (themes) for the study was used. The issues discussed included:

- Deaf identities and experiences of living as a DHH person in a multicultural environment;
- Sources of information and perceptions of HIV and AIDS communication;
- Constructed meanings from HIV and AIDS communication;
- The influence of significant others on DHH persons' response to HIV and AIDS communication;
- Other HIV and AIDS communication related issues.

All the interviews and Focus Group Discussions (FGDs) were conducted in the respondent's respective local language under the supervision of the lead author of this paper with the help of experienced research assistants and Ugandan Sign Language (USL) certified interpreters between September 2012 and July 2013. Before starting any interview, the researchers fully explained the purpose of the study in the local language (with simultaneous USL translation) to the respondents and assured them of confidentiality, anonymity, voluntary participation and the right to withdraw from the proceedings at any stage of the interview. The lead author—who is not DHH but has since learnt the basics of the USL--also ensured that respondents who accepted to participate in the study signed consent forms to confirm that they willingly volunteered to take part in it and fully understood its objectives and scope. In cases where the respondents were illiterate and could not sign the consent forms, the lead author had to strike a compromise between the ethical codes and situational common sense (Mattila 2011) by explaining to the respondents the need to give consent by nominating one of their significant persons to sign on their behalf; which they obliged to. During each of the 1-2 hour interview sessions, one sign language interpreter interpreted the finger spelling and lip movements of the respondent(s) while the second monitored the non-verbal emotions and other reactions in addition to writing field notes. The interviews were audio-recorded (with a few video recorded), with the participants' permission and signed consent.

Data analysis

Audio and video recordings, field notes and transcriptions from the discussions formed the data for this study (Wickenden et al 2012). The video tapes were converted to DVDs using Adobe Premiere Pro CS44.0.1 video software (Mprah 2013). These were, together with the voice recordings transcribed to text format which was used to develop the codes using Nvivo 10 qualitative analysis software. The lead author organised the codes into themes, based on the specific objectives of the study. It was on the basis of the themes (as presented in the results and discussion section of this paper) that the analysis and interpretation of the study findings was done phrase by phrase (Miller 2005).

Ethical and validity considerations

Fully aware of the limitations of qualitative research in which the researcher is often in direct contact with people (Marlene 2001), the lead author tried to avoid the 'good will' trap (Barron, 1997) in which the interviewer has the role of a professional as well as sympathetic fellow being (Nasman & Eriksson, 1994). Research on vulnerable persons (including the DHH) in some European countries has for some time been influenced by the normative rigor and ethical concern based on the maxim: "Nothing about us without us" (Barron, 1997). This entails working with the DHH persons throughout the various stages of the study process—including their involvement in validating some of the study findings. In some respects, I took this dictum into consideration by not only involving DHH individuals in helping me understand critical social processes that underlie "D/deafness" but also as part of the team that mobilized the respondents for personal interviews and FGDs and in validating some of the study findings. Besides, dissemination was done by the lead researcher in selected communities to provide feedback to the DHH community through workshops using videos with simultaneous USL interpretation. Further, to manage one of the most widespread criticism of qualitative studies, namely; the view that their results cannot be generalized to a wider population and the sample size and extent to which data saturation is reached are not quite convincing; rigor was attained by double-checking and in some cases, focusing on how the analysis of the data evolves into a persuasive narrative—a procedure described by Patton (1980) as cited by Creswell & Miller (2000) as one where qualitative analysts return to their data "over and over again to see if the constructs, categories, explanations and interpretations make sense."

Results and Discussion

Theme 1: Methodological issues in research on DHH persons

The core issues addressed by this paper emerge from the range of methodological and ethical issues encountered while conducting research on the DHH community in central Uganda. The findings of the study showed that conducting research on this sub-population poses as many challenges as those surrounding the choice of the research subject itself. Whereas most researchers might be experienced at choosing research designs, study approaches, data collection and analysis tools for many subjects of investigation; social inquiry into this area brings to the fore a host of new dilemmas ranging from the interaction between the informants and the interviewer and sign language interpreters (non-DHH) to the application of research instruments. Overall, the issues (sub-themes in this context) discussed in this section of the paper include:

- Complexities in sign language use;
- Translational procedures;
- 'Bias' among researchers;
- Conducting focus group discussions;
- Validity of sampling.

Complexities in using sign language[3]

Researchers investigating issues involving the DHH community in Uganda will certainly come face to face with the reality that the country is one of those in Sub-Saharan Africa whose sign language is not only in its formative stages but also rapidly evolving with time. Although most disability civil society activists and the significant persons[4] who take care of the DHH persons believe that the 'Ugandan Sign Language (USL)'[5] is now fully recognised by the national constitution and widely used by the largest proportion of the sub-population countrywide, this study showed there are several DHH individuals who understand its alphabet. Although this medium of communication involves the use of a visual language expressed with eye movement as well as facial expressions, its use and adoption in some areas has been hampered by the absence of formal structures to harness its 'vocabulary' at family and educational levels. The high illiteracy levels coupled with the limited numbers of formal schools for deaf children in the rural areas have particularly combined to ensure that a section of the Ugandan DHH community, has like in other developing countries, developed their own native gestures for signing and lip-reading that formally trained sign language interpreters can understand.

Therefore, whilst most researchers on this population may argue that the USL is widely ‘spoken’ by the largest proportion of the DHH community (especially those living in urban and peri-urban areas), its adoption and use in the countryside is largely based on a set of informal alphabets whose finger spelling tells more about the local beliefs and value systems of the community itself than the message it intends to deliver. In effect, the development of most of the facial expressions, movement of the hands, eyes, face, lips and body movements of the language user is more an outcome of an unconscious and often long-term trial and error experiment than the conventional formal socialisation process.

Other issues that complicate the use of USL highlighted by this study include the shortage of publications and videos in sign language (for those who can use them), limited support to research and development of the language and the difficulties in its use by DHH persons with multiple handicaps and special needs such as the deaf blind. In addition, the study findings also showed that there is still limited awareness of USL understanding among persons without hearing impairments—who form the larger section of society.

The above findings therefore, mean that researchers on this sub-population would face multiple challenges in collecting, analysing and interpreting the data. Although there are presently many qualified and experienced USL interpreters in the country, hiring the services of such persons poses two immediate methodological sub-problems: Firstly, the level of expertise and training of the sign language interpreter hired is always likely to affect the quality of the data collected. Depending on the training background, experience and probably intention of the interpreter, the information obtained might not be of sufficient quality to be representative of the points of view which are valid within both the DHH and academic community. Secondly, the physical appearance, expertise and posture of such a sign language interpreter might create cultural incompatibility and signing disparities which might in turn affect the extent of disclosure by the respondent. In this way, a lot of vital information could be lost in translation and other related processes.

Besides, even if Sign Language is certainly the primary language DHH persons in most parts of the world, the disconnect between the way it is used by such persons and the hearing public (the majority who have no hearing impairments) in Uganda is a major obstacle for researchers. The study findings show that most respondents have limited USL 'vocabulary' at family level; a situation that has given rise to a variety of 'home-grown' sign language symbols and systems. Uganda is one of those countries where sign language does not have official status in any formal institutions—such as schools and hospitals. Even in the few available special schools for the deaf such as Ntinda school for the deaf on the outskirts of the capital city, Kampala, where it is used in classrooms and virtually all activities, the school management said they face problems of insufficient training of their staff in USL.

Findings of the study were consistent with those of others earlier done on this sub-population. While examining the issue of deafness in sub-Saharan Africa, Nassozi & Moores (2003) discuss similar personal, household and institutional challenges to conducting research in Gabon, Angola and Chad. Similarly, Mprah (2013) also alludes to similar issues while studying the sexual and reproductive health needs assessment of the deaf people in Ghana.

Translational procedures of sign language

Closely related to the challenge of using the USL is that of how to translate the data obtained from the DHH informants in a reliable and acceptable manner to the wider community of researchers. Given that a sizeable proportion of DHH persons communicates more often with their significant persons than any other community, this study showed that researchers on this sub-population face a daunting task of ensuring reliability of the translations made by the sign language interpreters hired for the data gathering exercise. The adoption and strict adherence to measures aimed to ensure that all interviews are translated using a standardized criteria--regardless of the original language used—is therefore critical.

This case was demonstrated during one of the FGDs held in Wakiso district (neighbouring the capital city, Kampala) during which, an experiences USL interpreter hired for the study and had for long been involved in the implementation of HIV and AIDS prevention and management programmes among DHH persons admitted to failing to understand the meaning of some of the 'expressions' of a participant during the discussion as shown by the following conversation:

> **USL interpreter:** Do you know HIV/AIDS?
> **DHH respondent:** Gestures
> **USL interpreter:** I mean, HIV/AIDS
> **DHH respondent:** Gestures again, smiling
> **USL interpreter:** Ok. Tell me about any disease that you know of
> **DHH respondent:** Gestures vigorously by finger spelling and using the lips.
> **USL interpreter:** I don't understand him. His gestures don't make any sense to me. He is not using USL. Let's leave him.

From the above 'dialogue', it can be noted that even if Uganda currently has many highly qualified and experienced USL interpreters, their work is still hampered by the multiplicity of the 'home made' finger spellings and gestures used by DHH persons—especially in rural areas. In some instances therefore, any researcher interviewing such a person may have to hire not only the services of a professional USL interpreter but also a 'local interpreter' who could be well versed with the signing of the respondent. Although such a move might seem practical, its implications on the rigor of the findings from such a study may raise more questions than answers.

This leads to the issue of translational procedures for sign language data which has always been part of the discourse in disability research. Edwards (1998) emphasises the role of back translation to ensure agreement of a 'correct' version of a text. Ladd (2003) and Duranti (2003) also extensively discuss a range of paradigms around translating the American Sign Language (ASL). Goldstein *et.al* (2010) describes three techniques for attaining translation equivalence namely: back translation, decentering, and a translation team approach (Echardt, Steinberg, Lipton, Montoya & Goldstein, 1999; Edwards, 1994; Montoya, Egnatovich, Eckhardt & Steinberg, 2004). According to the authors, back translation is a method of assessing whether a translation is accurate by which a bilingual individual who has not seen the original text translates the new translation back into the original language. They define decentering as the iterative process of translating from a source language to a target language, back-translating to the source language, and negotiating the modification of both the source and target language as needed so that the original construct is as conceptually, linguistically, and operationally equivalent in both languages as possible. Such a process includes a translation team, item review, videotaped sign language translations, back translation, sign language expert review, focus group review, finalized sign language script, sign model selection and final digit videotaping of sign language items. The translation team should comprise deaf and hearing individuals who are fluent in sign language and English and have extensive experience working with cross-sections of the population included in the study sample. Specifically, it should consist of: a deaf social worker with extensive research and translation experience and a senior research assistant (a senior sign language interpreter) with training and experienced in working with DHH persons.

Ideally, the translation team is tasked with reviewing each written English item to confirm understanding of content and intent of each question. In cases where content or intent will be deemed unclear, the team should consult with the principal investigator before discussing various sign language translations in order to maintain the content and intent; bearing in mind the cultural and linguistic accuracy required. All the videotaped interviews and their translations are then sent to the back translator and expert sign language reviewer for feedback and suggestions.

But to what extent can this critical methodological aspect of the research process be achieved in Uganda? Is it for instance, possible to set up a translational team comprising the above mentioned professionals for a study resulting into a Masters or PhD thesis? How feasible is it, financially? This study has shown that whereas it is possible to obtain minimal funding to hire experienced and well trained sign language interpreters, a DHH bilingual person (one who knows both English and USL) back translator and an expert reviewer from say, institutions where such training is conducted—a view noted by one key informant:

> Such a process is very lengthy. In addition to the bureaucratic procedures of appointing such experts and signing contract forms for their remuneration, a lot of time will be needed for them to go through the entire process and submit their reports to examiners and reviewers. It cannot work in developing countries like Uganda.

Other issues that emerged in this study were that researchers are likely to be constrained by the dearth of experienced translators, back translators and experienced sign language reviewers in a country where the subject does not feature highly in the teaching programmes of most universities—including the country's oldest and one of Africa's highest ranked, Makerere University. And, in cases where such expertise can be found, they are likely to be constrained by the financial resources at their disposal to hire them to review or externally examine their work.

To deal with the above and other related issues, some researchers (see Creswell 2008) have proposed other validation criteria such as the use of audit trails under which individuals external to the study (but with some background knowledge of the subject) are asked to examine the narrative account and attest to its credibility by examining both the process and product of the inquiry and the trustworthiness of the findings. Others have proposed the use of peer debriefing whereby a senior researcher at the department or faculty is asked to play devil's advocate by challenging the researcher's assumptions, pushing the researcher to the next step methodically and asking the hard questions about the methods and interpretations of the study (Lincoln, 1995). The main disadvantage with this procedure in Uganda though, is the difficulty to find reviewers who have enough knowledge about the research area to be able to fulfill this role. Such peer reviewers may either not be available in the academic unit or have no time to review the study.

These findings corroborate findings of studies conducted in Tanzania, Swaziland and Nigeria (Lee, 2012; Groce *et.al,* 2007). In her study, Lee (2012) for instance, found that the deaf in the northern Tanzania region (predominantly rural) were largely either self-taught in signing and lip-reading or learnt from the other deaf people. Whereas it is evident from her study that Tanzania has more entrenched 'deaf clubs' in the countryside than Uganda (basing on the results of my study), both studies show great reliance on family (and other significant others) for the development, use and transmission of sign language. They also demonstrate a high level of cultural and linguistic multiplicity in both countries. Unlike in Europe, the United States and other developed countries where the disability movement often use the expression "nothing about us without us" (Barron, 1997), researchers in developing countries have to contend with all the above methodological issues and the fact that they are outsiders who can only take an etic view of their study population—a situation that in itself, presents a multiplicity of cognitive and social challenges. Critically, the findings also confirms the assertion that researchers involved in translating sign languages must realise that such languages are—unlike the spoken ones--not visual representations of the spoken word, but have their own grammatically distinct structures (Sutton-Spence and Woll, 2000).

'Bias' among researchers

Regardless of the specific subject of inquiry on the DHH sub-population, questions about how a researcher deals with bias[6] at the conceptualisation, data collection and interpretation stages of the process are bound to arise. While the detection and reduction of bias is a matter concern for researchers on any population, it is handled in different ways in different research traditions (Eckhardt & Anastas, 2007). Given the 'vulnerability' status of DHH persons, research involving this sub-population presents another opportunity to explore the long running debate among the traditional positivists and the qualitative-oriented researchers as to how and even whether or not, bias can be completely eliminated in the research process. In this study, theorising about studying the DHH community provided the challenge as to whether this socially vulnerable group is just one of those regarded as a minority and can therefore be ignored by policy makers or conceptualising it from the point of view that an interpretive approach to understanding this sub-population would bring to the fore a more realistic picture about their plight; albeit at the risk of being viewed more as an advocate for the community being studied than an academician. While I opted for the latter, I found it critical to categorically state my paradigm assumptions and personal positioning on the larger study.

Findings of this study showed that researchers on this community must also beware of the temptation to either exaggerate or over-generalise the statements made by informants as being true or applicable to all DHH persons in Uganda. A case in point was one of the respondents who during an interview, said that some DHH persons who go for HIV and AIDS counseling and testing get confused when they are told that their status results indicate that they are 'HIV positive'. According to this respondent, the finger spelling for 'positive' means 'all is fine' (good news). Therefore, many DHH persons initially get excited by the meaning of a positive HIV test until they receive further explanation of its true implications. This is further compounded by the double standards scenarios involving researchers who interprete similar characteristics of the study population differently in different groups and settings (Eckhardt & Anastas, 2007).

All in all, research 'bias' in deaf studies not only presents dilemmas in generalising findings by only a few respondents to the entire population but also creates a host of complexities related to interview reciprocity and its associated ethical challenges. Although a researcher may for instance, clearly set out his or her preconceptions about the DHH population at the time of writing the proposal, the extent to which this is methodically and ethically acceptable still divides opinion within the research community. And, venturing into a debate on how far and in what ways varying degrees of research bias affect the collection, analysis and interpretation of data for such a population might, as Mercer (2007) observed, "prove just too numerous and too fluid to fit into a tidy taxonomy."

Conducting FGDs for DHH respondents

The process of conducting FGDs for DHH informants presents a host of methodological challenges right from the organisation stage through to the transcription of the discussion proceedings. Whereas it was fairly easy to mobilise and sample the FGD participants for this study through contacts at the national and district associations of DHH persons in all the districts of study, I faced challenges managing the group dynamics during the discussion as some participants were more intent on agreeing with positions already stated by others. Unlike FGDs for persons without hearing impairments where most participants want to have a say on most of the themes being discussed, moderating a similar discussion for the DHH community requires more than the regular skills as the proceedings of the latter tend to be more heavily influenced by the emotions that result from the use of sign language and other gestures. Depending on the sensitivity of the topic under discussion, DHH FGD participants often get more agitated and emotional as they outdo each other in driving their points home. Any researcher involved in such an exercise must therefore be cognisant of the other intervening factors during the discussion most notably the influence of the sign language interpreters and any other persons without hearing impairments whose roles influence the proceedings of the discussion. There are also challenges in translating (already discussed above) and transcribing the proceedings of the FGDs especially where the video recordings were not used due to denial of consent by some participants (further discussed below).

Similar findings on the use of this technique of data collection were also found in Ghana where Mprah (2013) discusses 'difficulties' making direct quotes from what has been signed among FGD participants. Ladd (2003) also highlights methodological issues related to transcribing sign language videos.

Validity of sampling

It is another ongoing debate in the academia: What constitutes adequate empirical evidence and how should it be interpreted? Given the reality that most researchers and examiners in Uganda (and probably other developing countries) have what is variously referred to as 'quantitative minds', anyone venturing into this field of social inquiry is likely to be put on the spot on issues related to the sampling procedure—especially the sample size, nature of sampling and its validity. By its qualitative nature, this particular study faced questions of sample size adequacy and the validity of its findings. Specifically, the choice of non-probability sampling, did-- whereas providing an appropriate and cost effective strategy to constitute a suitable sample-- raise questions on the extent to which analytical generalisation of the study findings could be made.

Crain & Kulwin (2006) address the problem of small non-probability samples in research in the education of the DHH persons in the face of an increasing emphasis on scientifically based research. The authors examine the gains and losses in information using non-probability samples. Noting that it is very difficult to conduct research with probability samples drawn from populations of individuals who are deaf or hard of hearing, the authors point to the simple numerical minority of individuals who are culturally and audiologically deaf, or hard of hearing and the increasing diversification of the population in question from which it is increasingly difficult to draw random samples.

Theme 2: Ethical issues in research on the DHH community

Under this theme, the issues discussed in this paper include: Obtaining informed consent; confidentiality and anonymity of participants and the 'pretence syndrome'.

Obtaining informed consent

Conventional research procedures dictate that before starting any interview, the researcher fully explains the purpose of the study to the respondent and seeks his or her consent to participate in the exercise and/or discontinue it when the need arises. It is also incumbent upon researchers that the respondents also sign consent forms to confirm that they willingly volunteered to take part in it and clearly understood the purpose of the study. This decision must be made freely, without coercion, and must be based on a clear understanding of what participation involves (Pedroni & Pimple 2001). Obtaining informed consent from DHH informants is, however, an entirely different proportion. Researchers lacking expertise in the use of sign language face a daunting task convincing DHH respondents of the need for their participation in a study largely because this sub-population is not often involved in research projects. For this study, I faced difficulties obtaining the informed consent of respondents who are illiterate and thus, could not sign the consent forms. Although I decided to strike a compromise position between the ethical codes and situational common sense (see Mattila, 2011) by explaining and empowering them to give consent by nominating one of their significant persons to sign on their behalf, this had serious implications on their level of confidentiality (discussed below). This study also raised another related 'informed consent issue' noted by Mprah (2013) in Ghana namely; the appropriateness of using informed consent forms not written in the first language of the participants.

Confidentiality and anonymity of participants

Unlike research on populations without hearing impairments, studies on the DHH community demand that the use of both video and audio recordings of interviews and focus group proceedings is essential for ease of translation and validation purposes. The use of video recordings presents two further issues in this type of study: First, it becomes problematic when one or two respondents declines to be video recorded during say, an FGD yet the rest have given their consent. Secondly, it also means that in case consent to use video recordings during the interview or FGD is given, the researcher (and his or her sign language interpreter/s)—who will certainly be pre-occupied with asking questions and probing—will have to introduce another person or two to record the proceedings on video. The presence of these ancillary staff compromises the anonymity and confidentiality of the data collection process (Pollard 2002). This 'forced' compromise on the confidentiality and anonymity of the respondents is therefore a major ethical issue whose repercussions extend beyond just the data gathering process to the validity of the findings.

The 'pretence syndrome'

Given that the DHH persons are one of the numerical minorities who also live geographically apart from each other, it is often not easy for researchers on this sub-population to constitute an appropriate sample. For this study, I was able to obtained what I considered the most appropriate sample through contacts at the national and district associations of DHH persons (by sms text messages and mobilization) and in some cases, by snowball sampling. This technique proved to be a double-edged sword, however. Firstly, it emerged that not all respondents mobilized and sampled to participate in the study were DHH persons. Some were in fact, part of the general community of persons without hearing problems who felt that this study provided them with a money minting opportunity in form of signing for an allowance—such as transport refund or airtime--before, during and probably after the interview or FGD. Secondly, there were other non-DHH persons who believed that I was one of the representatives of the non-government organizations that 'had brought another project' to their district to among others, ameliorate the problems of the DHH community. Although such ethical issues are not necessarily limited to studies on this sub-population, researchers should beware of the tendencies of such persons and devise a creative research team recruitment process (Crain & Kulwin, 2006) that would include additional screening of respondents to eliminate those who might masquerade as 'DHH persons' for motives beyond the scope of the intended study.

Conclusion

The dearth of literature on studies involving DHH persons is a key pointer to—among other things—the host of methodological and ethical dilemmas that affect the data gathering, analysis procedures and rigor of knowledge generated from such studies. Although some researchers could as well be dissuaded by the minority status and the geographical and/or social distance between DHH persons, the issues presented in this paper also pose a major stumbling block in efforts to venture into this line of social inquiry.

In undertaking this study, the researchers anticipated that there would be underlying issues related to studying DHH persons. Whereas the study team members were to a great extent, aware of the importance of using well trained and experienced USL interpreters, little did they envisage that venturing into this area of study would pose such a host of methodological and ethical issues. One of the key contributions of this study to the general discourse of disability and/or deaf studies research is that it paves the way to the interrogation of the key methodological and ethical issues that any researcher into this population needs to beware of. This paper therefore, brings to the fore the need for the adoption of 'a diversity-sensitive and dynamic approach to methodological designs targeting DHH adults' (Levinger & Ronen) by researchers interested in this study population. With such methodological and ethical dilemmas largely arising from the unique social and linguistic characteristics of this 'silent' group of respondents, researchers need to be as flexible and dynamic as possible while applying the universally applied research methods and techniques. The situation even calls for more pragmatism when none of the research team members is neither deaf nor hard of hearing—as it was in this case.

End Notes

1. DHH has been used by some researchers on this subject such as Marschark & Spencer (2003) for ease of writing and reference to Deaf and Hard-of-Hearing persons. In this thesis, it refers to the population of the study which comprised respondents categorised as either D/deaf (both audiologically/medically and socially) or with varying degrees of hearing loss—ranging from slight to profound (Hunt & Marshall, 1999). In some countries, the DHH are widely referred to as persons with a hearing impairment.

2. This paper is an output of a larger study aimed to investigate the perceptions, construction of meaning and response to HIV and AIDS communication by DHH persons in Uganda. One of its specific objective (theme) was to examine the methodological and ethical dilemmas in investigating issues involving the DHH community.

3. Sign language is a visual and gestural language based on the use of hands, eyes, face, mouth and body (UNAD, 2010). It is a considered to be the primary means of communication for DHH persons.

4. The concept "significant persons" in this study is used as a modification of Charles Horton Cooley's (1864-1929) definition of "significant others" to refer to those people in our lives whose opinions matter to us and who are in a position to influence the way we think about things, especially about ourselves. This is contained in Cooley's theory of socialisation in which he argued that individuals develop their self-images through their interactions with significant others (Ritzer, 2004). Such persons include; caregivers (such as family, friends and neighbours), sign language interpreters, religious and opinion leaders.

5. 'Uganda Sign Language' has been placed in quotation marks because Uganda is one of the countries where sign language is still in its formative years. Although it was formally recognised in the mid-

1990s and there is a fully fledged Deaf Studies Programme at Kyambogo Univerity, it does not have official status in schools. Even when it is used in classrooms (based on finger spelling), the sign language skills of the teachers are often not adequate due to insufficient training (UNAD, 2010).

6. In this paper, bias is defined by as "systematic error in research" (Eckhardt & Anastas (2007).

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