



Informed consent and deafness in South Africa: Guidelines for clinicians and researchers

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Persons with severe to profound hearing loss are potentially vulnerable participants in research trials. Standard enrolment practices are likely to threaten or limit the process of informed consent. Misconceptions held by the hearing community about hearing loss and the impact of amplification of hearing, as well as on the nature of signed language, may jeopardise the process. This is particularly the case in the complex sociopolitical context of South Africa, which has significantly influenced the educational and linguistic status of deaf persons. This paper describes factors of importance, and suggests a number of guidelines for researchers using deaf participants. The paper will highlight some relevant dimensions of deafness to take into account, and the impact of socioeconomic context on this issue. Three case examples will be used to illustrate the complexities of the issues.

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There is a significant history of exploitation of and unethical experimentation with deaf people across the centuries – a factor which Harlan Lane^[1] and others have described, and which has led to a strong deaf-rights movement and acute concern with ethical practices.^[2] In the unique context of South Africa (SA), with its particular illness profile and recognised historical, social and educational inequities, deaf individuals are rendered especially vulnerable.^[3] While it might be argued that most researchers working with deaf people will already have an understanding of these factors, it cannot be assumed, especially in biomedical research, that the researchers are familiar with the complexity of argument. Many myths and assumptions continue to exist in the field of deafness.

This article addresses some important variables to consider when undertaking research with deaf individuals, provides some case examples to illustrate issues of informed consent and suggests some guidelines to ensure proper informed consent for this vulnerable group.

Factors of relevance

Severity and type of hearing loss

Hearing loss is measured on an audiogram, and typically, severe to profound bilateral hearing loss is associated with marked difficulties with the acquisition of spoken (or oral) language. Despite huge advances in technology, including high-powered hearing aids and cochlear implantation, children with a congenital severe to profound hearing loss may have minimum benefit from amplification, and will require specialised and regular input and education to acquire oral language skills and literacy. The success of such amplification and rehabilitation attempts will depend on the age at diagnosis and access to suitable rehabilitation. In SA, limited resources, awareness and access, and inadequate follow-up, account for delayed diagnosis and intervention.^[4-8]

Age at acquisition of hearing loss makes a substantial difference.

The person who has acquired oral language before becoming deaf, and who had normal hearing during the critical language-learning years of childhood, will retain such oral language skills in the event of severe or profound hearing loss. A typical cause of such profound acquired deafness in this country is meningitis. Another alarming and currently prevalent cause is ototoxicity. Tuberculosis (TB) patients on treatment are at high risk for sudden and profound hearing loss as a consequence of the ototoxic properties of some of the lifesaving drugs they take.^[9] While such individuals with acquired hearing loss may no longer be able to hear, reading and writing will be unaffected, and lip-reading skills may assist their understanding of others. Of course, the profound trauma of permanent and sudden hearing loss, and the social isolation that may ensue, will render such individuals further vulnerable. Furthermore, given the current epidemiology of TB, it is likely that some of these individuals will come from communities in which literacy may be limited, because of lack of educational opportunity.

'Deafness' v. deafness

A distinction is widely recognised between 'Deafness' as a cultural category and deafness as a biomedical category. The use of the lower-case 'deaf' refers to people who may have audiological deafness as described by their audiometric results and their measurable deafness. They tend to use hearing aids to support their use of spoken language.^[10] The upper-case 'Deaf' refers to the cultural and social categorisation of people who identify with Deaf culture. Deaf (in the upper-case sense) people do not consider themselves disabled; instead, they consider themselves part of a minority grouping whose members share similar beliefs and a 'naturally occurring human identity ... manifest through ... norms of behaviours, cultural perspective, conventions and shared histories.'^[10] The identity of being Deaf, and the experience of being deaf and Deaf, seems

to transcend other identities, such as ethnicity, because 'common experiences seem to have shaped their Deaf identity, in the sense that alienation from hearing people has led to solidarity among Deaf people (even from different ethnicities).'^[11]

The implications of this distinction are important for a researcher using deaf participants. We can assume neither deafness nor Deafness, until we ask. The presence of a hearing aid and the use of sign language provide some clues, but individuals often consider themselves to be both, depending on the people they are communicating with. These identities will have a significant impact on the process of informed consent.

Education and literacy

Research evidence suggests that internationally, the literacy level of deaf school-leavers is about Grade 5. Many reasons for this exist, including the fact that there is often a mismatch between the needs of the child and the educational programmes offered.^[12,13]

Although plain and simple language is the hallmark of all good written informed consent, those compiling a written informed-consent sheet for deaf persons should be aware of the difficulties with literacy faced by most deaf persons, and the possible interference of another language (sign language) on the understanding of grammatical devices such as word order or the passive construction. It is acknowledged that signed language is 'not grammatically structured in a linear subject-verb-object structure. Rather it is a topic-comment language in which inflection is produced through facial expression, visual orientation, movement and spatial location.'^[14] The researcher should therefore be careful not to assume full understanding of written text without carefully checking. To this end, it is also advisable to prepare consent forms that have been submitted to a readability analysis to check the reading age and grade level at which the consent forms have been written.

This is obviously compounded by the fact that in SA, the language of schooling is usually different from the oral language of the home. All specialised schooling for the deaf in SA takes place in English and Afrikaans, and the mismatch between home and school language exposure poses another obstacle to age-appropriate language development. The multilingualism policy has created a complex and typically SA situation where, in the context of 11 official languages, deaf people who speech-read are expected to do so in various spoken languages.^[7,15]

Sign language

Sign language is the natural language of the deaf community, and like spoken language, is complex, grammatical and nuanced. Specifically for Deaf people, the use of sign language is a hallmark of their identification with Deaf culture and ethnicity, and for significant numbers of Deaf people, it functions as their primary vernacular language, while people who are deaf may use hearing amplification devices and spoken language or spoken and signed language. There is a natural sign language in SA, South African Sign Language (SASL), that is used by the Deaf in communicative interactions and that is characterised by extensive lexical variation, related to regional and educational background, but underlying syntactic unity.

Although it is not an official language in SA, there have been calls to recognise SASL as an official language, and, in the Constitution's

recognition of the country's eleven official languages, it also makes provision for the Pan South African Language Board to promote and develop SASL.^[16] SASL has also recently been recognised as an additional language for teaching at schools.^[17] Despite such enabling legislation based on the Constitution, SASL remains, by and large, a stigmatised language variety in the SA context, and there remain many misconceptions about it even amongst linguists, health professionals, educators and policy makers.

Another important factor in understanding challenges to informed consent is the fact that there are regional and dialectal variations in sign language. Deaf people in SA continue to use a number of sign dialects. Because of a history of segregated education systems, a wide variety of sign-language dialects exists, determined not only by region and ethnicity but by the educational background of the Deaf individual,^[18,19] which often do not match the dialectal version of the interpreter appointed by the researcher.

Anonymity and confidentiality considerations

Several threats to anonymity and confidentiality exist when working with deaf individuals in research (and indeed in any clinical interactions between deaf persons and healthcare professionals).

The first of these links to the role of video-recording. The advent of the videotape has enabled a full appreciation and documentation of the complexities of sign language. Because sign language is temporally fleeting, video-recording is often the only reliable way to collect and store data from Deaf people and to check the reliability of the process of informed consent. This presents additional challenges in the process of gaining informed consent, as currently in the hearing world, significant limitations are placed on research using video-taping with human participants because of issues of confidentiality.^[20]

The way that the data are presented in publications is also an important issue. Janse van Vuuren^[21] has suggested that 'researchers in sign language are faced with a challenge which is unavoidable in the context of a visual-gestural language: participants are always identifiable because non-manual features (including facial expressions) form an important part of the linguistic structure of the language. Often, still-frames of digitally recorded signed texts are used in research publications to show these features. The implication of this is that participants have the right to know exactly how the digital texts will be utilised.'

Interpreting quality and confidentiality

The use of a sign-language interpreter is strongly recommended when recruiting Deaf persons in research studies, especially if sign language is used as his/her main medium of communication with family and peers. At present, because of discrepancies between policy and practice, fewer than 100 SASL interpreters are officially registered in SA.^[22] This poor provision and regulation of interpreting services results in inadequate services. Nowhere was this more vividly demonstrated than in the fake sign-language interpreter debacle of Nelson Mandela's funeral.^[23]

Another challenge exists around issues of confidentiality when working with the Deaf community, when a sign-language interpreter is used in an informed-consent process. Typically, the Deaf community is a small community with defined familial, professional and social

Table 1. Three research studies using Deaf and deaf participants illustrating the management of informed-consent issues

| Case study | Goal of study | Participants | Adaptations for deafness | Data management |
|--|---|--|--|--|
| 1) De Andrade ^[25] | To explore the experiences of caregivers of deaf children in a rural context | Deaf parents of Deaf children were interviewed | Two third parties used to gain informed consent: a Deaf teacher-assistant with a longstanding history of engagement with the Deaf community in this district, and a hearing person with a number of deaf and Deaf family members, fluent in the regional SASL dialect | The data (including the process of informed consent) were videorecorded and later transcribed by a Deaf sign language user who is a lecturer in SASL |
| 2) Penn, <i>et al.</i> ^[24] | To describe the linguistic and cognitive profiles of five deaf adults with a sign-language disorder | Two clinical groups were studied: three male learning-disabled deaf adult signers and two male deaf adult signers with acquired right-hemisphere damage as a result of a stroke; their performance was compared with that of five male deaf controls matched for age, degree of deafness and signing dialect | The test battery was translated into two sign dialects in SA and included only one-handed signs (to control for the presence of hemiplegia). All test instructions were given in sign language. All the tests were piloted on three deaf persons prior to the study. A carefully selected and trained sign-language interpreter was involved at each of the research sites | The process of informed consent and all participants' responses on the test battery were video-recorded and later scored and analysed by two adult deaf signers and the researchers, with high levels of inter-rater agreement |
| 3) Janse van Vuuren ^[23] | To document classifiers in sign language narratives | Five deaf adult signers in Johannesburg, SA | Each participant received the written participant-information sheet and informed-consent form. The researcher (fluent in sign language) also translated these documents into SASL, which was recorded on DVD and given to each participant to take home and view before giving consent | As the data presented in the thesis (and in future publications) are linked very specifically to still photo frames, the researcher made explicit all possible uses of the visual data in the letter of consent |

SA = South Africa; SASL = South African Sign Language.

networks.^[10] This implies the need to explain and reinforces the need to protect the participants' rights to anonymity and confidentiality. In the absence of a formally trained interpreter, while it might be possible to deploy persons in the participant's environment such as family members, there are ethical problems with this choice, such as the risk of coercion, and this suggests the need for some checking of the integrity of the process.

As with any third party in research-project selection, proper briefing and monitoring of the interpreter are important. The person selected should be regionally, educationally and dialectally matched to participants to ensure an efficient process. Furthermore, where a sign-language interpreter is deployed, it will be difficult for the hearing researchers to monitor the effectiveness and accuracy of the process (as indeed it is for hearing persons in an interpreter-mediated oral-language informed-consent session in a multilingual context). This implies the need for some checks and balances around the validity of the procedure (see for example case study 2 in Table 1).

Because of the visual nature of sign language, ethically, the venues chosen for conducting the interviews need careful consideration to ensure confidentiality. Similarly, good lighting is required in the data-collection setting to ensure proper access to signs and facial expressions for research participants.

Distress-protocol considerations

Because of the broader vulnerabilities of deaf and Deaf persons in our society to illness, including HIV/AIDs, sexual exploitation and mental-health issues, it should be borne in mind that aside from language difficulties, the specific research topic may pose some additional challenges for deaf people, and may require the use of a specific distress protocol. Clearly, referrals and actions should be commensurate with the participants' communication preferences and abilities, and should incorporate professionals such as social workers, counsellors and psychologists who are familiar with deafness.

Illustrative case studies

In Table 1, three studies using deaf participants are summarised that reflect adaptations from standard research protocol to the process of informed consent.

These studies illustrate: the use of a combination of written and signed instructions; a sensitivity to regional variations of sign language; the use of videotape in research; and sensitivity to confidentiality issues.

Recommendations

Based on these considerations, a summary recommendation sheet for the use of RECs is proposed below.

Informed consent and the Deaf community: Suggested guidelines

Protocols involving the use of deaf persons as participants will need to take into account the following:

- the level of deafness of the individual
- whether the hearing loss is congenital or acquired
- the level of education and literacy of the proposed participant.

Certain members of the Deaf culture may be considered potentially vulnerable in the research setting.

For severely to profoundly deaf individuals, oral language skills (talking and lip reading) and literacy may be a problem. This is particularly the case for congenital deafness, as literacy for persons with acquired deafness (after school age) is likely to be inadequate. The presence of a hearing aid (or cochlear implant) does not imply that the message is adequately heard!

It is possible therefore that a standard informed-consent approach is inappropriate, and researchers should bear in mind the following factors.

The written form

Research evidence suggests that internationally, the literacy level of deaf school leavers is about Grade 5. Special efforts should therefore be made to make the written version of the form user-friendly – simple language (vocabulary and sentence length), clarification of terms, etc. Pictorial supplements may help here. Note that given current special-education policy in SA, English (or Afrikaans) is likely to be the language of education and literacy, regardless of the spoken oral language of the person's background.

The verbal/sign form

The use of a sign-language interpreter is strongly recommended, especially if the deaf person concerned is a member of the Deaf community and uses sign language as his/her main medium of communication with family and peers. Sign language (like spoken language) has many varieties, and the researcher should endeavour to ensure that the interpreter deployed is familiar with the dialectal variety of the participant.

Videotaping is frequently a necessary aspect of research with the deaf, and should be viewed from a different perspective from the use of video with hearing persons. Extra precautions should be taken to ensure confidentiality. Adequate lighting is essential for sign language, and privacy is essential (because of the strong visual nature of the message). Special care should be taken to inform the participants of how and where the material will be published (particularly in the case of photographs or videotaping).

There are sign-language interpreters available through organisations such as the Deaf Federation of SA. It might also be possible to deploy persons in the participant's environment, such as family members. However, there are ethical precautions with this choice (e.g. the possibility of coercion) that may operate here, and ideally there should be some checking of the integrity of the process.

We would recommend that both written and signed versions of the informed-consent process are made available, and that researchers are advised to specify the particular steps taken to minimise vulnerability and reduce distress in the informed-consent process in their ethics applications.

Conclusion

This paper has highlighted the special vulnerabilities of deaf persons taking part in clinical trials, the complexities around the use of the term 'deafness' and some particular considerations which need to be taken into account by research ethics committees when reviewing protocols for studies involving deaf and Deaf persons. The recommendations will hopefully serve as a practical guideline which can obviously be supplemented by the appointment of consultants where relevant from the Deaf community.

Ethical informed consent with deaf/Deaf participants will require explicit insight into potential barriers to enrolment and the deployment of context-specific strategies and resources.

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