

# Privacy and confidentiality in health care access for people who are deaf: The Kenyan case

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At the international level, Kenya is a signatory to the UN Convention on the Rights of Persons with Disabilities. It signed and ratified the same on 30 March 2007 and on 19 May 2008 respectively. At the regional level Kenya is also a signatory to the African Charter on Human and Peoples' Rights. The Kenyan constitution 2010 and the persons with disabilities act 2003 all offer guarantees on the rights for persons with disabilities (PWDs). PWDs in most countries are part of groups that, have traditionally been victims of violations and thus they may require special protection for the equal and effective enjoyment of their human rights. Despite the fact that these human rights instruments set out additional guarantees for persons belonging to these groups over and above the universal declaration of human rights, PWDs in general and the deaf in particular continue to face challenges especially in the health sector. For people who are deaf their main challenge is communication. Since they normally have no access to their auditory faculty, their main means of

communication is Visual through Kenyan Sign Language (KSL). Majority of people are hearing including majority health practitioners thus creating a communication barrier that interferes with the right to access quality medical care for people who are deaf. This paper examines the challenges that people who are deaf in Kenya face in accessing medical care. First they are more often than not forced to use KSL interpreters a fact that may interfere with their privacy and confidentiality. In the absence of qualified interpreters, people resort to writing under the false impression that all people who are deaf can read and write. Then sometimes relatives of the deaf are used as interpreters just because they may have some knowledge of KSL forgetting that they are not interpreters. The paper also looks at some initiatives that have tried to teach medical practitioners KSL so that they can communicate with people who are deaf directly and argue that though not adequate in terms of the numbers trained so far but this is the way to go.

**Key Words:** *People who are deaf; Kenyan sign language; Access to health; Privacy; Confidentiality*

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## CASE REPORT

Privacy, the "Freedom from unauthorized intrusion" [1] and confidentiality, the state of keeping or being kept secret or private, which is "one of the most important pillars of medicine." And which normally involves "Protecting the private details of a patient is not just a matter of moral respect, it is essential in retaining the important bond of trust between the doctor and the individual" [2]. There two are two important components in building patient-doctor rapport and understanding and therefor necessary for healthcare access. The question then is what is at stake for people who are deaf and who more often than not have to give up the above two components in order to access health care. Is the health care they access quality healthcare? What are the chances that many people who are deaf get misdiagnosed and give wrong medication? What recourse do these people have in such cases?

People who are deaf normally have lost their auditory faculty for one reason or another. They thus cannot access the world using sound as majority of the people in the world do. Given this scenario, the world is accessible to them through vision. This presents to people who are deaf a unique communication problem since unlike the majority of the people in the world, who communicate using an audio based symbol system (read speech), people who are deaf in Kenya communicate using a visually based symbol system i.e. Kenyan Sign Language popularly abbreviated as KSL. Their use of KSL makes them a language minority and renders them vulnerable to discrimination. This discrimination manifests itself in all facets of their life but more so in the health care system.

In Kenya health care access for people who are deaf largely depends on the availability of a Kenyan Sign Language (KSL) interpreter. This is a person who is hearing but has learnt Kenyan Sign language and is able to mediate the language barrier that exists between a person who is deaf and the medical practitioner. This is due to the fact that most medical

practitioners in Kenya cannot communicate in KSL. This then necessitates the presence of a third party in the transaction between a person who is deaf and the medical practitioner. What are the implications of this in terms of the privacy of person who is deaf? As defined above privacy is "freedom from unauthorized intrusion," however in this case the person who is deaf has no option but to allow the intrusion.

It is intrusion into the deaf persons private medical affairs whether authorized or not. In any case lack of options make it even more intrusive. To mitigate against this intrusion efforts have been made to try and train medical practitioners in KSL so that deaf patients may have a chance to directly engage with the medical practitioner thus cutting out the third party. All this so as to safeguard the privacy and confidentiality of patients who are deaf. One such laudable effort is by the National Council for Persons with Disabilities (NCPWD)-Kenya.

## The NCPWD efforts

The Disability act 2003 amended in 2015 led to the established the National Council for Persons with Disabilities (NCPWD) in Kenya. The NCPWD is a state corporation established by an Act of Parliament; the Persons with Disabilities Act No. 14 of 2003 and set up in November 2004. NCPWD mission is: To Mainstream Disability issues in all aspects of Socio-Cultural, Economic and Political Development. NCPWD has over the years provided assistive devices for PWDs to enable them live a near "normal life as possible." It has provided white canes, wheel chairs, hearing aids etc. however it was felt that the best assistive device you can give a person who is deaf is the use of their language KSL. The idea of training health professionals in KSL was the mooted. Thus the training program that was eventually developed was a product of a stakeholders meeting held at the NCPWD offices on 12<sup>th</sup> July 2011.

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The purpose of the meeting was to discuss and strategize on how to provide sign language to health service providers in the country so as to increase access to reproductive and other health care services to persons who are deaf. Part of the resolution passed in that meeting was to start a Kenyan Sign language (KSL) training programs that would involve selected health professionals who would be given a six months intensive KSL training and a further three months attachment to enable them to serve people who are deaf better in their stations after the training and by extension increase health care accessibility for them. In collaboration with the Kenya Sign Language Research Project (KSLRP) based at the University of Nairobi, NCPWD in sponsored trainees into what we called the KSL proficiency training program for professionals. The trainees were selected by the ministry of health from across Kenya. The aim of this 3 year program (2011-2014) was to provide Sign Language communication skills to health service providers in the country so as to increase access to reproductive and other health care services to persons who are deaf.

In the 2011-2012 period KSLRP received 32 trainees. 13 of them were from the nursing profession, 5 were from the Kenya Medical Training Colleges (KMTC)-an institution that trains nurses and other medical professionals and the remaining 8 were from other institutions that deal with persons who are deaf. In the 2012-2013 cycle a total of 38 trainees were admitted for training comprising of 21 nurses, 9 KMTC staff, others included 4 police officers and the rest were social workers. In 2013-2014, a total of 55 students were admitted majority of whom (21) were nurses. The rest were drawn from the police force, social workers and other professions that directly deal with people who are deaf. In 2015, the ministry of health also sponsored a class of 33 learners composed mostly of nurses, physiotherapists and occupational therapists for the same KSL proficiency training.

In 2017, NCPWD took a devolved approach where training was done in counties. They identified 6 counties but KSLRP was responsible for 3 counties namely: Nairobi, Mombasa and Kisumu. The other 3 counties were given to another service provider. In total KSLRP trained 108 medical practitioners and an equal amount trained by the other service providers. This training is still on going through other service providers.

### The KSLRP training

The trainees underwent a 6 months intensive full time KSL training before going for another three months industrial attachment in institutions dealing with people who are deaf. The purpose of the attachment was to enable the students to be able to practice KSL with deaf people in natural occurring context away from the controlled classroom environment and also to enhance their communication ability in KSL. However, the 2017 training sponsored by NCPWD trainees did training for 3 months and another 3 months for industrial attachment. All in all KSLRP has so far trained 243 health professionals for NCPWD and 33 for the ministry of health total 276. In total there are about 300-400 health practitioners that have undergone KSL training and they can communicate with people who are deaf directly without an interpreter. For a country that has over 1 million persons who are deaf, this is a drop in the ocean though a step in the right direction. The training of medical practitioner in KSL was no doubt a brilliant idea. However, there are emerging issues that need to be addressed.

### The emerging issues

Most of these trainees are the first time in patient care and they play an important role in provision of health care. The few who were trained can effectively hold a one on one discussion with a Deaf patient in KSL. However as pointed out earlier they are very few medical practitioner with these KSL communication skills who are scattered across the country. What happens then when a deaf patient goes to a facility without such a medical practitioner? He or she may be required to come along with a KSL interpreter an important person in the life of the deaf in terms of facilitating communication. However then the question of confidentiality and privacy of the person who is deaf arises. As if that is not enough chances are that they may get an interpreter who is not competent and

therefore instead of enhancing communication they may actually frustrate that communication between a person who is deaf and the medical practitioner say a nurse.

It gets worse as Geer [3] puts it: Examples include providers asking a Deaf patient to bring a friend or relative to interpret, using a staff member who can fingerspell to communicate, and hiring an incompetent interpreter. This is a major hindrance to effective communication. Interpretation is a profession and needs to be conducted by trained professionals. An Interpreter, especially a KSL interpreter must be both linguistic and cultural competent. They must be competent in a spoken language in the Kenyan case English and or Kiswahili and also KSL without losing sight of the fact that each language is a way of seeing and reflecting the delicate nuances of cultural perceptions, and it is the translator who not only reconstructs the equivalences of the words across linguistic boundaries but also reflects and transplants the emotional vibration of another culture. Schulte [4]. This is not something every Tom Dick and Harry can do. Thus it must be remembered that the mere fact that one has learnt KSL does not qualify them to be interpreters.

Ideally interpreters need to be competent in their area of specialization. Interpreter training need to be more specialized. For example we need medical, legal, educational, broadcast interpreters etc. Ironically in Kenya the interpreter training offered has not reached this level. So Kenyan interpreters fall under the category "jack of all trades and masters of none." This is not to say that they are not good in what they do but this lack of specialization possess a challenge especially in interpreting in specialized fields for example in the medical field.

It is also paradoxical that though the right to sign language for people who are deaf is enshrined in the Kenyan constitution, article 54 i) d states: A person with any disability is entitled – to use Sign language, Braille or other appropriate means of communication; the truth is that there is hardly ever provision for interpreters in places where public services are provided. It is also instructive to note that most of the time the available interpreters are not employees of the government which by right ought to provide them, but rather they are private ones that the persons who are deaf are forced to bring to hospital with them. While some of medical facilities have the medical practitioners trained as mentioned above, they are not enough and they are not really trained interpreters but rather medical practitioners that know KSL.

While they can assist in a one to one situation, it may difficult for them to mediate between say the patient and a doctor because most of them are not professional interpreters. McAleer [5], sums up the complexity of this situation in the British medical field which is similar to the Kenyan scenario: "Nurses who are not trained interpreters but have some knowledge in BSL (British Sign Language) should not act as interpreters." The situation where hospitals tend to think that anyone who has some knowledge of KSL can interpret should cease. This has led to situations where hospitals or health care providers tend to use staff members who are acquainted with KSL, or some relatives or friends of the person who is deaf to act as interpreters. Errors are more likely to occur in this kind of situation. As Chen [6] put it untrained interpreters are "reliably unreliable" (p. 1745). The worst case scenario this can lead to death of the patient.

Another assumption that is detrimental to effective health care communication is one where any time a medical practitioner comes across a person who is deaf they pull out a pen and paper so as to communicate with the deaf patient through writing back and forth. It is important to note that in most cases people who are deaf in Kenya are at the bottom of the socio-economic ladder, they have poor literacy skills. The truth of the matter is that in Kenya most people who are deaf are marginally literate in a spoken language thus they may not have the ability to adequately use it to explain complicated conditions. But it should not be lost that they have their own language which can be used to explain any condition if the atmosphere is conducive.

Apart from a few first line medical care givers trained in KSL, the situation is worse when it comes to doctors. Of all the trained Medical Practitioners there were one or two doctors trained in the language. Meaning that for patient who is deaf the following scenarios unfold when

they go seeking medical assistance: they must use an interpreter if they bring one or use a nurse who knows some KSL if they are lucky to find one in the medical facility or make do with paper and pen when they get to see a doctor. This situation definitely comes with a cost to the patient, misdiagnosis, and frustration, being passed by as hearing patients who came after him/her go straight to be served and in some instances death.

All in all, it is apparent that people who are deaf therefore have problems assessing health care mainly because there is a communication barrier in communicating with health care professionals. How can we break these barriers? The most ideal situation in respect to privacy and confidentiality would be to ensure that most of the health professionals are trained in KSL to a near native speaker competence level and then placed in medical facilities so that people who are deaf will communicate directly with them without a third party to safeguard their privacy and confidentiality. Sounds like a tall order though. However, it can be done if KSL is introduced in medical school right from first year. It can also be introduced in medical training centers. On average, Kenya produces about 600 doctors a year. If we target about 100 doctors graduating with KSL skills this can boost the health care sector in terms of people who are deaf access to health care. The same can be done for clinical officers and nurses to enhance that access.

Another important step that can be taken to improve access to health care to people who are deaf is deaf awareness training. All health care professionals need to be sensitized about deafness, deaf culture and KSL. This will not only make them aware of the communication challenges people who are deaf face in accessing services provided by them but also they will be able to understand that these challenges are mostly communication based and that they are putting people who are deaf at risk. This awareness is a step in addressing the issues of access. There is need in doing this awareness to have clear guides in medical institutions of how staff are expected to handle a person who is deaf. Once the first tier medical professional realizes he/she is dealing with a person who is deaf, there must be a clearly laid down procedure that is to be followed that may include taking the patient directly to a medical professional who knows KSL and can handle the situation or a qualified interpreter is sought to provide services. The emphasis here being on a qualified interpreter because they are bound by professional ethics and thus are bound to protect the privacy and confidentiality of the patient.

Another approach is to treat this issue of access to health care for people who are deaf as a human rights issue. Human rights are commonly understood as being those rights which are inherent in the mere fact of being human. The concept of human rights is based on the belief that every human being is entitled to enjoy her/his rights without discrimination. Human rights are universal and they belong to everyone regardless of sex, national or ethnic origin, colour, religion, language, or any other status such as disability or deafness. However, how human are these rights for people who are deaf when it comes to health care? Health care access is a human rights issue [7].

The right to health is fundamental to the physical and mental well-being of all individuals and is a necessary condition for the exercise of other human rights including the pursuit of an adequate standard of living. This is provided for in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) which provides for the "enjoyment of the highest attainable standard of physical and mental health conducive to living a life of dignity". The Kenyan constitution 2010 reinforces this: The right to health is a fundamental human right guaranteed in the Constitution of Kenya. Article 43 (1) (a) of the Constitution provides that every person has the right to the highest attainable standard of health, which includes the right to health care services, including reproductive health care [9]. If this is the case then how come access to sign language for people who are deaf and therefore easy access to health care and other services is not respected? This can be attributed to the fact that the either the government of Kenya does not take its role as a duty bearer seriously or has abdicated it all together.

Similarly, the people who are deaf in Kenya also are most likely unaware of their constitutional granted right to health as rights holders in the human rights discourse. The Kenyan state and its agencies are duty

bearers since they are the ones who are charged with the responsibility of dealing with the main issues deriving from human rights this duty does not fall on individuals. At the same time a human rights based approach give vulnerable citizens the power to demand for delivery of the rights and services which they are entitled too. The relationship between the right holder (in this case people who are deaf) and the duty bearer (the government and its agencies) needs to be a reciprocal one. The most important thing in this relationship is the truth that a right that is not respected leads to a violation, and its redress or reparation can be legally and legitimately claimed [9]. Thus people who are deaf have every right to seek legal redress on this issue of health care access that is denied them. However, more than anything else, their vulnerability make them lack capacity to lay claim on their rights as enshrined in the Kenyan constitution and also in many international instruments that Kenya is a signatory to.

In conclusion, there is no denying how important health care is for anyone. However, it is the ability to access it that matters most. For people who are deaf, they mostly access health care through interpreters. It is debatable whether they do this using competent and trained interpreters. If they do, then their privacy and confidentiality is guaranteed since professionally trained interpreters are bound by their code of ethics. If they use quacks, this is not guaranteed. The other way people who are deaf can access health care is a situation where most medical practitioners are conversant with KSL and thus a patient who is deaf has direct access to the medical practitioner without the need for a third party. This way then patients who are deaf will have their privacy and confidentiality respected while at the same time bearing in mind that "Protecting the private details of a patient is not just a matter of moral respect, it is essential in retaining the important bond of trust between the doctor and the individual" [2]. Finally access to health care is a human right of major concern and it must be treated as such.

## DISCUSSION

In conclusion, there is no denying how important health care is for anyone. However, it is the ability to access it that matters most. For people who are deaf, they mostly access health care through interpreters. It is debatable whether they do this using competent and trained interpreters. If they do, then their privacy and confidentiality is guaranteed since professionally trained interpreters are bound by their code of ethics. If they use quacks, this is not guaranteed. The other way people who are deaf can access health care is a situation where most medical practitioners are conversant with KSL and thus a patient who is deaf has direct access to the medical practitioner without the need for a third party. This way then patients who are deaf will have their privacy and confidentiality respected while at the same time bearing in mind that "Protecting the private details of a patient is not just a matter of moral respect, it is essential in retaining the important bond of trust between the doctor and the individual" [2]. Finally access to health care is a human right of major concern and it must be treated as such.

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