

Health Literacy and Communication Technology in a Neglected Population with Specific Needs Access



Sunghea Park¹ PhD, Emanuel Lubart² MS, Ambrose Murangira³ MA

¹University of Basel; Swiss TPH, Switzerland, ²Johns Hopkins University, USA, ³Makerere University; Light for The World, Uganda
sunghea.park@unibas.ch, emanuel.lubart@gmail.com

Introduction

According to Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD), governments are obligated to provide access to health services for people with disabilities by establishing inclusive health policies and health systems. However, Deaf people are still left behind in accessing health information and services. In Switzerland, CRPD was ratified in 2014 but has not been applied in health services for Deaf people as their specific health literacy needs were not considered in the national strategy of Health 2020. In Uganda, CRPD was ratified in September 2008, but like as in Switzerland, no efforts have been made to implement provisions provided for under Article 25, particularly for the Deaf.

Health literacy is an important topic for promoting health equity. It refers to a capacity to access, understand and use health information and services in maintaining and promoting health (1). Limited health literacy is associated with poor health outcomes (2). Deaf people, who use a sign language as their primary language, are easily excluded in accessing health information and services. Their main issues are limited health literacy and health disparities (3). Nowadays, communication technologies, including the WhatsApp channel, present opportunities for Deaf people to access health information by using mobile and digital devices (4;5). **This presentation attempts to raise awareness of specific health literacy needs of Deaf people in Uganda and Switzerland and to call for providing comprehensive health information and services to the Deaf population.**

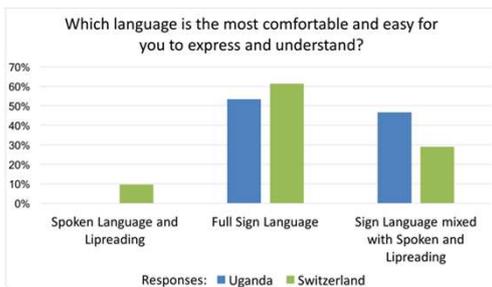
Method of Study

We applied a mixed research method using two an e-survey and additional interviews to examine health literacy needs and use of communication technologies among Deaf people living in German-speaking Switzerland and Uganda. A questionnaire included written and sign languages for Deaf people in each country. A sample of 31 Deaf people (7 men and 12 women, average 33 years old) from Switzerland and 32 Deaf people (23 men, 8 women and 1 unknown, average 28 years old) from Uganda participated in the survey. Three individual interviews in Switzerland and a focus group discussion (FGD) in Uganda were conducted. All interviews and the FGD were carried out in sign languages, and transcribed in English by two Deaf co-authors, A. Murangira and E. Lubart. We analyzed interviews and FGD data by using qualitative analysis software, NVivo 12.

Key Findings

Language Preference in Deaf People

Over 50% of Deaf respondents (53.3% in Uganda, 61.3% in Switzerland) showed full sign language preference and followed the preference of sign language with spoken language (46.7% in Uganda, 29% in Switzerland). This result indicates that **sign language is a primary or preferred language for Deaf people in accessing, understanding and communicating information.**



Communication Barriers in Accessing Health Information

The outcome was that 62.5% of Deaf respondents in Uganda and 93.6% in Switzerland use the Internet to search for medical and health-related information. Of Deaf respondents in Uganda, 65.5% have received and sent health-related messages via the WhatsApp channel, compared with 29% of participants in Switzerland. However, **Deaf people have experienced health literacy and language barriers due to text and audio formats while searching for health information on the Internet. Lack of medical and health information in sign language and the complexity of written information hinder Deaf people from obtaining the information they need for care. For continuation, see continued Findings.**

Key Findings (continued)

Deaf people in both countries reported difficulty in understanding health and medical information in text which was searched by themselves or given by healthcare providers. They have better understanding of health information provided in sign language as well as when plain written language is used. Also, visual images of pictures and videos are helpful for Deaf people to comprehend health information.

Lack of Cultural Competence of Healthcare Professionals in Communication with Deaf Patients

In the survey, 56% of Deaf people who use WhatsApp in Uganda responded that they have exchanged WhatsApp messages on health concerns, symptoms and side-effects with their healthcare providers while 32.1% in Switzerland have used the channel. However, the biggest challenge for Deaf people is communication with doctors, nurses and healthcare providers. **They were not satisfied with their use of health services mainly due to poor attitudes of healthcare providers.**

Communication Technology in Sharing Health Information with Deaf Communities

According to our survey, Deaf people in both countries use the WhatsApp channel and other social media mostly for sharing and exchanging health information with Deaf friends, Deaf community groups as well as a mixed group of Deaf and hearing members. In Uganda, Deaf people use WhatsApp mainly for exchanging in groups containing more than two people. In Switzerland, Deaf people exchange information mainly with individual persons. Deaf people in Uganda perceived the WhatsApp channel as more useful in accessing health information compared to Deaf people in Switzerland.

Specific Health Literacy Needs in Deaf Population

In Uganda

Deaf people use the WhatsApp channel actively for sharing useful health information in Deaf groups. They have an issue of affordability when using web data and TV channels as service fees are expensive for them. They experience communication barriers with and ignorance from healthcare providers. They have a strong request for Ugandan Sign Language interpreting services which are employed by national and regional hospitals. Also, plain English and visual images are useful for them to understand health information well.

In Switzerland

Deaf people use WhatsApp messages with their healthcare providers on a limited basis, e.g., making an appointment or for an emergency case. Deaf people have disability insurance which covers limited use of sign language interpreting services. With the insurance, they have to make a decision for which cases to use the services, e.g., team meetings at their workplace. Deaf people have specific needs for health information in plain German and Swiss-German Sign Language.

Conclusion

Communication technologies have increased access to health information for Deaf persons: in particular, our study identifies the use of WhatsApp as a useful tool for information exchange between Deaf people in Uganda and highlights the use of the Internet by Deaf people in Switzerland. However, medical jargon, convoluted language and negative attitudes of healthcare providers still prevent them from full access to information and services. As a result, Deaf people utilize their social networks for better access to appropriate health information and communication. Furthermore, **health literacy in the Deaf population is not promoted by individual capabilities of Deaf people, but rather by raising cultural and communication competences of health professionals and also by employing inclusive communication approaches in healthcare systems.**

Watch Sign Videos and Deaf Participant Interviews



An Interview on Barriers in Accessing Health Information

Another challenge, I as a Deaf person I lack information on symptoms of different diseases. Hearing people usually learn about such symptoms and signs through audio sources such as radio. - FGD participant in Uganda -

It would be nice if she/he (healthcare provider) is persuaded to explain to me my medical conditions, diagnosis and treatment plans at my health literacy level, using simple German, plain words. - Informant A in Switzerland -

Another problem is that when doctor is prescribing medication, he doesn't give you attention. He just speaks looking at different direction or computer. It is hard to lipread him/her to understand something. You just go back home with drugs which you don't understand. - FGD participant in Uganda -

We need employment of sign language interpreters in regional hospitals. Most of the time I get confused at government hospitals, they so big to understand where to go first... - FGD participant in Uganda -

In fact, I want to bring a sign interpreter with me to a health professional each time I have an appointment, but I cannot do so because of maximum spending limits set by the IV (disability insurance) on sign interpreting services. I have requested many times for sign interpreters for my team meetings, so all my spending limits have been used. I am not able to ask for additional funds for these services. - Informant C in Switzerland -



Seven Recommendations for Inclusive Health Communication

References

1. WHO website, The mandate for health literacy, available to access at: <http://www.who.int/healthpromotion/conferences/9gchp/health-literacy/en/>
2. WHO (2013) Health Literacy – the solid facts (EU Health Literacy Survey), edited by Ilona Kickbusch, Jürgen M. Peilkan, Franklin Apfel & Agis D. Tsouros
3. Barnett S., McKee M., Smith S.R. and Pearson T.A. (2011) Deaf Sign Language Users, Health Inequities, and Public Health: Opportunity for Social Justice, *Preventing Chronic Disease*, 8 (2), A45
4. Chinihorn P., Glaser M., Tucker W.D. and Diehl J.C. (2016) Exploration of Deaf People's Health Information Sources and Techniques for Information Delivery in Cape Town: A Qualitative Study for the Design and Development of a Mobile Health App, *JMIR Human Factors*, 3 (2), e28
5. Karras E. & Rintamaki L.S. (2012) An Examination of Online Health Information Seeking by Deaf People, *Health Communication*, 27:2, 194-204