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Positive Influences and Challenges for the Deaf Community Navigating Access to HIV Information, Testing, and Treatment in Kampala, Uganda: A Qualitative Study

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Abstract

Although sub-Saharan Africa has the highest HIV burden globally, few studies have investigated disabilities and HIV in this region. We conducted a secondary analysis of text data from in-depth interviews (2014–2015) to describe HIV perceptions among a subsample of 73 deaf individuals participating in the Crane survey, Kampala, Uganda. Being deaf was defined as being profoundly or functionally deaf, having deafness onset 5 + years ago, and preferring sign language to communicate. Among participants ever tested for HIV (47%), most (88%) had a negative test. Thematic analysis revealed overcoming challenges/barriers followed by socioeconomic status, support systems, HIV, stigma, abuse, and health conditions as major themes. An unanticipated finding was the role of sex work to support basic living needs. The data showed related themes

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Conflict of interests The authors declare that they have no conflict of interests.

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Declarations

Ethical Approval The Crane survey was approved by Makerere University's Institutional Review Board and the Center for Global Health in the United States Centers for Disease Control and Prevention. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to Participate Informed consent was obtained from all individual participants included in the study. All deaf participants reviewed a video-based informed consent, and provided non-written consent through sign language.

Data Availability The questionnaire is provided as an additional file. The data are not publicly available.

Code Availability The qualitative codebook is provided in the manuscript.

among participants, suggesting a complex context in which deaf participants experience HIV prevention and treatment. It is important to tailor HIV interventions for deaf and disabled persons.

Keywords

Deaf; HIV; Stigma; Uganda; Disability

Introduction

Persons with disabilities are uniquely vulnerable [1, 2], and although the disabled represent 15% of the global population [3], very few studies have examined HIV prevalence, risk factors, knowledge and attitudes among people with disabilities [1]. People with disabilities represent a heterogeneous group [4] and are often erroneously grouped together [4]. This is especially true for the deaf community despite their shared language and culture [5]. A 2010 review reports on the very few estimates of HIV prevalence among the deaf community [6]. A systematic review and meta-analysis of HIV among persons with disabilities (defined as persons who were blind, deaf, or who had cognitive and physical impairments) in sub-Saharan Africa found a greater risk of HIV in this population compared to persons without disabilities [4]. Factors associated with a greater risk for HIV among deaf participants include misperceptions of HIV and limited access to HIV related information and medical services [6]. In the medical setting, barriers arise as medical staff are not able to use sign language and deaf participants must use an intermediary for communication, potentially compromising patient confidentiality [7].

The 2016 Uganda Demographic Health Survey found that among persons aged 15 years, 1.1% of the population self-reported having a lot of difficulty hearing or not hearing at all [8]. Since the late 2000s, the Crane survey has used respondent driven sampling and “seeds” to select vulnerable groups which traditionally lack sampling frames (men having sex with men, female sex workers, university students, transport workers, persons engaged in multiple concurrent partnerships, drug users, persons with disabilities, and self-settled urban refugees) within Uganda considered at higher risk for HIV [9–12]. Seeds are individuals who may be well connected in the study population [12]. These individuals (seeds) give coupons to community members to participate in the survey [9, 10]. As part of the Crane survey [13], 1011 deaf participants were recruited (2014–2015) in Kampala, Uganda and participated in a video computer-assisted self-interview survey (VCASI) [14]. Using a VCASI software package for the quantitative survey developed in the United States (University of Rochester) for the Deaf, the English language questionnaire was translated into video-based Uganda Sign Language (USL); and then back translated into English. Where necessary, sign language was re-translated and VCASI files reproduced. The VCASI interview was started through a tutorial in the presence of survey staff. In this tutorial, respondents were acquainted with the navigation of the software using touch screen compatible notebooks and were familiarized to the different types of questions formats. After the tutorial, trained survey staff left but remained within eyesight in case the respondent had a question as they continued with the VCASI by themselves. Findings from the VCASI survey indicated HIV prevalence was 1.9% with only 22% of participants in

active care for HIV treatment [14]. Regarding self-reported sexual behaviours in the past year, 21% had multiple partners, 26% had sold sex, 17% had bought sex, and 45% reported coercive sex [14]. We conducted a secondary analysis of text data from in-depth interviews among a subsample of the Crane VCASI deaf survey participants in Kampala, Uganda to describe perceptions of HIV.

Methods

Study Design and Participants

A convenience subsample of 73 persons from the Crane survey who self-identified as deaf were interviewed using an open-ended questionnaire guide. Being deaf was defined as: profoundly or functionally deaf, becoming deaf 5 years ago, and preferring sign language to communicate. Among the 1011 deaf participants, half had previously tested for HIV [14]. The subsample was chosen based on individuals indicating in the VCASI survey (initial study of deaf participants $n = 1011$) they had negative feelings, positive HIV test, difficulty accessing health care, or were men attracted to other men. Interviews (see additional files for questionnaire guide) using open-ended questions were held in a closed room in the survey office, with only the participant, interviewer, and translator present. Average interview time was 25 min (range 10–87 min). Interviews were held in Ugandan Sign Language and translated into English, recorded on tape, and later transcribed.

Data Analysis

Descriptive analysis was performed for the demographic and health characteristics of the subsample. A secondary analysis of text data from the in-depth interviews using open-ended questions was conducted. Grounded theory [15] was used in developing the major themes and sub-themes. As coders reviewed the data themes emerged. These themes were later merged into groups. A coder reviewed the first 20 interviews to develop the first codebook. A second coder developed a more refined codebook, which was subsequently applied to the first 20 interviews. A third coder resolved discrepancies between the first and second codebooks. This coder developed the third version of the codebook which was reviewed by the first two coders and applied again to the first 20 interviews. The third version of the codebook became the final version used to code the interviews using Atlas.ti [16] qualitative software. When there was disagreement, a third coder helped reach consensus. Two interviews were not included in the final analysis due to incompleteness and duplication, resulting in 71 coded interviews.

Ethical Considerations

The Crane survey was approved by Makerere University's Institutional Review Board and the Center for Global Health in the United States Centers for Disease Control and Prevention. All deaf participants reviewed a video-based informed consent, provided non-written consent through sign language and were compensated for their time and transport costs. For the qualitative study, consent was also obtained from participants for the interview and audio recording. After translation of the interviews, audio recordings were destroyed. Qualitative interviews were not recorded via video.

Results

Participants

Most participants were men (63%). Median age was similar for men (23.1 years) and women (25.4 years). More than half the participants (55%) were aged < 35 years old and had completed secondary school or higher (56%). About two-thirds of participants (66%) were single/previously married and had a job at the time of their interviews (63%). Of those who had ever previously tested for HIV (47%), most (88%) indicated the result was negative. Most (80%) were completely deaf.

Participants' Experience

We identified eight major themes in the interviews: challenges/barriers, support systems, socioeconomic status, health information, abuse, health conditions, stigma, and reasons for study participation. These major themes were formed after reviewing the individual themes and grouping for similarities (Table 1). The interviews were not linked to the demographic characteristics of participants; therefore, we are unable to report our results by age or sex. In this paper, we included participants' experiences based on deaf individuals contributing 40% to a subtheme.

Challenges and Barriers

Among the subsample of 71 deaf individuals, participants reported both negative and positive experiences in addressing and overcoming challenges and barriers. Interpersonal communication was central in the lives of participants. Deaf participants communicated with the hearing community through writing: "We use the local signs or write a note and sometimes we request for someone who can understand us to bridge the communication gap...". However, some participants were frustrated by the limited use of sign language outside the deaf community: "The main challenge is communication difficulties since not all people can communicate using sign language." Some deaf participants reflected on being informed: "Where I stay there are many deaf people so in my free time, we discuss ideas and share information." However, other deaf participants reported difficulties in receiving information: "Most of these [television] programs are actually meant for hearing people. If you don't have somebody in the family who can sign, then you will not benefit from some of these programs...". Deaf participants reported minimal usefulness of radios in rural areas: "When there is any information being passed out in the village, they always use radios...". Participants also reported their struggles for ongoing gainful employment: "We are not given the same work as the hearing people whom we are working with, yet we have the same qualifications...".

Two thirds of study participants (65%) discussed resorting to sex work: "Most deaf people have no jobs so they end up selling sex to earn a living. Remember, at most times they have unprotected sex, this has happened to a few deaf persons...". Ongoing challenges were the ability to access medical services in a manner culturally appropriate for the deaf community and lack of information on where to access care:

“When a deaf person is sick with HIV, they will not open up and will not go to some of these hospitals to receive services, because they actually don’t have information on where to go, ... we don’t know where to receive free services”. Confidentiality in the medical setting was reported as an issue for deaf participants: “When I am sick, I use the local sign language or write a note or sometimes I go with my cousin sisters who help me explain my problem to the medical personnel because sign language interpreters are very expensive for me to hire.”

Socioeconomic Status

Several participants reported a link between education, employment, and information:

“Information is printed, but few deaf people have gone to school. Getting information means someone has to be educated...” and

“I acquired vocational training in Art and Design, and when I completed that, I returned back to Uganda and started doing my own business.”

Daily living needs, including financial status, food security/insecurity and housing arrangements, could be achieved individually by deaf participants or by the support of others. Frequently, deaf participants praised their families: “It’s my brother whom I stay with and he is supporting me, he helps me a lot when I have a problem, he counsels me and helps me to move around.” Family members also helped participants become independent: “After completing my studies, my parents bought me a sewing machine which I use to earn a living.” Experiences living in rural areas compared to urban areas differed: “In towns, it’s easy since some deaf people can read any printed materials and some have access to televisions and newspapers, but in rural areas it’s hard since they cannot read and neither can they write...” and “The deaf in the villages are oppressed, segregated and subjected to forced labour.”

Support Systems

Family support was reported frequently by deaf participants: “Since my parents died, my elder brother took care of me and I completed my school”. Families were described as caring: “My family supported me in paying my school fees, encouraged me to read, they even bought for me clothing. When I am sick, they take me to the hospital for treatment and they have not neglected me.” Government and non-governmental organization (NGO) support was viewed as both positive and negative:

But I would like to appreciate the government and the NGOs for the services provided to the disabled community. For instance, the formative action at the universities where we are admitted on government sponsorship. As a deaf person, we have sign language interpreters who interpret for us during lectures, and they are paid by the university.

Conversely, another participant suggested the government could do more:

“There are many government programs concerning HIV/AIDS established in rural areas ... but it’s not benefiting deaf people since there are no sign language interpreters and the doctors do not know sign language...”.

Community support was reported for a variety of reasons ranging from the use of sign language, feelings of inclusion, friendship, and information:

In the deaf community, I use sign language as a mode of communication because I had the opportunity to learn sign language and can communicate with my deaf community. So, when I am with the deaf community, I feel so happy to communicate, because it is not as before when I could not communicate with the hearing people...

As a group, the deaf community shared advice and life experiences: "We share about sexual issues; we share a lot of advice with one another... we can always share ideas to see how we can live a very good life...".

HIV

HIV knowledge was reported by some participants and lacking for others. This deaf participant communicated the following: "I don't receive clear information about HIV/AIDS, but my friends tell me that AIDS kills, and that I have to be very careful and protective about my life." Some were specific in what they thought placed someone at risk for HIV: "What I know about HIV/AIDS is that when one is infected, it brings signs and symptoms, and it can be spread through kissing and having unprotected sex." Some had extensive HIV knowledge: "I am educated, and I have the skills and am a trainer, there are deaf people who are in the community, but they don't have access to information, ...other deaf people they even don't know what a condom is...".

HIV testing was known among this subsample. Some had previously tested for HIV: "The last time I tested I was not counselled. I got the results, but they were not clearly explained to me." Others were tested for the first time during this survey: "...If my girlfriend gets pregnant, I propose I will bring her here also for testing so that we all will know our status. It is not good if we get HIV". Some knew the importance of knowing one's HIV status before participating in the study. For example, this deaf participant described learning their HIV status: "The results were negative. It's my friend who explained to me and I understood. She told me to continue protecting myself very well." Others did not previously know their status: "I came here because they told me that they provide services, thus I came to test and know my HIV/AIDS status."

Stigma

This deaf participant summarizes the impact of stigma on risk of HIV: "So many deaf people are stigmatized, thus they lack the knowledge and assistance on where to go [for HIV services]." Another deaf participant shared: "There are very few deaf people who are respected, many people undermine us, thinking that we can't do something good." There was also an undercurrent of hopelessness:

"Concerning stigmatization, I think this happens a lot... if I am punished all the time and I do not know the cause for my punishment, it becomes very difficult for me to know what I have done...very difficult for me to communicate with the family member or that person [who punished me] as they may not know sign language. This in the end creates

stigmatization and the deaf people may resort to staying alone or looking for other deaf friends.”

In some instances, deaf participants recalled the use of the term “kasiru”, a Luganda term which translates to stupid. In other instances, participants expressed social isolation and loneliness as a direct result of being stigmatized by the public or family members.

Abuse

In comparison to other abuses (physical, verbal), sexual abuse was reported more often: “You know some people think we are stupid, and they take advantage to sexually abuse us.” Other reports of sexual abuse included: “Some hearing people use deaf persons and leave them suffering...”.

Reasons for Participation in this Survey

The inclusion of HIV testing and counselling for individuals in the Crane survey was reported positively by study participants. The use of peers to facilitate survey participation was also reported positively. For example, this study participant shared: “She is my best friend, she is the one who gave me the coupon and told me to come here and screen my blood, she told me that you go and test for HIV and STDs at Crane survey, so I came.” Another participant described the process of enrolling in the study: “I got this coupon from a friend. Then he advised me with this coupon that there is a survey for deaf persons. He told me there is HIV/AIDS counselling and testing...”.

Discussion

In this secondary analysis examining in-depth interviews of deaf individuals, eight major themes were identified: challenges/barriers, support systems, socioeconomic status, health information, abuse, health conditions, stigma, and reasons for study participation. Not surprisingly, challenges/barriers were reported most often by deaf participants. Despite these challenges, deaf persons are aware of the importance of their HIV status, testing, and education.

Progress for the deaf community is hindered in part by the hearing community’s inability to communicate with deaf persons using sign language [6, 17], and, for some deaf individuals, the inability to read and write due to limited educational opportunities. Ensuring access to HIV prevention messages, confidential care and communication specific to the deaf community will decrease HIV burden and disparities [18–21]. We also see the importance of support systems in mitigating challenges/barriers for the deaf community. Deaf individuals may learn about HIV-related services, including testing, differently. In Kenya, deaf individuals learned more about HIV testing services through the community, religious meetings, and newspapers rather than a mass media campaign [22]. Non-governmental organizations, such as deaf associations, play a significant role in helping the deaf community access HIV resources, and deaf peer educators help influence access to testing services [22]. However, some members of the deaf population may also spread misperceptions of HIV [17].

Lack of education, rural residence, and inadequately meeting basic needs are socioeconomic factors negatively impacting lives of deaf individuals in Kampala. Deaf participants experienced difficulties in finding employment and, in some cases, sold sex because they had no other means to support themselves. Lack of money can lead to exploitation of deaf individuals. To our knowledge, our study is one of the first to report sex work among deaf individuals due to economic hardship, especially on the African continent.

Deaf participants reported being abused and taken advantage of based on their inability to hear, which has been observed in other settings. In Zambia, increased risk of abuse was related to deaf individuals being “silent,” [17]. In Uganda, a hearing-impaired female respondent reported deaf community vulnerability due to the inability to discern honest relationships with men [17]. These patterns of abuse, especially sexual abuse and early pregnancies could potentially correlate with increased risk of HIV exposure.

Despite the tremendous achievements in HIV control thus far, stigma remains and is compounded for deaf persons and those with other disabilities [16, 23]. Stigma was a major theme but was supported with fewer quotes when compared to challenges/barriers. *Kasiru* was sometimes mentioned by the participants, who reported that the hearing community often implies deaf individuals were less intellectual compared to the hearing community. As a result of stigma, deaf participants suffered social isolation. This isolation, stemming from the stigma of deafness, likely imposes additional barriers to accessing HIV information and healthcare.

In our review of the major themes and subthemes, we observed that subthemes were related and were difficult to separate individually. Thus, even though we report quotations for most subthemes in this paper, these quotations may contain multiple subthemes. We opted to include multiple subthemes to provide the full context of how deaf individuals navigate daily life in Kampala, Uganda. Major strengths of this study include: the number of completed interviews (71) conducted using sign language, and information on HIV testing and status. Further, our findings are similar to other studies in the literature and include many themes and subthemes summarizing the diverse experiences of the deaf community in Kampala, Uganda. However, our study had several limitations including: the inability to generalize findings outside of Kampala, lost information in the translation from Luganda to English, and de-linkage of demographic characteristics for the individual interviews.

Conclusions

There is a lack of information in the literature regarding the deaf community and HIV. Available studies are limited in sample size, often consider all disabilities together instead of separately, and mainly focus on youth. Our findings are similar to available evidence, but also highlight a new finding, sex work for economic purposes; the role of sex work among deaf individuals warrants further exploration. As governments, health practitioners, and communities strive to end HIV, it is important to tailor interventions for deaf and disabled persons. The findings in this study suggest a complex context in which the deaf community in Kampala experience HIV prevention and treatment, which is exacerbated by the lack of timely access to information compared to the hearing community.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Major themes and subthemes of a subsample of deaf individuals (n = 71) who participated in the Crane survey in Kampala, Uganda (2014–2015)

Table 1

Major theme	Subthemes	Number of quotations
Challenges/barriers		1050
	Interpersonal communication ^a	320
	Access to information ^a	236
	Employment/financial difficulties ^a	261
	Access to medical services ^a	172
	Confidentiality ^a	38
	Lack of challenges ^b	28
Socioeconomic status	Education ^a	655
	Participants' needs ^a	364
	Geographical location ^a	240
		51
Support systems		627
	Family support ^a	328
	Government and non-governmental support ^a	175
	Deaf community ^a	86
	Support from private entities ^b	10
	Religious support ^b	20
HIV		422
	Knowledge ^a	232
	Testing ^a	124
Stigma	Status ^a	66
		195

Major theme	Subthemes	Number of quotations
Abuse	General ^a	135
	Social isolation ^b	37
	Associating deafness with stupidity ^b	23
		134
Health conditions	Sexual ^a	87
	Physical ^b	24
	Verbal ^b	19
	No abuse ^b	4
Reason for study participation	Pregnancy ^b	69
	Malaria ^b	48
	Reasons ^a	21
		38

^a 40% of participants contributing at least one quote per subtheme.

^b < 40% of participants contributing at least one quote per subtheme.