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② SUPERTITLE

HIV/AIDS and disability: Differences in HIV/AIDS knowledge between deaf and hearing people in NigeriaN. E. GROCE¹, A. K. YOUSAFZAI² & F. VAN DER MAAS³

¹Global Health Division, Yale School of Public Health, Yale University, New Haven, USA, ²Center for International Child Health, Institute of Child Health, University College London, UK, and ³CBR EFFATA, Omuorudu Iseke, Abakaliki, Ebonyi State, Nigeria

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Abstract

Purpose. Studies both in North America and Europe have found that deaf individuals lack access to AIDS information, due to problems in communication, low literacy and tightly woven social networks within the deaf community. However few comparable studies are available from countries in the Developing World. The present study was undertaken in Nigeria where there is an estimated adult HIV prevalence rate of 5.4%. We sought to compare HIV knowledge among deaf and hearing individuals in order to identify how effectively deaf members of the community are being reached by HIV/AIDS messages.

Methods. A survey comparing knowledge about HIV/AIDS among deaf and hard of hearing adolescents ($n = 50$) and young adults ($n = 50$) was undertaken.

Results. Significant differences ($p < 0.05$) in levels of understanding about certain aspects of how AIDS is spread were identified as well as differences in available resources for access to accurate information among deaf members of the population.

Conclusion. These findings from Nigeria speak strongly to the need for the development of interventions that include people with disabilities in public health and HIV/AIDS strategies and that address their specific vulnerabilities. Evaluating the adaptation of education material and the inclusion of the deaf population in HIV awareness programmes is an urgent 'next step.'

Keywords: HIV, AIDS, disability, deafness, Nigeria

Introduction

The World Bank's recent Global Survey on HIV/AIDS and Disability [1] identifies people with disabilities as a significantly overlooked high-risk population. Specifically cited was the lack of data on disabled populations and HIV throughout the Developing World. This study attempts to provide one piece of this larger puzzle by identifying the extent of knowledge, and local access to information around HIV/AIDS among a deaf population in Nigeria. It is argued that specific knowledge such as this is vital to the development of best practices ensuring the inclusion of disabled people in HIV/AIDS prevention and management efforts.

This study was undertaken in Nigeria where there is an estimated adult HIV prevalence rate of

5.4% [2]. The purpose of the study was to compare HIV knowledge among deaf and hearing young people in order to identify whether there are significant differences in the amount of AIDS information reaching each population.

While no census data is available from this region on the number of individuals with disability in general or deafness in particular, the United Nations estimates that approximately 10% of the world's population lives with a disabling condition [1]. The rate of deafness in this region of Nigeria is believed to be particularly high due to high rates of cerebral malaria, meningitis, poor antenatal care and lack of adequate clinical care, particularly for young children.

Concern about the amount of HIV/AIDS information available to deaf individuals is an ongoing issue.

Findings from surveys from the Developed World, especially, the United States, have established the fact that individuals with substantial hearing loss or deafness have significantly less access to HIV/AIDS information, resources and services than do their hearing peers [3].

There are a number of interrelated reasons for lower levels of access to information and services. For example, deaf individuals who rely on sign language as their primary means of communication often face substantial communication barriers. The mass media is largely inaccessible to them [3–5]. Deaf populations, on the whole, tend to have less access to education than the surrounding hearing population [3]. Even when educated, individuals who are deaf have significantly lower levels of literacy, a circumstance which interferes with their ability to understand AIDS information [5]. Much AIDS information is simply inaccessible – radio campaigns and non-captioned television campaigns rarely reach the deaf and lower literacy results in less recourse to magazines and newspapers [1].

Sign language is rarely used by AIDS outreach workers in dissemination of AIDS messages and sign language interpreters are rarely available in HIV+ clinics or testing centers. Communication barriers limit open discussion with hearing family and community members, with the result being that deaf individuals are often isolated from the surrounding society. Cut off from easy communication with the larger society, the information that deaf individuals rely on is often received through an active ‘deaf grapevine’ – a collection of stories, folklore and rumours commonly found within the deaf population. The deaf grapevine routinely carries and reinforces information – and all too often, misinformation about HIV/AIDS that is difficult for AIDS experts not fluent in sign language to monitor or correct [3].

The issue of knowledge and attitudes towards HIV/AIDS within disabled populations in general and among deaf populations in particular, has not been extensively studied, but it is clear that they are no less at risk for HIV infection than the rest of the population [1]. Findings from qualitative studies in Uganda and Rwanda [6] show adolescents with disabilities are highly vulnerable to HIV and sexually transmitted infections due to sexual abuse, misconceptions about sexuality and rights and issues of self-efficacy affecting control in relationships. Choquet and colleagues [7] reported that chronically ill and physically impaired adolescents in France had a higher rate of sexual intercourse than their non-disabled peers. Suris and colleagues [8] reported that adolescents with disabilities were more likely to experience sexually transmitted infections as a consequence of sexual behaviour, which may in part reflect lack of knowledge or means to negotiate safer

sex. Disabled adolescents in Uganda and Rwanda faced physical, attitudinal and societal barriers in accessing information and services [6]. Poor physical access to health centres, lack of confidentiality for people with communication impairments and a lack of disability-friendly education material (particularly for blind, learning disabled and again the deaf groups), are additional barriers of concern [1].

In 2003, a qualitative study investigating perceptions of personal risk for HIV/AIDS among disabled and non-disabled adults in Swaziland [9] found disabled adults obtained information about HIV/AIDS from a limited range of sources and were more likely to be significantly misinformed about modes of HIV transmission compared with their non-disabled peers. Based on this qualitative study, a survey to ascertain the differences in knowledge about HIV/AIDS was developed and piloted on deaf and hearing populations in Swaziland [10]. This survey was used here as the basis for data collection in Nigeria, both allowing us to ascertain the current status of knowledge among a deaf population and to compare, for the first time, levels of HIV knowledge in deaf communities in two developing nations.

Method

This study was undertaken in rural towns in the South East of Nigeria. The population in this area is mostly of the Christian faith. The study population comprised deaf and hard of hearing participants ($n=50$) recruited from two schools for the deaf located in Omorodu Iseke town in Ebonyi State and a town close by in Enugu State. The schools provide primary education for adolescents and young adults. All deaf participants were above the age of 12, but exact ages were impossible to determine because traditionally, individuals do not keep track of their age in this section of rural Nigeria. Of the deaf participants, the majority were still attending the schools ($n=40$), while a smaller number were either graduates or drop outs ($n=10$). Because children in general do not start school until older in Nigeria, and disabled children in particular, may not start their educations until later, although the deaf students who responded to the survey were all above the age of 12, all were attending primary school. For surveys of the deaf population, participants are often conveniently sampled from known networks of the deaf such as schools for the deaf or deaf associations. The comparative hearing population ($n=50$) was recruited from the same towns at random in the market place where every third person was asked whether they would be able to spare the time for a brief interview about HIV/AIDS.

The survey was conducted by trained staff from EFFATA, a non-government organization (NGO)

delivering disability services in the area, with overall supervision by co-author van der Maas. The survey format was a series of structured questions examining HIV/AIDS knowledge and access to information about HIV/AIDS previously used with a deaf population in Swaziland [10]. The survey was administered in English to the hearing population. For the deaf population, the American Sign Language, (which is locally used) was interpreted by the school teachers from the schools for the deaf. The responses were double entered into the statistical Package for Social Sciences (SPSS, version 11.5). Standard statistical methods were applied to compare responses for the deaf and hearing population.

Results

Table I shows the demographic data of the largely rural study population. The deaf group was significantly younger ($p < 0.05$), less likely to have received any secondary education and more likely to be unemployed. The majority of the deaf respondents used sign language to communicate (86%).

Overall, nearly all of the study population had heard of HIV/AIDS (91%). Some key messages about HIV transmission were understood by the majority of respondents; for example more than 80% of the study group was aware that HIV could be transmitted sexually between a man and woman,

Table I. Demographic data for the deaf and hearing respondents.

	Deaf (n = 50)	Hearing (n = 50)
Gender (male:female, %)	62:34	62:38
Age (%)		
≤25 y	82*	28
26–30 y	16	38
31–35 y	2	16
36–40 y	0	16
≥41 y	0	2
Urban: Rural (%)	16:84	26:74
Literacy (%)	86	90
Level of education		
None	14*	8
Primary	80	22
Secondary	6	38
Vocational	0	10
University	0	22
Currently employed (%)**	8*	58
In household access to (%):		
Television	20	36
Radio***	82	98
Newspapers	36	54

*Categories that are significantly different by *t*-test ($p < 0.05$); **Deaf participants worked as manual labourers, while employed hearing participants were more likely to report working in semi-skilled or skilled professions; ***While radios are not accessible to deaf individuals, access by other members of a deaf person's household to radio may increase the amount of overall AIDS information available all members of that household.

although there was less certainty about transmission through homosexuality. The deaf respondents were significantly more likely ($p < 0.05$) to believe in incorrect modes of HIV transmission such as kissing (deaf 44% vs. hearing 20%), touching (deaf 42% vs. hearing 10%) and transmission due to a dirty environment (deaf 30% vs. hearing 4%). The deaf respondents were also significantly less likely ($p < 0.05$) to be familiar with the possibility of mother-to-child HIV transmission (deaf 52% vs. hearing 74%) (Table II).

Knowledge about HIV prevention was similar among deaf and hearing respondents (Table III). Key messages were well known by both groups, such as sterilization of needles ($\geq 76\%$). Abstinence as a prevention message was more strongly agreed with by all respondents compared with condom use (abstinence $\geq 74\%$ vs. condom use $\geq 42\%$). Avoiding dirty places and not hugging as a means of prevention were generally more strongly agreed upon among deaf respondents reflecting their beliefs about HIV transmission. However, there was a significant difference ($p < 0.05$) between the two groups in that the deaf respondents were less likely to be familiar with testing blood prior to transfusion (44%) compared with the hearing respondents (82%).

The survey also addressed the range of sources of HIV/AIDS education (Table IV). In every category of HIV/AIDS information source, the deaf respondents were significantly less likely ($p < 0.05$) to have access. Hearing respondents' main source of information was from the radio (86%), a source of information largely inaccessible to the deaf and hearing impaired group. The next significant source of information for the hearing group came from the religious (church) organizations (84%), which was also by far the main source of information for the deaf group (50%), although a significantly smaller percentage of those deaf individuals surveyed are

Table II. The modes of HIV transmission believed to be true by the deaf and hearing respondents.

	Deaf (n = 50) %	Hearing (n = 50) %
Mosquito bites	38	12
Kissing	44*	20
Sex (man-woman)	80	88
Sex (man-man)	62	50
Sex (woman-man)	78	86
Sharing bowls, utensils	20	30
Touching or hugging	42*	10
Unsterilized needles	64	80
Unsterilized razors	78	88
HIV+ mother to baby	52*	74
Germs in the air	26	6
Dirty places	30*	4

*Categories that are significantly different by *t*-test ($p < 0.05$).

being reached in this manner. Despite a reported literacy rate of 86% for the deaf respondents, information accessed by posters (17%), magazines (22%) and newspapers (20%) was poor compared with the hearing respondents (72%, 76% and 74% respectively). The hearing group also had information provided from family, the general community, events and meeting places (e.g., community plays 44%, co-workers 72%, clinics 82%), which the deaf respondents find significantly less accessible (community plays 8%, co-workers 12% and clinics 46%).

Discussion

Studies of deaf populations can be limited by sample size making results less generalizable, however some trends still emerge from our findings. The data on knowledge about the transmission and prevention of

Table III. The modes of HIV prevention believed to be true by the deaf and hearing respondents.

	Deaf (n = 50) %	Hearing (n = 50) %
Sterilization of needles, razors	76	82
Avoiding dirty places	44	24
Testing blood before transfusion	44*	82
Not sharing bowls, utensils	34	40
Using condoms	42	46
Not hugging	42	24
Abstinence (no sex with anyone)	78	74
Eating healthy foods	42	32
Washing hands	32	24

*Categories which are significantly different by *t*-test ($p < 0.05$).

Table IV. Different sources of HIV/AIDS information accessed by deaf and hearing respondents.

	Deaf (n = 50) %	Hearing (n = 50) %
Television	8*	60
Radio**	10*	86
Newspapers	20*	74
Magazines	22*	76
Internet	0*	12
Friends	36*	76
Parents	28*	60
Disability organizations/CBR***	20*	54
Hospitals, clinics	46*	82
Community health workers	14*	70
Posters	18*	72
Community plays	8*	44
Community meetings	4*	46
Religious organizations	50*	84
Fellow workers	12*	72
Relatives	16*	72
Community leaders	4*	58

*Categories that are significantly different by *t*-test ($p < 0.05$);

Hearing impaired could access some information from the radio; *EFFATA NGO.

the HIV virus indicate the deaf group was more likely to agree with incorrect ideas. In agreement with data from a deaf and hearing population in Swaziland [10,11], the deaf respondents were significantly more likely ($p < 0.05$) to believe that HIV could be transmitted by kissing, hugging and dirty places. Furthermore, as also shown in data from Swaziland, the deaf group was significantly less likely ($p < 0.05$) to be familiar with testing blood prior to infection as a means of preventing HIV transmission.

The quality of the knowledge and accessibility of up-to-date information for deaf populations also appears to be a very real concern. In agreement with data from Swaziland, deaf people had significantly less access ($p < 0.05$) to all sources of HIV information listed in the survey. Despite high levels of reported literacy, access to HIV information in print material was poor among the deaf population, which may reflect lower levels of functional literacy.

The folklore about HIV/AIDS found in this study from Nigeria also is similar to the findings from Swaziland. For example, in Swaziland, the deaf participants in the study were significantly more likely ($p < 0.05$) than the hearing participants to believe that the virus could be transmitted by kissing (deaf 56% vs. hearing 28%) or by germs in the air (deaf 53% vs. hearing 4%). Such misinformation is not unknown in the general population in either country, so it is possible that once introduced into the 'deaf grapevine' it has been picked up and reinforced. It is also possible that misinformation about HIV/AIDS is being carried from one deaf population to another across Sub-Saharan Africa, with the result being the regular repetition and reinforcement of incorrect AIDS information. Knowing that similar incorrect information is found in both Nigeria and Swaziland is important for those running AIDS intervention efforts, as these findings may allow us to better predict and address misinformation among local sign language users.

The deaf respondents all had some access to formal education and exposure to HIV/AIDS awareness while in school, but future concerns include the fact that once out of school, information about HIV within the general community appears to be less accessible to deaf citizens (e.g., community meetings). Indeed, the main source of information on HIV/AIDS for the hearing groups in Nigeria (and also documented in Swaziland) is the radio, which is not accessible to the deaf population.

The findings from this study tie in well with what is already understood about HIV/AIDS and disability. Access to formal education for individuals with disability in many developing countries is low or non-existent [1] but the identified gaps in knowledge, attitudes and practices around topics of HIV/AIDS among disabled people in these studies are not

460 simply a result of a lack of formal education. Rather
 it is related to complex issues around communica-
 465 tion (particularly for the deaf and learning impaired
 groups), a lack of accurate impairment-friendly
 education and health services, misconceptions by
 AIDS experts about sexuality and disability, in-
 creased rates of sexual abuse of individuals with
 470 disability and negative attitudes about disability,
 which are compounded by poverty [1,6,12]. Studies
 about quality of healthcare for deaf people have
 highlighted dissatisfaction of services by deaf users
 [13]. However, the transfer of knowledge about good
 475 practices is less well documented for international
 audiences. Some evaluations of disability friendly sex
 education (including AIDS education) for young
 people with learning impairments and deaf adoles-
 cents is also reported in the medical literature [14–
 16]; however, such educational materials need to be
 re-packaged to be culturally sensitive in order to
 meet the needs of disabled people in many develop-
 ing nations.

480 Conclusion

These findings from Nigeria speak strongly to the
 need for the development of interventions that
 include people with disabilities in public health and
 HIV/AIDS strategies and that address their specific
 485 vulnerabilities. Evaluating the adaptation of educa-
 tion material and the inclusion of the deaf population
 in HIV awareness programmes is an urgent next
 step. Equally important, there is a clear need to
 train and support deaf individuals themselves to
 490 become AIDS education and outreach workers,
 capable of providing increasingly better and more
 accurate AIDS information and services to the deaf
 community.

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