Systems of communicating sexual and reproductive health issues between hearing parents and their deaf adolescent children in western Kenya

Abstract

Background: Deaf adolescent children face greater challenges in accessing information, particularly on sexual and reproductive health (SRH) than those with other forms of disability. Parents therefore represent the first source of information for such children. However, the extent of this and systems of communication used by these parents remain largely unknown. Therefore, it is against this backdrop that we sought to study systems of parents communicating SRH issue to their children.

Method: A mixed method design was used to collect quantitative and qualitative data on the system of communication used by the sign-language illiterate parents respectively, their perceptions on such discussions,a nd the choice of system of communication.

Results: Majority of the male parents 90 (49%) were in the age range of 51-60 years, while most female parents 134(56%) were in the age category of 40-50 years. Nearly 70% (67%) of the children were in the age range of 15-19 years. Overall, use of picture came out as the main mode/format of communication (33%), with females using it more (23%) compared to males 12.3%.Lip-reading (lip reading by the children), was principally used by male parents. 32(10%)parents falling within the age group 41-50 and 51-60 years felt the information about SRH was inadequate. However, in a qualitative interview, most parents were not satisfied that they had provided enough information to their children on matters of SRH due to commutation barrier.

Conclusion: Children with hard hearing are less likely to get adequate information on SRH than their counterparts with no hearing impairment.

Key words: Deaf children, parents, communication systems

1. Introduction

People living with any form of disability are some of the most marginalized and excluded groups in many societies in Africa[1]. In most circumstances, children with disability and their families are deprived of basic resources and services, including limited access to such critical opportunities such as education and healthcare[2]. Additionally, problems facing children with disability are further compounded by stigma and negative attitudes in their daily lives. Surveys indicate that even though people living with disability are a high-risk group with regards to HIV/AIDS infection, they are often neglected in disease prevention campaigns[3, 4], largely due to misconceptions about their vulnerabilities and sexuality[5]. Indeed, the fight against risks associated with lack of information on sexual and reproductive health (SRH), including HIV/AIDS, shows that the exclusion of people living with disability such as the deaf is an influential vulnerability factor that slows down prevention measures[6].

It is estimated that deaf persons are up to 8 years behind the general population in their level of knowledge of disease prevention and other SRH issues[7], compounded by their low self-esteem relative to those with hearing ability[8]. Due to the difficulties encountered in accessing information from formal sources, deaf people often turn to informal sources such as friends and family members for information[9, 10]. However, this often has dire consequences when it comes to learning about SRH issues. Studies, for example [9]have reported differences in levels of knowledge on HIV/AIDS between deaf college students and their hearing counterparts. This implies that deaf students are less likely to have accurate knowledge as information from informal sources may be incomplete or inaccurate while hearing students obtain information from teachers, and mainstream media. Although data suggests that deaf people in parts of Africa have limited knowledge about SRH issues[11], little is known about the extent and nature of the problem.

In much of Africa, parents are the first sources of information for their children on a range of issues including SRH, with other sources such as television sets being only occasionally available. Difficulty in communicating with deaf children arises from the fact that most of deaf children have hearing parents who frequently do not have a fully effective means of communicating with them[12]. The Kenyan sign language, for example, is also only recognized

by a limited number of institutions such as the Kenya Law Courts and a few government schools and churches. Furthermore, users of sign language have demonstrated a weakness in capturing information on SRH issues, especially in the context of HIV/AIDS. Even workshops organized to discuss SRH issues have failed to interpret complex SRH issues into sign language[13]. Two systems of communication have been employed by different stakeholders to deliver required SRH messages/services to people who are deaf: i) participatory approach in awareness creation, and ii)deaf-friendly testing, counseling, care and treatment[14]. These services would work better for well-equipped institutions, but not for resource-constrained parents in much of rural Africa. This means that systems of communication with deaf persons by those who are not trained in sign language remain unknown. The objective of the current study was therefore to establish the systems of communication between parents and their deaf adolescent children on SRH issues.

2. Materials and Methods

2.1 Study design, area and population

The study employed a descriptive mixed method design, combining both qualitative and quantitative components. A mixed method approach combines elements of qualitative research approaches in a single study thereby allowing a researcher to answer quantitative and qualitative questions concurrently. This approach aims at drawing from the strengths and minimize on the weaknesses of both in a single research study. A structured questionnaires was used to collect quantitative data while, a semi-structured questionnaires was used to collect qualitative data in form of a focus group discussions (FGDs). The study was carried out in ten schools randomly selected from a sample frame comprising of a list of primary and secondary schools for deaf children within the former Nyanza region of western Kenya. Due to confidentiality issues and the need to protect the schools and students concerned, the names of these schools are not provided. The region has a population of about 650,000, with a population of adolescent youths, that is, those aged 10 – 24 years[15], who are deaf are estimated to be about 10,000.
Additionally, the region has one of the highest HIV/AIDS prevalence rates, at 14% of 1.4 million Kenyans living with the scourge[16]. The study population was made up of paired parent-deaf

adolescent children that were attending approved schools for deaf persons in the region. For a parent-student pair to be eligible for inclusion, the pupil/student had to be aged between 10 and 24 years; had to be enrolled in a school, and be in between class VI (year six) and form IV (year twelve); must have lived with the parent(s) and in location of origin for at least the preceding 3 months; the parent had to be the biological parent or be a guardian and sign language illiterate.

2.2 Sample size and sampling techniques

The target population for this study was parents to children with hearing impairment. Since there is no previous studies carried out in Kenya and reporting the proportion of parents of children with hearing impairment, we assumed 50%,with a standard normal variate at 5% type 1 error (P<0.05) and 5% precision. Based on this assumption, we calculated a minimum sample size of 384 and after factoring in 5% individual non-response rate or partial interviews/breakoffs[17, 18], we further arrived at a minimum sample size of 405of paired parents to children with hearing impairment.

1.2.1. Sampling technique

To generate 426 parents to children with hearing impairment for the quantitative component of the study, class registers provided sampling frame, and a simple probability sampling technique was used to select parent-student pairs. For the qualitative component, respondents were recruited using a purposive convenience sampling method; while it is non-representative sample, it allows the investigator to choose participants who are best suited to provide the intended perspective. Eight FGDs consisting of about 8-10 parents of children with hearing impairment were conducted.

1.3. Data collection

Ten interviewers, fluent in the two national languages, i.e. English and Kiswahili, were recruited to facilitate data collection using a pre-tested anonymized questionnaire. Prior to implementation of the questionnaire, the interviewers were trained on the general objective of the study, detailed content of the questionnaire, the methodology in relation to the study objectives and on how to administer the instrument in a way that maintains confidentiality and privacy of the respondents as well as on how to collect reliable, valid and trustworthy data. Following the training, the

questionnaires were pre-tested among a similar population in the region and adjusted accordingly.

Structurally, the questionnaire for the quantitative data had closed and open-ended questions organized within key sections capturing (i) socio-demographic information of the study participants, (ii) system of communication on SRH matters with their deaf adolescent children, and (iii) factors influencing communication between such parents and their children. Similarly, FGDs were used to collect data from the respondents in a bid to verify and authenticate some of the responses received from the questionnaire surveys as is often the case in such surveys[19]. Eight FGDs comprised 8-12 participants per group were conducted. A semi-structured guide comprising open-ended questions that sought to elicit descriptive and explanatory comments from the participants was used to lead the discussions, which were carried out to saturation.

1.4. Data Analysis

1.4.1. Quantitative data analysis

Quantitative data as obtained from questionnaires were entered into Statistical Package for Social Sciences (SPSS) software version 20 (SPSS Inc.Chicago, USA), cleaned, and coded. For the purposes of this study, the systems of communication were categorized and coded as 1 = picture, 2 = word of mouth, 3 = video, 4 = combination of methods. Participant characteristics were presented by use of frequencies and percentages for categorical variables. Format of communication and adequacy of the information passed to the children with the hearing impairment were presented in a table by use of frequencies and proportions.

1.4.2. Qualitative data analysis

Data analysis for qualitative was done concurrently with data collection and commenced as soon as the first interview was completed. This allowed for any adjustments and gave the most reliable and valid data.

A codebook was developed and NVivo 10, a qualitative data analysis program, was used to organise the data and code themes from the transcribed interviews and discussions. Analysis was started by organizing data according to the interviews of the study participants, complete

transcription by typing the text files collected during interviews. Then from each transcript, we identified key phrases or sentences, which relate to the study questions. Thereafter, formulated meanings from these significant phrases and sentences, which finally allow common themes to surface. A ‘‘grounded theory’’ method was used for data analysis, an inductive approach where theory is generated from the data. Descriptive summaries and quotes representing the main themes were captured. Quotes were selected on the basis of their clear representation of the themes

3.0. Results

3.1. Quantitative

Table 1 presents the characteristics of parents and their children; who participated in the quantitative survey. A total of 422 parents paired to their children participated, of which, 184 (43.6%) were males, and 238 (56.4%) were females. The age of parents ranged between 31 and 70 years, with majority 203 (48.1%) falling between 41 and 50 years. Majority of the parents falling within the age group 41-50 were females (34% vs. 66%, p-value= 0.036). Only a few of the parents 13 (3.1%) were below 41 years of age, with almost similar number and proportion 12 (2.8%) being over 60 years old.

More than a half of the respondents were married 276 (65.4%), while minority were either single 16 (3.8%) or divorced 14 (3.3%). A relatively large number 116 (27.5%) of the respondents were, however, widowed with a significant higher percentage of females than males reporting being widowed (15.2% vs. 37.0%, p-value > 0.001). Majority of the respondents 308 (73.0%) lived in rural areas, and most of them (69.2%) acknowledged the gravity of the problem of HIV/AIDS in their localities (**Table 1**).

With regards to the children, their ages ranged between 10 and 24 years as shown in **Table 3** , with a higher number and proportion 285 (66.9%) being in the 15-19 years’ age range. Only 52 (12.3%) and 89 (20.9%) were aged below 15 and over 20 years respectively. Similarly, there were slightly higher numbers and proportions of male 241 (57.1%) than female children 181

(42.9%) in the sample (**Table 1**), a further demonstration of limited education opportunities available for the girl child since deafness is a phenomenon that equally affects both boys and girls (Absalan et al., 2013).

Parents used lip reading by the children, picture, video and a combination of systems to communicate SRH issues with their deaf adolescent children. Overall, there were significant differences among the systems of communication used by male respondents, with lip-reading being the most used (38.6%) followed by picture (27.2%) and a combination of systems (26.6%). The results in **Table 4** showed that older parents (41-60 years) were more likely to communicate using word of mouth compared to younger parents.

Video was the least used by the males (**Table 4**). Noteworthy, this method was only used by males aged between 41 and 60 years old, with none of the younger and older males using this system. Conversely, picture was the system used by a significantly higher proportion of female respondents (66.8%), followed by a combination of methods (18.1%) and word of mouth (14.3%), with video similarly being the least used (0.8%).

3.5 Adequacy of information passed to deaf adolescent children

Overall, significantly higher proportions of male, female and total respondents were not satisfied that they had provided adequate information on SRH issues to their deaf adolescent children (**Table 5**).While all parents (males and females within the age group 61-70 felt they had provided adequate SRH message to their children, parents falling within the age group 41-50 and 51-60 felt otherwise (Table 5), with 30.5% vs. 20.6% males having a feeling that the information provided is inadequate; likewise females parents also having doubts if the information was adequate enough (29.8% vs. 19.1%)

3.2. Qualitative

During the focus group discussion, it emerged that the high proportion of widowhood respondents could have been occasioned by death of spouses resulting from HIV/AIDS and other

preventable diseases, but due to poverty, the victims were not able to access proper and timely medical care. The dialogue participants had a consensus that so many people die in the areas they came from but the causes of the deaths were never discussed or divulged to the public even when there was rumors that the diseased had been infected with HIV. The participants were of the opinion that HIV and AIDS is a very big health issue in their locations of residence. A parent emotionally shared that "*there is a lot of unfaithfulness in the society especially among those who know their HIV status*".

3.2.1. ***Severity of HIV/AIDS Pandemic in Villages of Residence and Susceptibility of Children with Hearing Impairment.***

The parents agreed that their children with hearing impairment are equally sexually active as their non-deaf counterparts. They unanimously agreed that their hearing impaired children were at an increased risk of contracting HIV if they practiced irresponsible sexual behavior. A parent was of the opinion that their children are at a greater risk of being infected because they can be easily cheated or misguided by HIV positive people who wish to take advantage of their condition. A parent said ...."*hearing impaired children are at a greater risk because of their communication problem. This is because parents of hearing-impaired children lack appropriate language mechanism of discussing HIV related matters with their hearing impaired children".*

3.2.2. ***Content of Discussion on Sexual and Reproductive Health issues with Hearing Impaired Children***

It emerged that the discussions were on advising especially girl children with hearing impairment to avoid teenage pregnancy, abstinence and waiting till the right time/age; advising the children to avoid bad company, discussing with the children on the causes, spread and effects of HIV and AIDS.An emerging issue was that majority of the parents had not talked with their children on

HIV prevention and treatment. One parent said, "*my emphasis is usually on avoiding the disease (prevention is better than cure)"*. Opinions were divided on whether to continue keeping quiet or start dialogue, for parents who confirmed that they never discuss HIV and responsible sexual behavior with their hearing-impaired children was finally sought.

3.2.3. ***Awareness of the youth friendly programs***

The other issue investigated was whether parents were aware of the existence of any youth program in their community/village that was involved with HIV and AIDS prevention among persons with hearing impairment. Nearly all the parents were not aware of any such programs in their villages. A parent however said, "*there is a program for such matters in North – Gem called North – Gem Dorcas. That group has a program that focuses on HIV prevention and that they build homes to those with HIV and AIDS.However, there are no specific youth programs involved with HIV prevention though KEMRI/CDCusually pitch tents in one community for what people say is tackling HIV matters.*

3.2.4. ***FGD: Extent and Systems of communication and parents Views about Parent-Children with hearing impairment communication on sexual and reproductive health***

Focus group dialogue revealed that most parents had difficulties communicating to their children on SRH. A parent said....."*I yearn to explain or talk about HIV prevention to my child but my major problem is the correct sign language to use*". "*Another parent said "I use crude and natural signs to explain to my daughter especially on the issue of pregnancy*."

4.0. Discussion

4.1. Communicating matters of sexual and reproductive health to deaf children

The most salient fact of deafness is that it renders spoken language inaccessible in the normal fashion. According to Morres and Marschark , the fact that over 90% of deaf children are born to hearing parents [20, 21], has far reaching implications for many aspects of development including language acquisition, familial and social relationships, and access to information and education

Communicating matters of sexual and reproductive health issues with a hearing impairment child in the context of parent-child relationship is extremely challenging. Our findings reveals that whereas majority of the respondents admitted to discussing sexual and reproductive issues with their adolescent deaf children, most of them observed that the information passed to them is inadequate. Some parents/guardians acknowledged not knowing sign language and resorting to use of crude/natural language to communicate. Therefore, due to this, HIV/AIDS remains a big threat to this population. This finding was corroborated during FGDs, where most participants concur that HIV/AIDS is such a big concern to the deaf children than their counterparts who are not deaf. Koester et al.,(2000) observed that for hearing parents of deaf children, parent-child communication becomes a central issue because parents must actively learn how to communicate with their children rather than rely on the intuitive communication strategies [22].

A study on parenting stress among parents of deaf and hearing children found that communication and behavior problem mediates the relation between hearing status and the parenting stress [23].Our findings conforms to those of Mprah Wisdom study (2013) from Ghana, which aimed to provide insights into factors that influence the acquisition, accessibility, and utilization of Sexual and Reproductive Health (SRH) information and services by deaf people who communicate using Ghanaian Sign Language (GSL)[24]. The study findings indicated that when accessing SRH information and services in Ghana, deaf people encounter numerous barriers such as problems with communication, ignorance about deafness, negative attitudes, and services that are not customized to their needs.

In particular, adolescents with hearing impairment face severe challenges because it is often difficult for parents, educators, and counsellors to discuss SRH issues with them, or else they are perceived to be sexually inactive [25]. Consequently, many of these young people are not familiar with basic vocabularies about their bodies, cannot describe what is happening to them

and are therefore vulnerable to SRH problems and sexual exploitation [26, 27]. Information on the SRH status of deaf people suggest that they are more likely to face difficulties in accessing common sources of information than their hearing counterparts [5, 26, 28-30]. Deaf people are less likely to access media such as television and radio [30]. They also encounter communication barriers in the healthcare system because healthcare providers typically cannot communicate with deaf people. Healthcare providers often underestimate the difficulties of speech reading and overestimate deaf people's ability to understand written notes [31].

4.2. Mode of communicating sexual and reproductive health issues

Parent-child communication plays a central role in social growth, as it does in other domains of development. Research shows that over 90% of deaf children, however, have hearing parents who frequently do not have a fully effective means of communicating with them[32]. This paper examined the systems/mode of communicating sexual and reproductive health issues between hearing parents and their deaf adolescents.

A communication option, mode, modality, or method is the means by which the child and family receive and express language. The choice of a communication modality that facilitates language development and allows the child who is hard of hearing or deaf to readily engage in communication interchanges with family and caregivers is a primary issue throughout childhood [33]. Our findings indicated that parents with children of hard hearing in this setting use different mode of communication, with word of mouth being used the most, followed by pictures. A sizable number of parents also used a combination of the systems. Early research observed that parents struggle to communicate with their hearing impaired children, hence some parents end up using gestures, facial expression, pointing, touching and other manual signs that are not recognised in trying to communicate with their children. In addition, some parents or guardians use speech and speech reading as a mode of communication. According to Mbaluka (2013) study on parents' mode of communication with their hearing-impaired children in Gweru urban in Zimbabwe, majority of parents / guardians use total communication mode when communicating with their children. Total communication philosophy combines the aspects of listening, speech reading, signing and finger spelling. Only 10% of parents use oralism as a mode of communication[34]

These results underscore the importance of word of mouth as a system of communicating SRH issues to the adolescent youth, especially by the male parents. As a number of studies have reported a general lack of knowledge and skills especially on SRH among parents(Bastien et al., 2011), it is therefore critical that these parents have the right information to convey and are equipped with the requisite communication skills and ability to deliver such information. There is therefore a need to target these parents in education campaigns and through specific programs as a means to delivering the requisite SRH issues to the deaf adolescent youth since parent-child communication plays a central role in social-emotional development of deaf children, as it does in their other domains of development(Vaccari & Marschark, 1997). Pursuant to this, there are inherent differences in the deaf children's lip-reading abilities [35]. Therefore, there is need to complement these efforts with training of the deaf children from their early years of development in lip reading that needs to be language and context specific in order to improve effectiveness of word of mouth as a communication tool, not only by the parents of these children but by all who are charged with the responsibility to convey such messages to such audience. Improved interactions through communication would also help address the fact that deaf children tend to display more language, attention, and behavioral difficulties, and spend less time communicatingwith their parents than normally hearing children [36].

5.0. Conclusions

Deaf people face greater access problems than people with other forms of disability, because mainstream sources of information are inaccessible to them. They are less likely to obtain information from formal sources such as health professionals and television broadcasts than hearing people**.** Whereas majority of the respondents admitted to discussing sexual and reproductive issues with their adolescent deaf children, most of them observed that the information passed to them is inadequate. Some parents/guardians acknowledged not knowing sign language and resorting to use of crude/natural language to communicate. The system/format of communicating SRH issue to the children differed by sex, with word of mouth being used mainly by male parents, followed by picture and a combination of systems.

The results showed that older parentswere more likely to use a combination of methods compared to younger parents, implying both experience and improved access to different methods of communication. Overall, these results in addition to identifying the various systems used by respondents and determinants of their choices, they underscore the need to improve access of the parents to the right information for conveyance to their adolescent deaf youth.HIV/AIDS remains a major issue among the children with hearing impairment.

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Tables

Table 1: Socio- demographics characteristics of the parents and the their children

Table 2: Age and sex distribution of the parents

Table 3: Age category of the children

Table 4: Format by which parents pass information to their hearing-impaired children

Table 5: Adequacy of information passed to deaf adolescent children

Table 1: Socio- demographics characteristics of the parents and the their children

Parameter	Range/status	Frequency	Percent
Age of parent	31-40 years	13	3.1
	41-50 years	203	48.1
	51-60 years	194	46.0
	61-70 years	12	2.8
Age of child	10-14 years	52	12.3
	15-19 years	282	66.8
	20-24 years	88	20.9
Gender of children	Male	241	57.1
	Female	181	42.9
Gender of parents	Male	184	43.6
	Female	238	56.4
Marital status of the parents	Married	276	65.4
	Single	16	3.8
	Divorced	14	3.3
	Widowed	116	27.5
Level of education of the parents	No education	29	6.9
	Primary	233	55.2
	Secondary	59	14.0
	Tertiary and Above	101	23.9
Residence	Urban	114	27.0
	Rural	308	73.0
Gravity of the problem of HIV/AIDS at place of residence			
	Minimal	103	24.4
	Bad	292	69.2
	Very bad	27	6.4
	Total	422	100.0

Table 2: Age and sex distribution of the parents

Gender	Age (years) 31-40	41-50	51-60	61-70	Total
Male	13 (7.1%)	69 (37.5%)	90 (48.9%)	12 (6.5%)	184 (43.6%)
Female	0 (0.0%)	134 (56.3%)	104 (43.7%)	0 (0.0%)	238 (56.4%)

Table 3: Age category of the children

	Frequency	Percent
10-14	52	12.2
15-19	285	66.9
20-24	89	20.9
Total	426	100.0

Table 4: Format by which parents pass information to their hearing-impaired children

Question: In what format did you pass sexual information to your child with hearing impairment											
		31-40		41-50		51-60		61-70		TOTAL	
		N	%	N	%	N	%	N	%	N	%
Word of mouth	Male	2	20	22	14.2	8	5.7	0	0	32	10.1
	Female	5	50	40	25.8	20	14.2	1	10	66	20.9
Picture	Male	1	10	39	25.2	8	5.7	1	10	39	12.3
	Female	0	0	17	11.0	6	4.3	0	0	23	7.3
Audio visual	Male	0	0	18	11.6	25	17.7	0	0	43	13.6
	Female	1	10	13	8.4	17	12.1	0	0	31	9.8
Others	Male	1	10	10	6.5	31	22.0	6	60	48	15.2
	Female	0	0	6	3.9	26	18.4	2	20	34	10.8
		10	100	155	100.0	141	100.0	10	100	316	100.0

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528 **Table 5**: Adequacy of information passed to deaf adolescent children

Gender/Age		31-40		41-50		51-60		61-70	
		N	%	N	%	N	%	N	%
Male	Yes	2	20	23	14.8	29	20.6	7	70
	No	2	20	37	23.9	43	30.5	0	0
Female	Yes	4	40	26	16.8	27	19.1	3	30
	No	2	20	50	32.3	42	29.8	0	0

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