

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

3

4 **Abstract**

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

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

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14 **Results:** Majority of the male parents 90 (49%) were in the age range of 51-60 years, while most
15 female parents 134(56%) were in the age category of 40-50 years. Nearly 70% (67%) of the
16 children were in the age range of 15-19 years. Overall, use of picture came out as the main
17 mode/format of communication (33%), with females using it more (23%) compared to males
18 12.3%. Lip-reading (lip reading by the children), was principally used by male parents.
19 32(10%) parents falling within the age group 41-50 and 51-60 years felt the information about
20 SRH was inadequate. However, in a qualitative interview, most parents were not satisfied that
21 they had provided enough information to their children on matters of SRH due to communication
22 barrier.

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

25 **Key words:** Deaf children, parents, communication systems

26

27 **1. Introduction**

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

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

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

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

68

69 2. Materials and Methods

70 2.1 Study design, area and population

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72 The study employed a descriptive mixed method design, combining both qualitative and
73 quantitative components. A mixed method approach combines elements of qualitative research
74 approaches in a single study thereby allowing a researcher to answer quantitative and qualitative
75 questions concurrently. This approach aims at drawing from the strengths and minimize on the
76 weaknesses of both in a single research study. A structured questionnaires was used to collect
77 quantitative data while, a semi-structured questionnaires was used to collect qualitative data in
78 form of a focus group discussions (FGDs). The study was carried out in ten schools randomly
79 selected from a sample frame comprising of a list of primary and secondary schools for deaf
80 children within the former Nyanza region of western Kenya. Due to confidentiality issues and
81 the need to protect the schools and students concerned, the names of these schools are not
82 provided. The region has a population of about 650,000, with a population of adolescent youths,
83 that is, those aged 10 – 24 years[15], who are deaf are estimated to be about 10,000.

84 Additionally, the region has one of the highest HIV/AIDS prevalence rates, at 14% of 1.4 million
85 Kenyans living with the scourge[16]. The study population was made up of paired parent-deaf

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86 adolescent children that were attending approved schools for deaf persons in the region. For a
87 parent-student pair to be eligible for inclusion, the pupil/student had to be aged between 10 and
88 24 years; had to be enrolled in a school, and be in between class VI (year six) and form IV (year
89 twelve); must have lived with the parent(s) and in location of origin for at least the preceding 3
90 months; the parent had to be the biological parent or be a guardian and sign language illiterate.

91

92 **2.2 Sample size and sampling techniques**

93 The target population for this study was parents to children with hearing impairment. Since there
94 is no previous studies carried out in Kenya and reporting the proportion of parents of children
95 with hearing impairment, we assumed 50%, with a standard normal variate at 5% type I error
96 ($P < 0.05$) and 5% precision. Based on this assumption, we calculated a minimum sample size of
97 384 and after factoring in 5% individual non-response rate or partial interviews/breakoffs [17,
98 18], we further arrived at a minimum sample size of 405 of paired parents to children with
99 hearing impairment.

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1.2.1. Sampling technique

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1.3. Data collection

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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

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

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

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1.4. Data Analysis

1.4.1. Quantitative data analysis

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133 Quantitative data as obtained from questionnaires were entered into Statistical Package for Social
134 Sciences (SPSS) software version 20 (SPSS Inc.Chicago, USA), cleaned, and coded. For the
135 purposes of this study, the systems of communication were categorized and coded as 1 = picture,
136 2 = word of mouth, 3 = video, 4 = combination of methods. Participant characteristics were
137 presented by use of frequencies and percentages for categorical variables. Format of
138 communication and adequacy of the information passed to the children with the hearing
139 impairment were presented in a table by use of frequencies and proportions.

1.4.2. Qualitative data analysis

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

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

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148 | transcription by typing the text files collected during interviews. Then from each transcript, we
149 | identified key phrases or sentences, which relate to the study questions. Thereafter, formulated
150 | meanings from these significant phrases and sentences, which finally allow common themes to
151 | surface. A “grounded theory” method was used for data analysis, an inductive approach where
152 | theory is generated from the data. Descriptive summaries and quotes representing the main
153 | themes were captured. Quotes were selected on the basis of their clear representation of the
154 | themes
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156 3.0. Results

157 3.1. Quantitative

158 **Table 1** presents the characteristics of parents and their children; who participated in the
159 quantitative survey. A total of 422 parents paired to their children participated, of which, 184
160 (43.6%) were males, and 238 (56.4%) were females. The age of parents ranged between 31 and
161 70 years, with majority 203 (48.1%) falling between 41 and 50 years. Majority of the parents
162 falling within the age group 41-50 were females (34% vs. 66%, p-value= 0.036). Only a few of
163 the parents 13 (3.1%) were below 41 years of age, with almost similar number and proportion 12
164 (2.8%) being over 60 years old.

165 More than a half of the respondents were married 276 (65.4%), while minority were either single
166 16 (3.8%) or divorced 14 (3.3%). A relatively large number 116 (27.5%) of the respondents
167 were, however, widowed with a significant higher percentage of females than males reporting
168 being widowed (15.2% vs. 37.0%, p-value > 0.001). Majority of the respondents 308 (73.0%)
169 lived in rural areas, and most of them (69.2%) acknowledged the gravity of the problem of
170 HIV/AIDS in their localities (**Table 1**).

171 With regards to the children, their ages ranged between 10 and 24 years as shown in **Table 3** ,
172 with a higher number and proportion 285 (66.9%) being in the 15-19 years' age range. Only 52
173 (12.3%) and 89 (20.9%) were aged below 15 and over 20 years respectively. Similarly, there
174 were slightly higher numbers and proportions of male 241 (57.1%) than female children 181

175 (42.9%) in the sample (**Table 1**), a further demonstration of limited education opportunities
176 available for the girl child since deafness is a phenomenon that equally affects both boys and
177 girls (Absalan et al., 2013).

178

179 Parents used lip reading by the children, picture, video and a combination of systems to
180 communicate SRH issues with their deaf adolescent children. Overall, there were significant
181 differences among the systems of communication used by male respondents, with lip-reading
182 being the most used (38.6%) followed by picture (27.2%) and a combination of systems (26.6%).

183 The results in **Table 4** showed that older parents (41-60 years) were more likely to communicate
184 using word of mouth compared to younger parents.

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185 Video was the least used by the males (**Table 4**). Noteworthy, this method was only used by
186 males aged between 41 and 60 years old, with none of the younger and older males using this
187 system. Conversely, picture was the system used by a significantly higher proportion of female
188 respondents (66.8%), followed by a combination of methods (18.1%) and word of mouth
189 (14.3%), with video similarly being the least used (0.8%).

190 3.5 Adequacy of information passed to deaf adolescent children

191 Overall, significantly higher proportions of male, female and total respondents were not satisfied
192 that they had provided adequate information on SRH issues to their deaf adolescent children
193 (**Table 5**). While all parents (males and females within the age group 61-70 felt they had
194 provided adequate SRH message to their children, parents falling within the age group 41-50 and
195 51-60 felt otherwise (Table 5), with 30.5% vs. 20.6% males having a feeling that the information
196 provided is inadequate; likewise females parents also having doubts if the information was
197 adequate enough (29.8% vs. 19.1%)

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199 3.2. Qualitative

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

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

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210 3.2.1. *Severity of HIV/AIDS Pandemic in Villages of Residence and Susceptibility of* 211 *Children with Hearing Impairment.*

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

220 3.2.2. *Content of Discussion on Sexual and Reproductive Health issues with Hearing* 221 *Impaired Children*

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

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

230

231 | 3.2.3. **Awareness of the youth friendly programs**

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

240 3.2.4. **FGD: Extent and Systems of communication and parents Views about Parent- 241 Children with hearing impairment communication on sexual and reproductive 242 health**

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

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249 **4.0. Discussion**

250 **4.1. Communicating matters of sexual and reproductive health to deaf children**

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

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

268
269 A study on parenting stress among parents of deaf and hearing children found that
270 communication and behavior problem mediates the relation between hearing status and the
271 parenting stress [23].Our findings conforms to those of Mprah Wisdom study (2013) from
272 Ghana, which aimed to provide insights into factors that influence the acquisition, accessibility,
273 and utilization of Sexual and Reproductive Health (SRH) information and services by deaf
274 people who communicate using Ghanaian Sign Language (GSL)[24]. The study findings
275 indicated that when accessing SRH information and services in Ghana, deaf people encounter
276 numerous barriers such as problems with communication, ignorance about deafness, negative
277 attitudes, and services that are not customized to their needs.

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

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

289

290 4.2. Mode of communicating sexual and reproductive health issues

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

296 A communication option, mode, modality, or method is the means by which the child and
297 family receive and express language. The choice of a communication modality that facilitates
298 language development and allows the child who is hard of hearing or deaf to readily engage in
299 communication interchanges with family and caregivers is a primary issue throughout
300 childhood [33]. Our findings indicated that parents with children of hard hearing in this setting

301 use different mode of communication, with word of mouth being used the most, followed by
302 pictures. A sizable number of parents also used a combination of the systems. Early research
303 observed that parents struggle to communicate with their hearing impaired children, hence
304 some parents end up using gestures, facial expression, pointing, touching and other manual
305 signs that are not recognised in trying to communicate with their children. In addition, some
306 parents or guardians use speech and speech reading as a mode of communication. According to
307 Mbaluka (2013) study on parents' mode of communication with their hearing-impaired children
308 in Gweru urban in Zimbabwe, majority of parents / guardians use total communication mode
309 when communicating with their children. Total communication philosophy combines the
310 aspects of listening, speech reading, signing and finger spelling. Only 10% of parents use
311 oralism as a mode of communication[34]

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

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331 5.0. Conclusions

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

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

347

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448 **Tables**

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

451 **Table 2:** Age and sex distribution of the parents

452 **Table 3:** Age category of the children

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

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

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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

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Table 2: Age and sex distribution of the parents

Gender	Age (years)				Total
	31-40	41-50	51-60	61-70	
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%)

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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

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504 **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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