HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya

HIV disclosure from parent to child is complex and challenging to HIV-positive parents and healthcare professionals. The purpose of the study was to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya. Sixteen HIV-positive parents, seven HIV-positive children, and five HIV-negative children completed semistructured, in-depth interviews. Data were analyzed using the Van Kaam method; NVivo 8 software was used to assist data analysis. We present data on the process of disclosure based on how participants recommended full disclosure be approached to HIV-positive and negative children. Participants recommended disclosure as a process starting at fiveyears with full disclosure delivered at 10 years when the child was capable of understanding the illness, or by 14 years when the child was mature enough to receive the news if full disclosure had not been conducted earlier. Important considerations at the time of full disclosure included the parent's and/or child's health statuses, number of infected family members' illnesses to be disclosed to the child, child's maturity and understanding level, and the person best suited to deliver full disclosure to the child. The results also revealed it was important to address important life events such as taking a national school examination during disclosure planning and delivery. Recommendations are made for inclusion into HIV disclosure guidelines, manuals, and programs in resource-poor nations with high HIV prevalence.

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Introduction

28   By 2012, over 35 million persons were infected with human immunodeficiency virus

29   (HIV) globally (UNAIDS, 2013). Resource-poor nations, especially those within Sub-Saharan

30   African (SSA) bear the brunt of the pandemic; 90% of infected persons live in SSA. Kenya has

31   1.4 million adults and 200,000 children living with the disease (NACC and NASCOP, 2012). As

32   of 2011, the prevalence of the disease for adults aged 15-64 years was 5.6%, and that of children

33   18 months to 14 years was 0.9% (National AIDS and STI Control Programme, 2013). Due to

34   increased access to antiretroviral treatment (ART), prevalence is expected to increase as infected

35   persons live longer, thereby making control of the disease a national priority in the decades to

36   come (NACC and NASCOP, 2012).

37   Disclosure of HIV status to children is important for HIV-positive parents, but many are

38   extremely challenged by the disclosure process (Blasini et al., 2004; Delaney, Serovich, &

39   Lim,2008; Kallem et al., 2011; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana,

40   2005; Menon et al., 2007; Vallerand et al., 2005; Vaz et al., 2008). HIV disclosure is a process

41   that moves a child from a state of nondisclosure to partial and then to full disclosure of illness

42   (Wiener et al., 2007). Nondisclosure of illness has been defined as a state in which the child has

43   no knowledge of the illness (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Oberdorfer et al.,

44   2006; Vaz et al., 2011). In partial disclosure the child has limited details (for example, awareness

45   of daily medication consumption and presence of chronic illness) of the illness (Bikaako-Kajura

46   et al., 2006; Rochat, Mkwanazi, & Bland, 2013; Vaz et al., 2011). A child with full disclosure is

47   aware that the illness in question is HIV/AIDS (Bikaako-Kajura et al., 2006; Kallem et al., 2011;

48   Rochat et al., 2013; Oberdorfer et al., 2006).

49   HIV disclosure studies in SSA have centered on telling infected children about their own

50   HIV statuses (Bikaako-Kajura et al., 2006; Brown et al., 2011; Kallem et al., 2011; Menon et al.,

51   2007; Moodley et al., 2006; Vaz et al., 2010; Vreeman et al., 2014); a few have focused on telling

52   children about their parents' HIV statuses (Madiba & Matlala, 2012; Nam et al., 2009; Palin et

53   al., 2009; Rochat et al., 2013; Rwemisisi et al., 2007). Recent studies on disclosure to HIV-

54   positive children have revealed HIV disclosure rates between 11% and 26% in Kenya (John-

55   Stewart et al., 2013; Turissini et al., 2013; Vreeman et al., 2014) and between 17% and 40% in

56   other SSA countries (Biadgilign et al., 2011; Bikaako-Kajura et al., 2006; -Fetzer et al., 2011;

57   Kallem et al., 2011; Madiba, 2012; Menon et al., 2007). Research suggests that the typical age

58   ranges of HIV-positive children receiving full disclosure of their own HIV statuses was between

59   3 and 19 years in Kenya (Vreeman et al., 2014); 8 and 18 years in the Democratic Republic of

60   Congo (Vaz et al., 2010; Vaz et al., 2008); and 5 and 15 years in South Africa (Heeren et al.,

61   2012; Moodley et al., 2006).

62   Rates of parental HIV infection status disclosure to children are slightly higher than those

63   of disclosure of the child's infection status. Recent studies conducted within SSA have revealed

64   such disclosure rates ranging from 29% to 50% (Nam et al., 2009; Palin et al., 2009; Rwemisisi et

65   al., 2007). The age ranges of children receiving full disclosure of their parents' HIV statuses were

66   between 9 and 17 years in Botswana (Nam et al., 2009) and 10 to 18 years in Uganda (Rwemisisi

67   et al., 2008). We found only one study in SSA that examined the process of disclosure of a

68   parent's HIV status to their HIV-negative children (Rochat et al., 2013). Therefore, the

69   knowledge on how parents approach and perform disclosure of their own HIV statuses as well as

70   that of their children to their HIV infected and uninfected children within the same household is

71   relatively undeveloped in the literature.

72   Three key theories have been published to help guide the HIV disclosure process. The

73   disease progression theory stipulates that infected persons are prompted to fully disclose when

74   their illnesses progress because they cannot hide their symptoms, ART consumption,

75   hospitalizations, or the use of HIV support services (Serovich, 2001; Qiao, Li, & Stanton, 2013).

76   The consequence theory of HIV disclosure expounds further by explaining that after disease

77   progression, the infected person weighs the benefits of disclosure versus the consequences that

78   might occur due to such disclosure, proceeding only when the benefits outweigh the risks

79   (Serovich, 2001; Qiao et al., 2013). According to the disclosure process model (Chaudoir, Fisher,

80   & Simoni, 2011; Qiao et al., 2013), the ultimate goal of full disclosure is to limit negative

81   outcomes (rejection, poor relationships) while maximizing positive outcomes for both the parent

82   (social support from children) and child (improved psychological and physical wellbeing). The

83   purpose of our study was to understand the lived experiences of HIV-positive parents and their

84   HIV-positive and negative children before, during, and after the disclosure process in Kenya.

Methods

Sample Selection

87   This study was conducted at the HIV Comprehensive Care Clinic (CCC) located at the

88   Kenyatta National Hospital (KNH) which is near the center of Nairobi, Kenya. HIV-positive

89   parents and children were purposively recruited by the lead author from the waiting areas of the

90   CCC; participants were also referred by clinical officers (equivalent of physician assistants in the

91   U.S.), nurses, and peer educators from the examination and triage rooms during their regularly

92   scheduled clinic visits. Additionally, a different group of HIV-positive parents were requested to

93   nominate and bring their HIV-negative children at a time of their choosing to the clinic for

94   participation in the study. Selected parents and children were not parent-child dyads because we

95   aimed to obtain rich data representing the perspectives of parents and children from different

96   families. Once referred by healthcare professionals (HCPs), the first author met with and

97   informed potential participants about the research and its procedures through the informed

98   consent process. She then escorted those who agreed to participate to a private room within the

99   clinic where informed consent was obtained and study procedures performed.

100   We purposively selected HIV-positive parents having biological HIV-positive and

101   negative children between the ages of 8 and17 at various stages of disclosure (no, partial, full) of

102   their parents' and/or child's own illness. To prevent inadvertent disclosure during conduct of the

103   interviews we selected HIV-positive children with partial and full disclosure of their own

104   illnesses; and HIV-negative children with partial and full disclosure of their parents' illnesses.

105   Children with partial disclosure of illness were interviewed based on what illness (for example,

106   tuberculosis or backache) those children knew they themselves or their parents were suffering

107   from. Purposive selection of participants was conducted over a six-week period; interviews were

108   conducted until saturation was reached.

109   Ethics approval was received from the KNH Research Standards and Ethics Committee

110   (Approval # P373/10/2010), and the Walden University Institutional Review Board (Approval #

111   11-10-10-03904). HIV-positive and negative children provided written assent to participate in the

112   study and their parents provided written informed consent. HIV-positive parents also provided

113   written informed consent. All participants consented/assented to the digital recording of their

114   interviews. Due to the sensitive nature of the research topic, the CCC psychologist remained

115   available throughout the data collection period to provide counseling if needed following their

116   interviews; one HIV-negative child was provided with counseling services. Participants were also

117   invited to visit the psychologist's office after study participation if they wanted to speak about

118   their experience.

119   **Data Collection and Instruments**

120   Interpretative qualitative data were collected using in-depth semi-structured interview

121   guides adapted from those used by Vaz et al. (2008). We adapted (with permission) the guides by

122   removing questions that did not specifically address disclosure. The adapted guides were

123   reviewed and approved by members of the research team (GB and AF) familiar with qualitative

124   instrument design. Interviews were performed in English (the official language of Kenya) by the

125   first author in a private room at the CCC and lasted from 30 to 90 minutes. All selected

126   participants were fluent in English. Parents of HIV-positive and negative child participants were

127   given the option of being in the room while their children were being interviewed but all

128   declined; all child participants assented to being interviewed alone.

129   HIV-positive parents' interview guide questions explored various aspects of the disclosure

130   process including reasons for and against full disclosure, parents' activities conducted in

131   preparation for full disclosure, the family's needs during the disclosure process, when and how

132   partial and/or full disclosure was performed to their children, their recommendations on how full

133   disclosure to children should be approached, and the anticipated/actual reactions and

134   consequences of full disclosure. HIV-positive and negative children's interview guide questions

135   explored when and how they had received partial or full disclosure of their own and parents'

136   illnesses respectively, how they felt during and after partial or full disclosure of their own and

137   parents' illnesses respectively, and their recommendations on how full disclosure should be

138   performed to children.

139   **Data Analysis**

140   Recorded interviews were immediately transcribed by the first author and a local

141   university student trained in transcription. Transcripts were rechecked against the interviews for

142   accuracy; two transcripts needed minor editing corrections. Five parents who had provided email

143   addresses were also sent their transcripts to verify the accuracy of the transcription, and they

144   verified the accounts of their interviews as being accurate. Transcripts were uploaded into NVivo

145   8 for management and analysis. Data analysis was performed using the modified Van Kaam

146   method (Moustakas, 1994) by the first author and cross-checked (by GB and AF). Analysis

147   included thorough reading of transcripts, listing and grouping those with similar information

148   while checking for codes, then clustering codes into emerging themes combined with

149   predetermined themes (age of disclosure, child maturity and understanding level, person to

150   perform disclosure) from prior research. Over 300 total codes emerged from the data, and these

151   were crosschecked (by GB and AF) against a select group of transcripts. A theme with six

152   subthemes detailing the disclosure process emerged as described below.

153   **Results**

154   **Sample Description**

155   Sixteen HIV-positive parents, seven HIV-positive children, and five HIV-negative

156   children were recruited into the study. The parents ranged in age from 30 to 54 years of age; 11

157   were women, the higher percentage of women was expected, as it is mothers who typically bring

158   their children to clinic. One married couple was interviewed to obtain a husband's and wife's

159   perspective on disclosure within the same family. Ten parents had 1-2 children, three had 3-4

160   children, and the last three (including the married couple) had 5-6 children. We sought children

161   between the ages of 8 and 17 years; however, children aged 12 years and older who had already

162   received partial or full disclosure of their own or their parents' illnesses comprised the children's

163   sample. Selected HIV-positive children were between 12 and 17 years of age. For six children,

164   parents had fully disclosed these children's illnesses to them, and one was only aware he was

165   suffering from TB. HIV-negative children were between 12 and 16 years of age; three had full

166   disclosure of their parents' illnesses, and two were sisters who were only aware their mother was

167   suffering from chronic backache. The study participants' genders and HIV statuses are displayed

168   in Figure 1 and their social demographic profiles are presented in Table 1.

169   The perceptions of the participants regarding how full disclosure should be delivered to

170   children are presented in the six subthemes below and displayed in Figure 2. These subthemes

171   include considering as a process the parent's right to disclose and the child's right to receive

172   disclosure. Issues needing to be addressed during the disclosure process included full disclosure

173   of multiple HIV infected family members' (parents and children) illnesses, the parent's and

174   child's health statuses, child's understanding and maturity level, and the person who should fully

175   disclose to children are further discussed.

Disclosure is a Child's Right and a Parent's Decision

176

177   All parents were willing at some point to fully disclose to their children; some felt it was

178 the right of the child to know about the parent's and/or child's illnesses. Parents expressed they

179 needed help from healthcare professionals (HCPs) to be able to fully disclose to their children.

180 However, with the exception of one parent who advised parents perform disclosure without

181 heeding from HCPs, a few were completely against being told by HCPs when to fully disclose to

182 their children. Parents wanted HCPs' advice on how to proceed with disclosure and then be given

183 adequate time to prepare and fully disclose at a time of their choosing:

184   *The question of passing information is dependent on each and every family, the time they*
185   *find is best suited for them. Even if they are talking to a counselor or anybody else, they*
186   *should be encouraged to get the most suitable time they think is important for them to*
187   *pass on the information to the child because they are the ones who know their child*
188   *because they need from them personal information that causes a lot of repercussions good*
189   *or bad.* 54-year-old father of two HIV-negative children and three untested children
190
191   Both HIV-positive and negative children agreed with parents that they needed to know

192 about the illness. HIV-positive children wanted to be told about their illnesses because once they

193 became fully aware of their health statuses, they could more easily deal with the illness:

194   *Children should know because somehow we take care of ourselves, you know now we eat*
195   *some fruits to boost our immune system, they should know.* 13-year-old HIV-positive boy
196
197   *At least I know so that if I get into a relationship without knowing I can infect the person,*
198   *and so it is not good. So at least they told me earlier that I will take the measures not to*
199   *make other people get infected so that we can eradicate AIDS for good.* 17-year-old HIV-
200   *positive girl*
201
202   The three HIV-negative children with full disclosure of their parents' illnesses were

203 curious about how their parents became infected but were happy to know because secrets were

204 eliminated and they realized the disease was real. HIV-negative children were highly in favor of

205 children being informed of their parents' illnesses followed by subsequent testing of all children:

206   *It is better for them [children] to know because this is what we live for, to know about our*
207   *parents, about ourselves, about our family and to know our status is knowing your whole*
208   *life, how it is going to be, how you are going to live it… If a parent hides his or her status*
209   *from a child, let's say he is doing bad behaviors or something, he might be having it and*

210   *contracts it to other people… I was relieved to know that me too, I can get tested for a*
211   *reason… I got tested at school, there were these people coming to test us at school. Then*
212   *they tested us, then we got our results, I was negative.* 15-year-old HIV-negative boy

213

214   Although parents thought children should know about the illness, they considered full

215 disclosure to be very challenging, describing it as "weighty," "hurting," and a "burden."

216 Disclosure was even challenging to parents who had already fully disclosed to their older

217 children and were in the process of preparing younger siblings. Parents were only willing to

218 proceed with full disclosure when they and their children were ready. In the meantime they

219 postponed full disclosure by telling their children the parent or child was suffering from another

220 illness such as tuberculosis, backache, and high blood pressure as explanation why there was

221 daily consumption of medication.

222   Both HIV-positive and negative children were against being lied to about the illness by

223 their parents because it betrayed their trust. They were all in favor of disclosure in a timely

224 manner because at some point it would be inevitable for them to know the truth:

225   *Even if they didn't tell me sooner or later I would come to know.* 16-year-old HIV-
226   negative girl with partial disclosure of her mother's illness

227

228   *Children should be given a chance to know because if you lie to your child, when he or*
229   *she grows up it becomes very difficult for you to relay the message to your child. So you*
230   *must tell your child when he or she is little coz a little child is easier for you to handle but*
231   *for a grownup it becomes very complicated.* 17-year-old HIV-positive boy

232
233 **Disclosure is a Process**

234   Parents expressed that full disclosure to a child be performed as a process. By disclosing

235 in stages, children absorbed the news better, suffered less negative impact, and did not forget

236 what they had been told. Some parents who had fully disclosed their children's illnesses

237 explained HIV-positive children needed to be reminded of their illnesses and to take ART:

238   *You know you don't tell them today and then you forget about it, keep on telling them the*
239   *awareness so as not to forget their status and their medication… They [5 and 7 year-old*
240   *HIV-positive children] know they are taking medicine for HIV but they don't understand.*
241   *Now we are waiting when they mature at 10, then we will tell them the problem you are*

242   *taking medicine is this and you should not stop.* 45-year-old HIV positive father of two
243   HIV-positive children and a HIV-negative child

244
245   HIV-positive children agreed taking ART was tedious and that they were sometimes

246 forgetful:

247   *HIV is a non-curable disease and you have to take drugs each and every day and*
248   *sometimes you forget and you become sick and many complicated issues.* 17-year-old
249   HIV-positive boy

250
251 HIV-positive and negative children also stated they preferred to receive disclosure over time.

252 Some children who had received full disclosure without lengthy preparation expressed they had

253 been impacted by the news:

254   *There is a newspaper that we had read together, it was about this woman who had lived*
255   *with HIV for 20 years, so we talked about it briefly. Then she [mother] came after*
256   *finishing cooking, I think she asked me how if I knew she was positive what would I do?*
257   *And I just told her that I wouldn't do anything since she is the one who has taken care of*
258   *us since the time we were young. So when she told me at first I was shocked... I really*
259   *didn't know, it was just a shock, and it came as a shock to me.* 14-year-old HIV-negative
260   girl

261
262 **Disclosing Multiple Illnesses in the Family**

263   Many parents in the study had HIV-positive living (or dead) spouses and children. None

264 of the HIV-positive children in the sample reported living HIV-positive siblings but some had

265 siblings or a parent who had passed away. None of these HIV-positive children expressed they

266 had been told the deaths were due to an AIDS-related illness; however, they voiced suspicions

267 about it. HIV-negative children in the sample also had no HIV-positive siblings, but three had lost

268 a parent due to a cause of death unknown to them. Children therefore had a need to know about

269 the illnesses and causes of deaths within their families. A 17-year-old HIV-positive boy expressed

270 he was surprised to learn of his illness because no one else in his family was infected except

271 *"maybe my mother, she passed away when I was three months."* A 12-year-old HIV-negative girl

272 expressed she wanted her mother "to comfort me and tell me why father had died because he had

273 no illness."

274   HIV-positive parents in the sample had a mixture of children with no, partial, or full

275 disclosure of illnesses within their households, and they performed preferential disclosures opting

276 to fully disclose all illnesses in the family to older but not younger children. Incidences of full

277 disclosure of a parent's illness at the time of diagnosis and disclosure of an infected child's illness

278 were reported by two parents either because the child guessed the parent was similarly infected,

279 or needed encouragement that they were not alone. Fully disclosing all illnesses in the family was

280 cathartic for some parents:

281   *Because it was very difficult for me to disclose I wanted him to know everything at once…*
282   *One day he asked about his [late] father in the morning and I got that opportunity… I*
283   *told him it was the chest due to HIV, he was HIV-positive… He said oh, no, no, no then*
284   *that explains why I take this medication am I also HIV-positive? So I just said yes… He*
285   *asked are you also sick? That is when I told him I am also sick… It was a relief for me I*
286   *just told him everything and then we discussed and it was a bit lighter. In fact at the end*
287   *of it all he said I will pray for you, we will take care of one another.* 37-year-old HIV-
288   positive mother of one HIV-positive boy
289
290 Some parents who had not yet fully disclosed planned to disclose all illnesses to their children at

291 the same time:

292   *I will try to do it in one session [disclose both parents' illnesses] if she understands me*
293   *and I see she understands the situation and accepts it, then I'll do all of it in one session.*
294   39-year-old father of a HIV-negative daughter with partial disclosure of the parents'
295   illnesses
296
297   Although cathartic for parents, full disclosure of many family members' illnesses at the

298 same time was traumatic for some children. One HIV-negative child was so upset recounting how

299 he received full disclosure that his interview was stopped early and he was referred to the

300 psychologist's office for counseling:

301   *He [father] told me that when I was five years my mother died and told me not to tell*
302   *anyone about it, I felt sad (starts to cry). He told he was using some drugs and I never*
303   *asked him more… He told me the current mother who took care of me until today I am*
304   *still staying with her is my stepmother (sniffles).* 14-year-old HIV-negative boy
305
306   Some child participants including children of HIV-positive parents, absorbed and

307 overcame the shock of the news, and subsequently moved on with their lives:

308 *I just take it to be normal because I cannot just hate her because she has got an illness. I*
309 *see her every day, but nothing comes to me, even I watch television, I see people talking*
310 *about AIDS, HIV how it kills. I don't even remember if my mother has such a kind of*
311 *illness, I just take her as normal and I am dedicated to taking care of her.* 15-year-old
312 HIV-negative child
313
314 Other children, especially those who received full disclosure as teenagers, took longer to recover.

315 A few parents whose older children received full disclosure poorly were hesitant to disclose to

316 younger siblings, especially if these younger siblings were close to them or were known to have

317 tempers:

318 *I know she [second-born daughter] is hot tempered, so I was thinking maybe let us leave*
319 *her because she is not even mature until she reached maybe I thought 17 there, I could*
320 *tell her after she had finished her fourth form. Even the one who is following her is the*
321 *same.* 37-year-old mother of one HIV-positive child, one HIV-negative child, and two
322 untested children
323
324 **Considering a Parent's and a Child's Health Status**

325 When considering full disclosure, parents took into account theirs and their children's

326 health statuses. Both parents and children cautioned even without full disclosure, children were

327 highly aware of the disease and were able to guess the nature of illness:

328 *If you have been in and out of hospital, you get very ill you are taken to Kenyatta Hospital*
329 *then you are tested you come out you are very weak, they will even know before you tell*
330 *them coz they might have already guessed, you are coughing, you are what.* 54-year-old
331 HIV-positive father of two HIV-negative children and three untested children
332
333 *Some parents when they don't tell you, the signs just show and the child doesn't let's say*
334 *study well, he just gets to feeling so low.* 15-year-old HIV-negative boy
335
336 Parents were unwilling to fully disclose their illnesses to their children when they

337 (parents) were in poor health; however, they advised it was permissible in certain instances.

338 These included when the parent was too sick to take him/herself to the hospital or pick up

339 medications from the CCC. The child with full disclosure could take the parent to the hospital,

340 pick up ART refills at the CCC, take care of siblings, and perform household tasks until the

341 parent was feeling better. HIV-negative children provided responses similar to parents about

342 being against full disclosure when a parent was unwell; and described vivid memories of the time

343 their parents had been severely sick:

344 *Father had died, she [mother] had an illness because she had carried a baby in her*
345 *stomach, my last sister… She was weak, very weak that even she could just fall down… I*
346 *thought that maybe she could pass away even her coz of the stress that she had. And with*
347 *the stress how could she manage to get all the school fees for us all and feed the family.*
348 12-year-old HIV-negative child
349
350 Generally parents were of the opinion that HIV-positive children should not be told of

351 their own illnesses when they were in poor health because it might make them lose hope and

352 cause their condition to worsen. They therefore advised other parents to wait until both the parent

353 and child were in good health prior to fully disclosing to a HIV-positive child:

354 *Tell them when you [parent] have the strength because she might have that feeling why*
355 *did my parents wait until they are bedridden, they can't walk? You have to tell them early*
356 *to prepare them psychologically. You also have to tell [HIV-positive] children when they*
357 *have the strength, they are energetic, they know what they can do because sometimes if*
358 *you tell them when they are bedridden it won't help. Tell them when they have the energy*
359 *then they will know what food they can eat, this medicine is for this.* 45-year-old father of
360 two HIV-positive children and one HIV-negative child
361
362 However, if the HIV-positive child's health had deteriorated due to poor ART adherence then it

363 was imperative he or she receive full disclosure:

364 *He has to know why he is taking medicine and why he is getting ill because maybe when*
365 *he is not taking the medicine proper, you have to tell him or her you have to take your*
366 *medicine so that you can be well.* 46-year-old mother of two HIV-positive children and
367 one HIV-negative child
368
369 **Child's Understanding and Maturity Level**

370 Parents expressed that children developed and matured differently; thus, the decision to

371 fully disclose should be assessed individually. Parents were especially hesitant to fully disclose to

372 young children because they feared these children would not understand the meaning of the

373 illness or keep the information a secret thereby exposing the family to stigma:

374 *You know when they are young they will just take it like this… She [nine-year-old*
375 *daughter] does not know how to keep a secret because she will shout to the other*
376 *children, that's why I fear to tell her.* 32-year-old mother of one HIV-positive daughter and
377 one untested daughter

378
379   Both HIV-positive and negative children agreed it was not wise to fully disclose to young

380   children:

381   *Even if you tell them [HIV-positive children] when they are small they cannot even know*
382   *what they are supposed to do.* 16-year-old HIV-positive girl
383
384   *You cannot tell a child at seven that they have HIV, maybe he will not understand it or he*
385   *will not handle it.* 15-year-old HIV-negative boy
386
387   One HIV-positive child thought children should receive full disclosure by five years

388   because when they sensed the information was important, they would always remember it. One

389   parent had fully disclosed his, his wife's, and two children's illnesses to all his children when

390   aged 3, 5, and 10 years but the two younger children did not comprehend what it meant and he

391   wanted to re-inform them again at 10 years of age. Other parents and children disagreed with full

392   disclosure at an early age preferring to provide limited information over time corresponding to

393   what children were being taught in school about the disease:

394   *When the child is about six years you cannot tell her or him that you are HIV-positive, but*
395   *you can tell the child that I am on medication and then after two years you just disclose*
396   *after 10 years. 10 years he has knowledge to know what is HIV.* 46-year-old mother of two
397   HIV-positive sons and one HIV-negative daughter
398
399   *I am saying [start telling them at] seven because by the time they are eight years most of*
400   *them are in class three and nowadays they teach at school, it is already in their books.* 37-
401   year-old mother of two HIV-positive children
402
403   Some parents reported children were initiating sex by 9 years and were therefore in need

404   of full disclosure around this age. HIV-positive and negative children agreed teenagers were

405   having sex mostly due to peer pressure and they needed to know of the illness so they would not

406   infect others or become infected respectively. The most frequently cited age by both parents and

407   children when full disclosure should be performed was 10 years because at this age, the child was

408   capable of understanding the illness. The participants' preferred ages of full disclosure to children

409   are displayed in Table 2:

410 *When the parents feel comfortable from 10 and above, tell them [HIV-positive children]*
411 *slowly about their illnesses.* 13-year-old HIV-positive boy
412
413 *Tell them [about a parent's illness] when the child is young, maybe about 10 years*
414 *because the child will have grown a bit.* 12-year-old HIV-negative child
415
416 *You can tell a child whom you can tell and understand, like now you can't tell a five-year-*
417 *old. I think that age of between 10 and 13 because the child is a bit mature but since the*
418 *way he said I should have told him earlier I feel that 10 is the best age.* 37-year-old
419 mother of one HIV-positive son who received full disclosure at 12 years
420
421 Both parents and children expressed children were mature enough to receive full

422 disclosure by 14 years of age. At 14-15 years of age, most children were in Standard 8 during

423 which they take their national primary school exit examination. Subsequently, the majority of

424 children are admitted to a boarding secondary school. Some parents and children advised children

425 be given the opportunity to take the examination first before being told of theirs and/or their

426 parents' illnesses:

427 *I liked it because if she [mother] had told me a while back, I don't know how I would*
428 *have done my KCPE [Kenya Certificate of Primary Examination], so I'm just glad she*
429 *told me after.* 15-year-old HIV-negative girl who had just finished taking the KCPE at
430 Standard 8
431
432 *When I knew about my HIV status I was about to do my KCPE, I was in class eight, I fell*
433 *so sick… The message really (pauses) intruded into my life and I was very depressed so it*
434 *made me to fail my exams.* 17-year-old HIV-positive boy
435
436 *I was feeling the best time will be after he completes his class eight because that is the*
437 *time we take them to a boarding school. So we feel it is good when the child knows*
438 *because he will be carrying his own medicine.* 39-year-old mother of one HIV-positive
439 son and one untested son
440
441 Nine parents had fully disclosed their illnesses to at least one child in their household; and

442 eight parents had fully disclosed a child's illness to at least one of their HIV-positive children.

443 Parents reported fully disclosing to their children when they were between the ages of 3 and 19

444 years. Six HIV-positive children received full disclosure of their own illnesses while between the

445 ages of 13 and17 years, and three HIV-negative children received full disclosure of their parents'

446   illnesses when they were 14 years of age. HIV-positive and negative children's disclosure statuses

447   are displayed in Table 3.

448   **Person to Perform Disclosure**

449   Participants were asked to state who they thought was the best person to deliver full

450   disclosure of illness to the child. Their responses are presented in Table 4. The majority of parents

451   felt they were the ones who should fully disclose to their children. Married parents felt it was

452   better for them to liaise and present the news to their children together with one taking the lead.

453   Parents who had already fully disclosed advised other parents to disclose in a calm manner at a

454   time when they could address all of the child's questions:

455   *You have to be straight to the point, you have to control yourself when you are saying this*
456   *in order for them also to be calm. You have to be their pillar now you are saying you are*
457   *sick they are seeing your emotions are controlled so they will sort of get the strength from*
458   *you. But if you break down and also bring words that will make them think the situation is*
459   *hopeless, now you also you have given up. Actually you have to choose your words but*
460   *generally the choice of words don't come in, it's just how well you are managing your*
461   *emotions in front of them.* 49-year-old mother of two HIV-negative children and three
462   untested children
463
464   Where parents felt incapable of fully disclosing on their own, they advised these parents

465   have a HCP or a relative (for example an aunty or grandmother) close to the child be present as a

466   support person:

467   *It is the duty of the parent to tell their children they are HIV-positive maybe through the*
468   *help of social workers, counselors, doctors or nurses to make their children understand*
469   *what is HIV, coz HIV is a scare if you do not understand what it is. It can destroy a child's*
470   *life if the child does not understand what HIV is.* 39-year-old father of one HIV-negative
471   child
472
473   One parent whose son received full disclosure from a VCT counselor following testing cautioned

474   against a HCP unfamiliar to the child delivering full disclosure:

475   *From the way my son reacted, I think it is the parent [who should deliver full disclosure],*
476   *that way whatever bad or silly question he might want to ask, he will be free to tell you*
477   *than in the presence of a counselor… You see he was just crying then he was sad, even*
478   *though we gave him time to ask questions or say whatever he wanted to say he couldn't,*
479   *this was a stranger he had never seen her, he was never close to the counselor. I think he*
480   *didn't want to say whatever he wanted to say, but if we could have been two, I am sure he*

481 *could have said many things or asked whatever he wanted to ask.* 37-year-old mother of
482 two HIV-positive children

484 Half of HIV-negative children were in favor of their parents' disclosing to them while the

485 other half wanted a relative (for example their older sister or aunty) close to fully disclose to

486 them. The majority of HIV-positive children thought full disclosure should be delivered to them

487 from a HCP trained in disclosure:

488 *Somebody who is not trained can come and tell you straight to the point. You know what*
489 *you are HIV-positive and he or she cannot explain more about it. And then after all you*
490 *hear about HIV it's a killer disease, some people end up committing suicide and so many*
491 *things, so I think a trained person is the one who should.* 17-year-old HIV-positive boy
492
493 One parent who had fully disclosed to her child while alone at home agreed it was wise to have a

494 trained HCP present at the time of full disclosure to an infected child:

495 *I think what I should have done is at least disclose in the presence of somebody else who*
496 *is aware like a counselor or something because immediately when he cried, I panicked, I*
497 *really panicked because he really cried, he cried a lot and I was like now what do I do*
498 *next, but I thank God I was able to control it.* 37-year-old mother of one HIV-positive boy
499
500 **Discussion**

501 Our study revealed six subthemes associated with the HIV disclosure process. Parents did

502 recognize it was a child's right to receive full disclosure but viewed disclosure as a process that

503 occurs over time; children agreed with them. When considering fully disclosing, it was important

504 for parents to decide who was going to disclose, which family members' illnesses and prior

505 deaths to disclose, whether to postpone disclosure until the parent and/or child was healthy, and

506 which child was capable of understanding or mature enough to receive the news. Overall, parents

507 appear to favor disclosure at their own time without prompting from HCPs but acknowledged

508 needing guidance during the process. Parents have reported requiring assistance from HCPs

509 during disclosure preparation (Heeren et al., 2012; Nam et al., 2009; Nostlinger et al., 2004;

510 Oberdorfer et al., 2006; Rwemisisi et al., 2008; Vallerand et al., 2005; Vaz et al., 2010; Vaz et al.,

511 2008). Despite parents' desire to delay full disclosure, both HIV-positive and negative children

512 reported wanting to receive full disclosure of all illnesses and deaths in the family in a timely

513 manner. Where many family member's illnesses are to be fully disclosed to a child, intense

514 predisclosure counseling should be provided to improve the child's resiliency and capacity to

515 absorb the news and also to assist the parent in delivering the news in an appropriate manner

516 (Murphy & Marelich, 2008). Post disclosure, HCPs should assess the family to check how they

517 are doing (Bikaako-Kajura et al., 2006; Murphy, Roberts, & Hoffman, 2006).

518   HIV-positive parents are known to delay testing their children due to fear of obtaining

519 another positive test result (Eisenhut et al., 2009; Ferrand et al., 2007; Ishikawa et al., 2010;

520 Rwemisisi et al., 2008). In this study, we found that, HIV-negative children supported testing of

521 all children in that household; their statuses would be known and hopefully this would prevent

522 HIV-negative children from becoming infected. HIV-positive children wanted to be informed of

523 their illnesses so they could adhere to their ART, take better care of themselves, and gain self-

524 independence. These needs expressed by HIV-positive and negative children should be a part of

525 regular counseling provided to HIV-positive parents who seek guidance on full disclosure to their

526 infected and uninfected children. Participants in this and another study (Heeren et al., 2012)

527 recommended full disclosure as a process starting with limited information at 5 years of age.

528 However, one parent in this study fully disclosed the parents' and children's illnesses to his 5 and

529 7-year-old children; the parent reported that the childrendid not understand what it meant. It

530 therefore appears children should receive full disclosure at an age when they are capable of

531 understanding. Many participants in the present study felt that this age is 10 years although few

532 children at this age had full disclosure. Fourteen years was the age when most children received

533 full disclosure of a parent's and/or a child's illness; this was the age when participants considered

534 children mature enough to receive full disclosure if it had not been delivered before. The

535 recommended age range of 10-14 years found in this study has been seen in prior studies

536 conducted in resource-poor nations (Biadgilign et al., 2011; Moodley et al., 2006; Oberdorfer et

537   al., 2006); and is in alignment with recommendations made by prior researchers that children

538   receive full disclosure before they reach adolescence where more negative impacts have been

539   noted (American Academy of Pediatrics, 1999; Blasini et al., 2004; Lester et al., 2002; Siripong

540   et al., 2007). Full disclosure within this age range would educate children about the illness before

541   sexual debut. Additionally, this study revealed that important life events such as completion of a

542   national examination should be incorporated into full disclosure planning and delivery.

543   Parents knew children were starting sexual activity at 9 years and children confirmed they

544   knew their teenage peers were having sex. Early sexual debut, many partners, and low condom

545   use has been cited as some of the reasons why HIV spreads in Kenya (Republic of Kenya, 2009).

546   This early onset of sexual activity among children is worrisome and has implications for the

547   control of the disease within the country. The present study as well as one conducted in Botswana

548   (Nam et al., 2009), revealed HIV-positive parents and their children are highly in need of sexual

549   programs aimed at increasing parent-child communication on sexual matters, counteracting early

550   sex initiation, reducing sexual-related peer pressure among children, and improving use of barrier

551   methods during sex. These programs could prompt parents to fully disclose to their children

552   during the recommended age period of 10-14 years if HCPs recommend testing of all children of

553   newly diagnosed parents (Rwemisisi et al., 2008; Were et al., 2006).

554   The majority of parents in this study wanted to be the ones fully disclosing to their

555   children, some alone and a few others with assistance from HCPs or close family members; the

556   desire for full disclosure by the parents has been confirmed in prior research (Bikaako-Kajura et

557   al., 2006; De Baets et al., 2008; Heeren et al., 2012; Kennedy et al., 2010; Kouyoumdjian et al.,

558   2005; Nam et al., 2009). HIV-negative children agreed with parents, expressing they preferred to

559   receive full disclosure from their parents or close family members such as older siblings or

560   aunties. It is interesting to note that most HIV-positive children preferred to receive full

561   disclosure from a HCP trained in disclosure delivery rather than a parent. As part of disclosure

562 planning, an assessment may be necessary to decide who is the best person suited to fully

563 disclose to a child (especially HIV-positive children), even where parents may want to be the

564 ones delivering the news.

565   The results of this study do not appear to provide support for the disease progression

566 theory (Serovich, 2001; Qiao et al., 2013). Parents were unwilling to fully disclose when they or

567 their children were in poor health. However, the results do support the consequence theory of

568 HIV disclosure, as parents were willing to fully disclose their illnesses to children when the

569 parents were very sick, so those children could support and take care of their parents (Serovich,

570 2001; Qiao et al., 2013). Parents were only willing to fully disclose to a sick child suspected of

571 poor ART adherence so the child could take their medications well and improve his or her health.

572 In these two aforementioned circumstances, the benefits of disclosure outweighed the

573 consequences of nondisclosure making it wise to fully disclose (Serovich, 2001; Qiao et al.,

574 2013). In support of the disclosure process model (Chaudoir et al., 2011; Qiao et al., 2013), both

575 parents and children favored full disclosure delivered in an appropriate manner that ensured a

576 good outcome for both parties. Training on HIV disclosure models is advocated for HCPs who

577 work with HIV-positive families so they can better facilitate full disclosure delivery from parent

578 to child and improve outcomes for all family members.

579   Qualitative research methodology focuses on revealing the meaning of sociocultural

580 practices by exploring new complex problems from the point of view of a small group of

581 participants (Creswell, 2009; Ulin, Robinson, &Tolley, 2005). We interviewed a small group of

582 purposively selected participants with the aim of understanding the lived experiences of HIV-

583 positive parents and their children during the disclosure process in Kenya. We believe our sample

584 of HIV-positive parents, HIV-positive children, and HIV-negative children provided us rich data

585 that revealed the circumstances faced by HIV-positive parents and their children during the

586 disclosure process. However, our sample presented two limitations. We interviewed more

587   mothers than fathers; future researchers may want to focus on fathers' experiences in the

588   disclosure process. Parents and children in our study were from different families (we did not

589   interview parent-child dyads), this also presents an important area of future research. Conducting

590   interviews in English may have limited the participants to only those fluent in the language,

591   future researchers may want to conduct interviews with those who only speak the native language

592   or who are less fluent in English. Larger quantitative studies from a public health perspective are

593   needed to determine the best way to fully disclose family members' illnesses and deaths within

594   heavily affected families. Additionally, the disclosure needs and preferences of HIV-positive and

595   negative children need to be investigated to see if they differ.

596   **Conclusion**

597   This article presents rich data on how HIV-positive parents approach full disclosure to

598   their HIV-positive and negative children; and how full disclosure is received and perceived by

599   HIV-positive and negative children. Prior studies have mostly focused on disclosure of a parent's

600   illness to their children or disclosure of their own illnesses to HIV-positive children. This study's

601   results are therefore important because they provide a thorough overview of full disclosure

602   delivery from the point of view of HIV-positive parents; and disclosure reception from the

603   viewpoint of HIV-positive and negative children. The recommendations provided by participants

604   in this study help address the gaps in knowledge on disclosing many family members' illnesses

605   and deaths to children. Other important factors that should be considered include parent's and/or

606   a child's health status, children's understanding and maturity level, important life events (for

607   example national examinations), and the person best suited to fully disclose to a child. The

608   recommendations from this study should be incorporated into preexisting or new guidelines,

609   manuals, and programs on HIV disclosure from parent to child in resource-poor nations with high

610   HIV prevalence.

611

612

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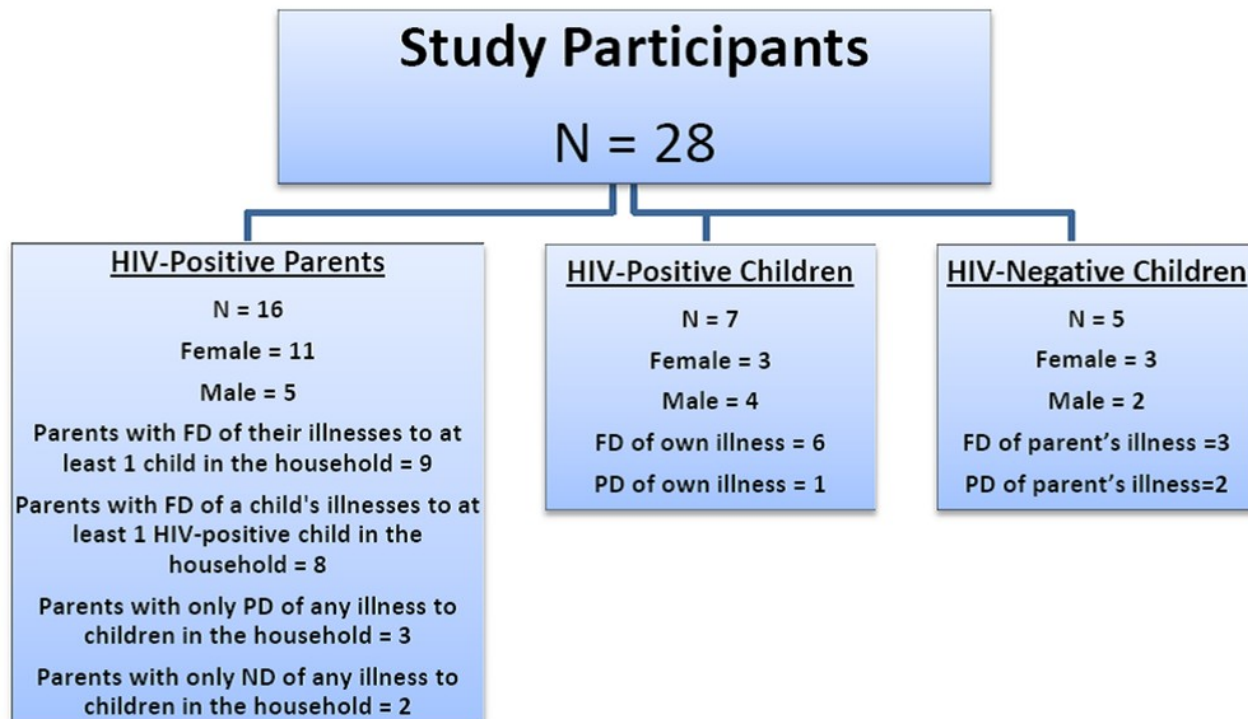
Figure 1

Sample description

FD = full disclosure

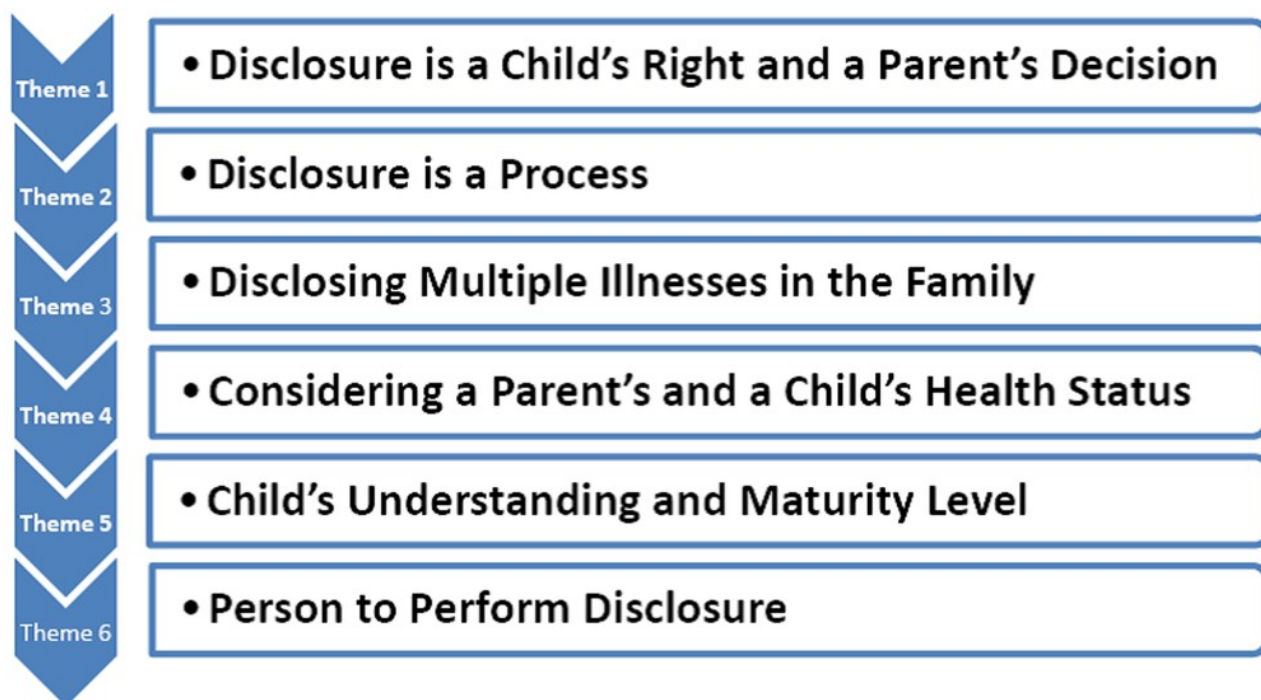
ND = nondisclosure

PD = partial disclosure

Participants' social demographic characteristics

NA = Not applicable

Variable	HIV-Positive Parents	HIV-Positive Children	HIV-Negative Children
Age			
Children 12-13		2	1
14-15		1	3
16-17		4	1
Parents 31-40	8		
41-50	7		
51-60	1		
Gender			
Female	11	3	3
Male	5	4	2
Educational status			
Primary	2	2	3
Secondary	7	5	2
College	7	NA	NA
Marital status			
Single	1	NA	NA
Divorced	1		
Widowed	4		
Married	10		

Figure 2

HIV disclosure subthemes

Age at which parents should fully disclose to children

^aOne HIV-negative child did not complete the entire interview ^bOne HIV-positive parent said when the child is mature ^cOne HIV-positive parent said immediately ART is commenced

Child's Age at Disclosure	5	9	10	11	12	13	14	15	17
HIV-negative children (N = 4[a])			1		2			1	
HIV-positive children (N = 7)	1		1			1	2	2	
HIV-positive parents (N = 14[b,c])		1	5	1			4		3
Total N = 25[a,b,c]	**1**	**1**	**7**	**1**	**2**	**1**	**6**	**3**	**3**

HIV-positive and HIV-negative child participants' disclosure statuses

F = femaleM = maleFD = full disclosureNA = not applicablePD = partial disclosure

HIV-Positive Children's Disclosure Statuses of Their Own Illnesses

Child	Sex	Age at Full Disclosure	Disclosure Status	Current Age
A	M	9	FD	13
B	M	"Very young age"	FD	15
C	F	13	FD	16
D	F	14	FD	16
E	M	14	FD	17
F	F	17	FD	17
G	M	NA	PD	12

HIV-Negative Children's Disclosure Statuses of Their Parents' Illnesses

Child	Sex	Age at Full Disclosure	Disclosure Status	Current Age
A	M	14	FD	14
B	F	14	FD	14
C	M	14	FD	15
D	F	8	PD	12
E	F	14	PD	16

Person to perform disclosure

aOne HIV-negative child did not complete entire interview

Person to Perform Disclosure	Parent	HCP	Relative
HIV-negative children (N = 4[a])	2		2
HIV-positive children (N = 7)	3	4	
HIV-positive parents (N = 16)	14	1	1
Total N = 27[a]	19	5	3