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## A rapid assessment of post-disclosure experiences of urban HIV-positive and HIV-negative school-aged children in Kenya

Grace Gachanja

There has been limited involvement of HIV-negative children in HIV disclosure studies; most studies conducted on the effects of disclosure on children have been with HIV-positive children and HIV-positive mother-child dyads. Seven HIV-positive and five HIV-negative children participated in a larger study conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya. In this study, the experiences of these 12 children after receiving disclosure of their own and their parents' illnesses respectively are presented. Each child underwent an in-depth qualitative semi-structured digitally recorded interview. The recorded interviews were transcribed and loaded into NVivo8 for phenomenological data analysis. Five themes emerged from the data, indicating that HIV-positive and negative children appear to have differing post-disclosure experiences revolving around acceptance of illness, stigma and discrimination, medication consumption, sexual awareness, and use of coping mechanisms. Following disclosure, HIV-negative children accepted their parents' illnesses within a few hours to a few weeks; HIV-positive children took weeks to months to accept their own illnesses. HIV-negative children knew of high levels of stigma and discrimination within the community; HIV-positive children reported experiencing indirect incidences of stigma and discrimination. HIV-negative children wanted their parents to take their medications, stay healthy, and pay their school fees so they could have a better life in the future; HIV-positive children viewed medication consumption as an ordeal necessary to keep them healthy. HIV-negative children wanted their parents to speak to them about sexual-related matters; HIV-positive children had lingering questions about relationships, use of condoms, marriage, and childbearing options. All but one preadolescent HIV-positive child had self-identified a person to speak with for social support. When feeling overwhelmed by their circumstances, most children self-withdrew and performed positive activities (e.g., praying, watching TV, listening to the radio, singing, dancing) to help themselves feel better. Many HIV-affected families have a combination of HIV-positive and negative siblings within the household. Pending further studies conducted with larger sample sizes, the results of this study should assist healthcare professionals to better facilitate disclosure between HIV-positive parents and their children of mixed HIV statuses.

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A Rapid Assessment of Post-Disclosure Experiences of Urban HIV-Positive and HIV-Negative School-Aged Children in Kenya

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## Introduction

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28 HIV/AIDS remains a public health issue affecting 35.3 million persons globally (UNAIDS,  
29 2013). In 2012, 22% of Kenya's population were children between 10-19 years old (UNAIDS, 2013).  
30 The HIV prevalence among children aged 18 months to 14 years was 0.9% (National AIDS and STI  
31 Control Programme, 2014) and 2.7% among youth aged 15-24 years (UNICEF, 2013). In 2012, the  
32 adult HIV prevalence was 6% (UNAIDS, 2013), and 5% of Kenyan homes had a HIV-positive head of  
33 household (National AIDS and STI Control Programme, 2014).

34 Following disclosure, HIV-positive and negative children are known to experience varying  
35 effects (Kennedy et al., 2010; Murphy, 2008; Vallerand et al., 2005). After disclosure of their illnesses,  
36 HIV-positive teenage children in Puerto Rico went through the five stages of grieving (denial, anger,  
37 bargaining, depression, and acceptance) before accepting their illnesses (Blasini et al., 2004). In  
38 studies conducted in the United States using mother-child dyads, HIV-negative children were reported  
39 as faring no worse after receiving disclosure of their mothers' illnesses (Jones et al., 2007; Murphy,  
40 Steers, & Stritto, 2001; Shafer et al., 2001). HIV-positive mothers in a South African study, reported  
41 that their HIV-negative children accepted disclosure of their illnesses calmly; however, some showed  
42 emotions such as surprise and confusion (Rochat et al., 2014; Rochat, Mwankazi, & Bland, 2013).

43 Some positive effects of disclosure on HIV-positive and negative children include increased  
44 closeness with their parents (Vallerand et al., 2005), fewer behavioral problems and aggression (Lee  
45 & Rotheram-Borus, 2002; Murphy, Steers, & Stritto, 2001), and improved resiliency, coping, and life  
46 perspectives (Kennedy et al., 2010; Murphy et al., 2010). Negative internalized effects of disclosure  
47 include poor functioning, increased stress, sadness, withdrawal, depression, and fear (Asander et al.,  
48 2009; Kennedy et al., 2010; Murphy, 2008; Petersen et al., 2010; Vallerand et al., 2005; Wiener et al.,  
49 2007). Negative externalized effects of disclosure include arguing with or ignoring parents,  
50 aggression, and practicing unsafe sexual behavior (Lee & Rotheram-Borus, 2002; Murphy, 2008;  
51 Nelms & Zeigler, 2008; Vallerand et al., 2005).

52 High levels of HIV stigma and discrimination are known to exist in Kenya (Gachanja,  
53 Burkholder, & Ferraro, 2014; Turan et al., 2012). Stigma is experienced externally as felt stigma when  
54 the HIV-positive or HIV-affected person experiences bullying, teasing, insults, gossip, and ostracism;  
55 or internally when he or she perceives him or herself as unworthy due to discriminative acts or  
56 stigmatizing behavior directed towards him or her by his or her community members (Ishikawa et al.,  
57 2010; Petersen et al., 2010). Midtbo et al. (2012) reported that HIV-positive children in their study  
58 conducted in Botswana and Tanzania experienced stigma from their peers and community members;  
59 however, most confidently took control of their illnesses without negatively internalizing their  
60 experiences. There have been few studies involving HIV-negative children; therefore, their stigma-  
61 related experiences in relation to disclosure of their parents' illnesses are not well documented.

62 The stress and coping theory was used as the foundation for this study (Lazarus, 1993).  
63 Coping is assessed by how well a person cognitively and behaviorally addresses the stress he or she  
64 experiences. The theory posits that stress management involves problem- or emotion-focused coping  
65 strategies, and that there is no universal good or bad way to cope with stress. A person's problem-  
66 focused coping is enhanced by self-adaptation to his or her environment, while emotion-focused  
67 coping is improved by being hyper vigilant and anticipative of which situations lead to stress, and then  
68 avoiding those stressors (Lazarus, 1993). Assessing a person's thoughts and coping behaviors is  
69 important because improved handling of stressors helps him or her understand, handle, and lessen  
70 the stress associated with his or her unchangeable circumstances (Lazarus, 1993).

71 It is not well understood if HIV-positive and negative children experience similar effects  
72 following disclosure of their own and their parents' illnesses respectively. Most studies on disclosure to  
73 children conducted in Sub-Saharan Africa have reported on the effects of disclosure on HIV-positive  
74 children after being told about their own illnesses (Brown et al., 2011; Menon et al., 2007; Petersen et  
75 al., 2010; Vaz et al., 2010). A few recent studies have reported on the effects of maternal disclosure  
76 on preadolescent HIV-negative children (Rochat et al., 2014; Rochat, Mwankazi, & Bland, 2013). A

77 larger study was conducted to understand the lived experiences of HIV-positive parents and their  
78 children during the HIV disclosure process in Kenya; seven HIV-positive and five HIV-negative  
79 children participated in that study. Data previously reported from this child sample conveyed these  
80 children's views on how HIV disclosure should be approached and performed to children (Gachanja,  
81 Burkholder, & Ferraro, 2014). In this current study, the post-disclosure experiences of these 12  
82 children are presented to add to the body of knowledge on the effects of disclosure on HIV-positive  
83 and negative children after they receive disclosure of their own and their parents' illnesses  
84 respectively.

## 85 **Methods**

### 86 **Recruitment of Participants**

87 Data collection for the larger study was conducted in December 2010 through January 2011 at  
88 the Kenyatta National Hospital Comprehensive Care Center located in Nairobi, Kenya. Participant  
89 recruitment for the larger study was continued until interview data saturation was achieved (Kuzel,  
90 1999; Morse, 2000), upon which recruitment was halted resulting in a child sample size of seven HIV-  
91 positive and five HIV-negative children (Gachanja, Burkholder, & Ferraro, 2014). The HIV-positive and  
92 negative children were purposively selected to be in the study because they were between 8-17 years  
93 old, conversant in English, and had already received partial or full disclosure of their own and their  
94 parents' illnesses respectively. Ethics approval for the study was received from the Kenyatta National  
95 Hospital (KNH) Research Standards and Ethics Committee (Approval # P373/10/2010) and the  
96 Walden University Institutional Review Board (Approval # 11-10-10-03904).

97 HIV-positive parents who had HIV-negative children meeting criteria for study participation  
98 were approached during their regularly scheduled clinic visits, provided with an explanation of the  
99 study, and requested to bring their HIV-negative children to the clinic at a time convenient to them.  
100 HIV-positive children who met criteria to be in the study were approached for participation during their

101 regularly scheduled clinic visits. An explanation of the study was provided to them and their parents.  
102 HIV-positive and negative children who expressed an interest to participate in the study were escorted  
103 by the researcher (accompanied by their parents) to a private room in the clinic where consenting and  
104 study procedures were performed. Following consenting procedures, those children who agreed to  
105 participate provided written assent and their parents provided written informed consent.

## 106 **Data Collection**

107 Qualitative interpretive phenomenological data was collected through in-depth individualized  
108 semi-structured interviews conducted with each child by the researcher. Interview guides used in the  
109 study were in English and had been obtained for use with permission from the authors of a study  
110 conducted in the Democratic Republic of Congo (Vaz et al., 2008). The guides were not translated into  
111 a local Kenyan language because only children conversant in English were purposively recruited into  
112 the study. HIV-positive children were interviewed on their experiences about receiving disclosure of  
113 their own illnesses, and HIV-negative children were interviewed on their experiences about receiving  
114 disclosure of their parents' illnesses.

115 The interview guide questions collected basic child demographic information; and also  
116 explored how and who had disclosed to the children, their reactions to disclosure, and their  
117 experiences following disclosure. Parents were given the option of being present in the room during  
118 their children's interview sessions; however, none chose to do so and all children assented to being  
119 interviewed alone. Interviews lasted between 30-45 minutes; however, one HIV-negative child did not  
120 finish his entire interview because he became very emotional when describing his disclosure  
121 experiences. He was referred to the psychologist's office for counseling and follow up.

## 122 **Data Analysis**

123 Recorded interviews were transcribed soon after data collection by the researcher and a local  
124 Kenyan university student experienced with transcription. The transcripts were checked twice against

125 the recorded interviews for accuracy and loaded into NVivo8 for analysis. The Van Kaam method  
126 (Moustakas, 1994) was used for phenomenological analysis of the transcribed qualitative data.  
127 Transcripts were listed, grouped, and scanned repeatedly for emerging codes. Repeating information  
128 within the transcripts was clustered into similar codes. The codes and themes were cross-checked by  
129 the research committee for coding reliability and consistency within each emerging theme. The codes  
130 were then grouped into five emergent themes describing the children's post-disclosure experiences.

## 131 Results

132 The 12 children's demographic characteristics are displayed in Table 1. Six HIV-positive  
133 children had full disclosure of their illnesses, and three HIV-negative children had full disclosure of  
134 their parents' illnesses. All HIV-positive children were taking antiretroviral therapy, multivitamins, and  
135 cotrimoxazole; all HIV-negative children were aware that their parents consumed medications on a  
136 daily basis. The five themes which emerged from the data include acceptance of illness, stigma and  
137 discrimination, medication consumption, sexual awareness, and coping mechanisms; they are  
138 displayed in Figure 1 and further described below. The key quotes from each theme are displayed in  
139 Table 2.

### 140 Acceptance of Illness

141 Regardless of the type of disclosure received, 11 of 12 children were shocked at the time of  
142 disclosure, but expressed they were happy to have been disclosed to. Now that they knew of the  
143 illness, one HIV-positive girl and a HIV-negative boy with full disclosure did not want to be frequently  
144 reminded of the illness. After their shock wore off, most of the six HIV-positive children with full  
145 disclosure became depressed, received counseling, accepted their illnesses, and returned to "normal"  
146 anywhere from a few weeks up to four months later. Two of these HIV-positive children still expressed  
147 blame and anger at their parents for infecting them (see Table 2, Quote 1). HIV-negative children (with  
148 partial and full disclosure) overcame their shock and accepted their parents' illnesses within a few



149 hours to a few weeks later; none received counseling. Most explained they grew closer to their  
150 parents, were empathetic about their illnesses, and helped out more with chores to ease their parents'  
151 burden of illness (see Table 2, Quote 2).

## 152 **Stigma and Discrimination**

153 Both HIV-positive and negative children were aware of high stigma and discrimination levels  
154 prevalent in the community; some expressed their siblings and close relatives did not know of theirs  
155 and their parents' illness respectively. HIV-positive children spoke of misconceptions and incidences  
156 of indirect stigma and discrimination shown them by their HIV-negative peers, and extended family  
157 and other community members (see Table 2, Quote 3). HIV-negative children, including those with  
158 partial disclosure, were secretive and protective of their parents' illnesses. Those with full disclosure  
159 expressed awareness of discriminative views held against HIV-positive persons by their extended  
160 family and other community members (see Table 2, Quote 4). As a result of stigma, HIV-positive and  
161 negative children generally hid theirs and their parents' illnesses respectively from others.

## 162 **Medication Consumption**

163 Medication consumption was a way of life for all the children. Most HIV-positive children were  
164 diagnosed after lengthy periods of illness and as such expressed they took their medications as  
165 prescribed to stay healthy. All of them were in boarding school, and consuming their medications  
166 there, was an additional burden because they had to hide them from their peers. Most disliked taking  
167 the medications, and some thought they interfered with their regular lives (see Table 2, Quote 5). Most  
168 HIV-negative children stated that they helped their parents remember to take their medications  
169 because the medications had improved their parents' health after prolonged ill health (see Table 4,  
170 Quote 1). Four hoped their parents would remain healthy, pay their school fees so they could finish  
171 school and have a better life; a few wanted to financially support their parents in the future.

**172 Sexual Awareness**

173 All the children expressed they were not sexually active. Although all HIV-positive children had  
174 acquired their illnesses through mother-to-child-transmission, three still had questions about the origin  
175 of their illnesses. Some who were teenagers stated they received peer pressure from their HIV-  
176 negative peers to engage in the highly prevalent sexual activity present among teenagers. Three of  
177 these HIV-positive teenagers expressed they had questions about their acceptability as relationship  
178 partners, use of condoms, marriage, and childbearing options. All three had spoken with healthcare  
179 professionals about these issues, but remained dissatisfied with the answers they were provided (see  
180 Table 2, Quote 7). Two teenage HIV-negative children with full disclosure suspected that their parents  
181 acquired the illness through sexual intercourse but were unable to ask them; however, they expressed  
182 that they had spoken with their parents about sexual-related matters. They also agreed that their  
183 teenage peers were having sex and expressed a wish for children, especially HIV-negative children, to  
184 be taught about the illness so they could be more careful about engaging in sex (see Table 2, Quote  
185 8).

**186 Coping Mechanisms**

187 All children except a preadolescent HIV-positive boy with partial disclosure of his illness,  
188 expressed that they had a close trusted person whom they spoke to when feeling down about their  
189 circumstances. These persons included their older siblings, cousins, aunts, uncles, grandparents, and  
190 friends. All the children including those with partial disclosure expressed that stressful situations,  
191 idleness, and periods of unhappiness negatively affected them, causing them to self-withdraw for  
192 periods ranging from 30 minutes to two hours. While alone, the children performed a range of  
193 activities to help themselves feel better such as thinking about how to improve their lives, praying  
194 about their circumstances, reading, watching TV, listening to the radio, and listening, singing and  
195 dancing to music. A few also cried and took naps; one HIV-positive boy who blamed his mother for his  
196 illness, hid from her and left the house to play with other children.

197 HIV-positive children with full disclosure expressed they gained extra support from their HIV-  
198 positive peers during support group meetings held at the clinic. They considered these peers as their  
199 only true friends and exchanged cell phone numbers so they could keep in touch when back in school.  
200 All HIV-positive children expressed a need to be understood, respected, educated on self-care by  
201 healthcare professionals, and loved by their parents, relatives, and peers. They especially wanted  
202 their HIV-positive peers to care about and look out for each other. Two of them expressed they did not  
203 want to be forced to do chores at home (see Table 2, Quote 9). HIV-negative children expressed a  
204 need for healthcare professionals to educate them about the illness and how best to support their  
205 parents. Those with full disclosure of their parents' illnesses expressed a desire to be brought together  
206 with other affected children so they could share their experiences and learn from each other (see  
207 Table 2, Quote 10).

## 208 Discussion

209 This study presents results from a small purposively selected and imbalanced sample size of  
210 seven HIV-positive and five HIV-negative children; as such the results should be interpreted with  
211 caution. Prior studies reporting on the effects of disclosure on children have been conducted with HIV-  
212 positive children (Brown et al., 2011; Menon et al., 2007; Petersen et al., 2010; Vaz et al., 2010) and  
213 HIV-positive mother-child dyads (Jones et al., 2007; Murphy, Steers, & Stritto, 2001; Shafer et al.,  
214 2001; Rochat et al., 2014; Rochat, Mwankazi, & Bland, 2013). This study presents the post-disclosure  
215 experiences of both HIV-positive and negative children. The results appear to indicate that HIV-  
216 positive and negative children have mostly differing post-disclosure experiences revolving around  
217 acceptance of illness, high levels of societal misconceptions accompanied by stigma and  
218 discrimination, indefinite daily medication consumption necessary for maintenance of good health,  
219 high sexual awareness accompanied by lingering questions about the source of illness, condom use,  
220 marriage, and childbearing options, and use of various mechanisms to cope with their circumstances.

221 HIV-negative children accepted and recovered from disclosure of their parents' illnesses faster  
222 than HIV-positive children recovered from disclosure of their own illnesses. Additionally, some HIV-  
223 positive teenagers experienced similar grieving reactions as those seen in HIV-positive Puerto Rican  
224 children following disclosure of their illnesses (Blasini et al., 2004). HIV-negative children expressed  
225 they became closer to their parents and were able to speak with them about difficult subjects such as  
226 sex. Unlike prior studies that reported increased post-disclosure bonding between parents and their  
227 HIV-positive and negative children (Kennedy et al., 2010; Petersen et al., 2010), HIV-positive children  
228 in this study did not report increased closeness with their parents. These differences in post-disclosure  
229 experiences of HIV-positive and negative children, especially in regards to acceptance of illness and  
230 recovery from full disclosure, need to be studied further.

231 HIV-negative children did not report direct incidences of stigma and discrimination, but all  
232 including those with partial disclosure, hid their parents' illnesses from others. HIV-positive children  
233 experienced externalized and internalized stigma through actions shown them by their peers, and  
234 extended family and community members. Prior researchers have reported high levels of depression,  
235 discrimination, self-stigma, and self-isolation in HIV-positive children after disclosure of their illnesses  
236 (Biadgilign et al., 2011; Ishikawa et al., 2010; Petersen et al., 2010; Vaz et al., 2010; Vreeman et al.,  
237 2014). From this study's results, it appears that HIV-negative children also self-isolate themselves  
238 when feeling overwhelmed about their circumstances. Given the prevalence of stigma in Kenya and  
239 other nations with high HIV prevalence, it seems that both HIV-positive and negative children may  
240 benefit from disclosure services and public education programs aimed at counteracting the high levels  
241 of stigma, discrimination, and misconceptions held by community members (Kouyoumdjian et al.,  
242 2005; Murphy & Marelich, 2008; Vaz et al., 2010).

243 The majority of HIV-negative children wanted their parents to stay healthy and pay their school  
244 fees so they could have a better life for themselves in the future. This was unlike findings reported by  
245 Kennedy et al. (2010), who found that following disclosure of their parents' illnesses, some children in

246 that study conducted in the United States, were so distressed that they could not function for a long  
247 time. In this study, HIV-positive children disliked taking their medications but appreciated their role in  
248 helping them stay healthy. Additional studies are needed to further understand and describe the post-  
249 disclosure desires of HIV-negative children in relation to medication consumption by their parents. It  
250 also appears that programs and services are needed to assist HIV-positive children to take their  
251 medications and maintain adherence.

252 The 2012 Kenya AIDS Indicator Survey found that despite high awareness of the illness,  
253 children were initiating sex as early as 10 years; some had multiple partners with low or no condom  
254 use (National AIDS and STI Control Programme, 2014). Teenage HIV-positive and negative children  
255 in this study, confirmed that their peers were having sex. Some HIV-negative children advocated for  
256 children to be taught about the illness, and HIV-positive children had many questions about condoms,  
257 relationships, marriage, and childbearing. This study's results appear to indicate that teenage HIV-  
258 positive and negative children have a desire to speak and be taught about sexual-related matters. The  
259 utility of innovative programs such as Project Mwana (UNICEF, 2014), which uses text messages to  
260 disseminate maternal and child health information to program participants, should be investigated in  
261 their capability to provide sexual-related information to children. Additionally, it appears that HIV-  
262 positive children may benefit from counseling programs and services that regularly apprise them on  
263 emerging research findings such as the use of pre-exposure prophylaxis (PrEP) for conception  
264 (Chadwick et al., 2011; Lampe et al., 2011; Savasi et al., 2013; Vernazza, Graf, & Sonnenberg-  
265 Schwan, 2011) and post-exposure prophylaxis (PEP) for their partners in the event of unprotected sex  
266 or if a condom breaks during sexual intercourse (Palmer, 2014; Sultan, Benn, & Waters, 2014)

267 Post-disclosure, prior researchers have called for parents to provide a safe person for their  
268 children to speak with (Murphy, 2008; Murphy et al., 2011). In this study, most children had self-  
269 identified a person to provide them with social support; HIV-positive children gained additional support  
270 within peer support groups. Support groups are known to help HIV-positive children cope with their

271 illnesses (Mawn, 2011; Petersen et al., 2010). HIV-negative children in this study wanted to be  
272 educated on how to support their parents and also wanted to be brought together with other similarly  
273 affected children. Given the scarcity of studies involving HIV-negative children, more studies need to  
274 be conducted to understand their post-disclosure needs and if peer support groups and other services  
275 (e.g., counseling) may be beneficial for them.

276 This study's results appear to support the stress and coping theory (Lazarus, 1993). As seen in  
277 prior research (Asander et al., 2009; Kennedy et al., 2010; Murphy et al., 2010; Murphy, 2008;  
278 Petersen et al., 2010; Vallerand et al., 2005; Wiener et al., 2007), HIV-positive and negative children  
279 in this study experienced both positive and negative effects of disclosure. However, they appeared to  
280 be effectively using emotion- and problem-focused behavioral strategies to cope with their ongoing  
281 circumstances. When they perceived their levels of stress as increased, most withdrew to be by  
282 themselves and performed positive activities to help themselves feel better. Further testing of the  
283 stress and coping theory's utility in addressing and lessening children's post-disclosure stressors is  
284 warranted, so that programs and services can be created to help HIV-positive and negative children  
285 better cope with their circumstances.

286 This study's limitations include a small purposively selected sample of mostly teenage children  
287 conversant in English who were recruited from an urban area. Due to the small sample size, the  
288 results may not be generalizable to other HIV-positive and negative children who have received  
289 disclosure of their own and their parents' illnesses respectively. Future studies should include larger  
290 sample sizes, use local languages, and recruit children of different ages from diverse cultural  
291 neighborhoods. The studies should also seek to fill the knowledge gap on the experiences of HIV-  
292 positive and negative siblings after they receive full disclosure of their own and their parents' illnesses  
293 within the same household.

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**Conclusion**

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Although from a small sample size, the results of this study appear to indicate that HIV-positive and negative children undergo different experiences after disclosure of their own and their parents illnesses respectively. Many HIV-affected families in highly prevalent nations have both HIV-positive and negative children in the household. Until larger studies are conducted, this study's results should assist healthcare professionals to provide targeted advice to HIV-positive parents who wish to disclose to their children of mixed HIV statuses.

302

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309

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310



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## References

- 312 Asander A, Bjorkman A, Belfrage E, & Faxelid E. 2009. HIV-infected African parents living in Stockholm,  
313 Sweden: Disclosure and planning for their children's future. *Health & Social Work* 14:107-115.
- 314 Blasini I, Chantry C, Cruz C, Ortiz L, Salabarría I, Scalley N, Matos B, Febo I, Diaz C. 2004. Disclosure  
315 model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and  
316 evaluation. *Developmental and Behavioral Pediatrics* 25:181-189.
- 317 Brown BJ, Oladokun RE, Osinusi K, Ochigbo S, Adewole F, Kanki P. 2011. Disclosure of HIV status to  
318 infected children in a Nigerian HIV Care Programme. *AIDS Care* 23:1053-1058.
- 319 Biadgilign S, Deribew A, Amberbir A, Escudero HR, Deribe K. 2011. Factors associated with HIV/AIDS  
320 diagnostic disclosure to HIV infected children receiving HAART: A multi-center study in Addis  
321 Ababa, Ethiopia. *PLoS One* 6:e17572.
- 322 Chadwick RJ, Mantell JE, Moodley J, Harries J, Zweigenthal V, Cooper D. 2011. Safer conception  
323 interventions for HIV-affected couples: Implications for resource-constrained settings. *Topics  
324 in Antiviral Medicine* 19:148-155
- 325 Gachanja G, Burkholder GJ, Ferraro A. 2014a. HIV-positive parents, HIV-positive children, and HIV-  
326 negative children's perspectives on disclosure of a parent's and child's illness in Kenya. *PeerJ*  
327 2:e486.
- 328 Gachanja G, Burkholder GJ, Ferraro A. 2014b. HIV-positive parents' accounts on disclosure  
329 preparation activities in Kenya. *Journal of Social, Behavioral, and Health Sciences* 8:18-37.
- 330 Ishikawa N, Pridmore P, Carr-Hill R, Chaimuangdee K. 2010. Breaking down the wall of silence around  
331 children affected by AIDS in Thailand to support their psychosocial health. *AIDS Care* 22:308-  
332 313.
- 333 Jones DJ, Foster SE, Zalot AA, Chester C, King A. 2007. Knowledge of maternal HIV/AIDS and child  
334 adjustment: The moderating role of children's relationships with their mothers. *AIDS and  
335 Behavior* 11:409-420.
- 336 Kennedy DP, Cowgill BO, Bogart LM, Corona R, Ryan GW, Murphy DA, Nguyen T, Schuster MA. 2010.  
337 Parents' disclosure of their HIV infection to their children in the context of the family. *AIDS  
338 and Behavior* 14:1095-1105.
- 339 Kidia KK, Mupambireyi Z, Cluver L, Ndhlovu CE, Borok M, Ferrand RA. 2014. HIV status disclosure to  
340 perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and  
341 healthcare worker perspectives. *PLoS ONE* 9:e87322.
- 342 Kouyoumdjian FG, Meyers T, Mtshizana S. 2005. Barriers to disclosure to children with HIV. *Journal of  
343 Tropical Pediatrics* 51:285-287.
- 344 Kuzel A J. 1999. "Sampling in Qualitative Inquiry," In BF Crabtree and WL Miller (Eds.) Doing  
345 Qualitative Research (2nd ed.). Thousand Oaks, CA: Sage Publications.

- 346 Lampe MA, Smith DK, Anderson GJE, Edwards AE, Nesheim SR. 2011. Achieving safe conception in  
347 HIV-discordant couples: The potential role of oral preexposure prophylaxis (PrEP) in the  
348 United States. *American Journal of Obstetrics & Gynecology* 204:488.e1-8.
- 349 Lazarus RE. 1993. Coping theory and research: Past, present, and future. *Psychosomatic Medicine*  
350 55:234-247
- 351 Lee MB, Rotheram-Borus MJ. 2002. Parents' disclosure of HIV to their children. *AIDS*, 16:2201-2207.
- 352 Mawn BE. 2011. Children's voices: Living with HIV. *MCN, American Journal of Maternal Child Nursing*  
353 36: 368-372.
- 354 Menon A, Glazebrook C, Campain N, Ngoma M. 2007. Mental health and disclosure of HIV status in  
355 Zambian adolescents with HIV infection: Implications for peer-support programs. *Journal of*  
356 *Acquired Immune Deficiency Syndromes* 46:349-354.
- 357 Midtbo V, Shirima V, Skovdal M, Daniel M. 2012. How disclosure and antiretroviral therapy help HIV  
358 infected adolescents in sub-Saharan Africa cope with stigma. *African Journal of AIDS Research*  
359 11:261-271.
- 360 Morse JM. 2000. Determining sample size. *Qualitative Health Research* 10:3-5.
- 361 Moustakas C. 1994. *Phenomenological research methods*. London, England: Sage Publications.
- 362 Murphy DA. 2008. HIV-positive mothers' disclosure of their serostatus to their young children: A  
363 review. *Clinical Child Psychology Psychiatry* 13:105-122.
- 364 Murphy DA, Armistead L, Marelich WD, Payne DL, Herbeck DM. 2011. Pilot trial of a disclosure  
365 intervention for HIV+ mothers: The TRACK program. *Journal of Consulting and Clinical*  
366 *Psychology* 79:203-214.
- 367 Murphy DA, Marelich WD, Armistead L, Herbeck DM, & Payne DL. 2010. Anxiety/stress among  
368 mothers living with HIV: Effects on parenting skills and child outcomes. *AIDS Care* 22:1449-  
369 1458.
- 370 Murphy DA, Marelich WD. 2008. Resiliency in young children whose mothers are living with HIV/AIDS.  
371 *AIDS Care* 20:284-291.
- 372 Murphy DA, Steers WN, Stritto MED. 2001. Maternal disclosure of mothers' HIV serostatus to their  
373 young children. *Journal of Family Psychology* 15:441-450.
- 374 National AIDS and STI Control Programme Kenya. 2014. Kenya AIDS Indicator Survey 2012: Final  
375 Report. Retrieved from  
376 [http://www.nacc.or.ke/attachments/article/403/KAIS\\_II\\_2014\\_Final\\_Report.pdf](http://www.nacc.or.ke/attachments/article/403/KAIS_II_2014_Final_Report.pdf). (accessed  
377 30 January 2015).
- 378 Nelms TP, Zeigler VL. 2008. A study to develop a disclosure to children intervention for HIV-infected  
379 women. *Journal of the Association of Nurses in AIDS Care*, 19:461-469.
- 380 Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, Mckay M, Mellins C. 2010. Psychosocial  
381 challenges and protective influences for socio-emotional coping of HIV+ adolescents in South

- 382 Africa: A qualitative investigation. *AIDS Care* 22:970-978.
- 383 Rochat JR, Arteche AX, Steind A, Mkwanazi N, Bland RM. 2014. Maternal HIV disclosure to young HIV-  
384 uninfected children: An evaluation of a family-centered intervention in South Africa. *AIDS*  
385 28:S331-S341
- 386 Rochat JR, Mkwanazi N, Bland R. 2013. Maternal HIV disclosure to HIV-uninfected children in rural  
387 South Africa: A pilot study of a family-based intervention. *BMC Public Health* 13:1-16.
- 388 Savasi V, Mandia L, Laoreti A, Cetin I. 202. Reproductive assistance in HIV serodiscordant couples.  
389 *Human Reproduction Update* 19:136-150.
- 390 Shafer A, Jones DJ, Kotchick BA, Forehand R, The Family Health Project Research Group. 2001. Telling  
391 the children: Disclosure of maternal HIV infection and its effects on child psychosocial  
392 adjustment. *Journal of Child and Family Studies* 10:301-313
- 393 Turan JM, Hatcher AH, Medema-Wijnveen J, Onono M, Miller S, Bukusi EA, Turan B, Cohen CR. 2012.  
394 The role of HIV-related stigma in utilization of skilled childbirth services in rural Kenya: A  
395 prospective mixed-methods study. *PLoS Med* 9:e1001295.
- 396 UNAIDS. 2013. Core Epidemiology Slides. Available at  
397 [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr20](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309_epi_core_en.pdf)  
398 [13/201309\\_epi\\_core\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309_epi_core_en.pdf) (accessed 30 January 2015).
- 399 UNICEF. 2014. Stories of Innovation: Project Mwana. Available at  
400 <http://unicefstories.org/2014/05/20/project-mwana/> (accessed 30 January 2015).
- 401 UNICEF. 2013. Kenya statistics. Available at  
402 [http://www.unicef.org/infobycountry/kenya\\_statistics.html#116](http://www.unicef.org/infobycountry/kenya_statistics.html#116). (accessed 30 January 2015).
- 403 Vallerand AH, Hough E, Pittiglio L, Marvicsin D. 2005. The process of disclosing HIV serostatus  
404 between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care and STDs*  
405 19:100-109.
- 406 Vaz LME, Eng E, Maman S, Tshikandu T, Behets F. 2010. Telling children they have HIV: Lessons  
407 learned from findings of a qualitative study in Sub-Saharan Africa. *AIDS Patient Care and STDs*  
408 24:247-256.
- 409 Vaz L, Corneli A, Dulyx J, Rennie S, Omba S, Kitetele F, AD Research Group, Behets F. 2008. The  
410 process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the  
411 Congo. *AIDS Care* 20:842-852
- 412 Vernazza PL, Graf I, Sonnenberg-Schwan U, Geit M, Meurer A. 2011. Preexposure prophylaxis and  
413 timed intercourse for HIV-discordant couples willing to conceive a child. *AIDS* 25:2005-2008.
- 414 Vreeman RC, Scanlon ML, Mwangi A, Turissini M, Ayaya SO, Tenge C, Nyandiko MN. 2014. A cross-  
415 sectional study of disclosure of HIV status to children and adolescents in Western Kenya. *PLoS*  
416 *ONE* 9:1-9.
- 417 Wiener L, Mellins CA, Marhefka S, Battles HB. 2007. Disclosure of an HIV diagnosis to children:

418 History, current research, and future directions. *Journal of Developmental & Behavioral*  
419 *Pediatrics* 28:155-166.

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**Table 1** (on next page)

Sample Demographic Characteristics

**Table 1: Sample Demographic Characteristics**

Variable	Frequency	
	HIV-Positive Children	HIV-Negative Children
<b>Age</b>		
12-13	2	1
14-15	1	3
16-17	4	1
<b>Gender</b>		
Female	3	3
Male	4	2
<b>Educational Status</b>		
Primary	2	3
Secondary	5	2
<b>HIV Disclosure Status</b>		
Partial Disclosure	1	2
Full Disclosure	6	3

## HIV-Positive and HIV-Negative Children's Post-Disclosure Themes

Acceptance of Illness	<ul style="list-style-type: none"> <li>•HIV-negative children accepted their parents' illnesses within a few hours to a few weeks later.</li> <li>•HIV-positive children accepted their own illnesses within a few weeks up to 4 months later.</li> </ul>
Stigma and Discrimination	<ul style="list-style-type: none"> <li>•HIV-negative children knew of stigmatizing views held by their extended family and community members but reported no direct incidences of stigma and discrimination.</li> <li>•HIV-positive children reported incidences of indirect stigma and discrimination shown them by their extended family members, HIV-negative peers, and other community members.</li> </ul>
Medication Consumption	<ul style="list-style-type: none"> <li>•HIV-negative children wanted their parents to take their medications and stay healthy so they could continue paying for their education. They wanted to finish school and have a better life for themselves.</li> <li>•HIV-positive children disliked taking medications and viewed it as a necessary ordeal to help them stay healthy.</li> </ul>
Sexual Awareness	<ul style="list-style-type: none"> <li>•HIV-negative children had questions about sex and their parents' source of illness. They expressed a wish for parents to speak to them about sexual-related matters.</li> <li>•HIV-positive children had questions about the source of their illnesses, sex, condom use, relationships, marriage, and childbearing options.</li> </ul>
Coping Mechanisms	<ul style="list-style-type: none"> <li>•When feeling down about their circumstances, all the children coped by speaking to a close trusted person such as an older sibling, cousin, aunt, uncle, grandparent, and friend.</li> <li>•Children also self-withdrew to perform positive activities to help themselves feel better. These included thinking about ways to improve their lives, praying about their circumstances, watching TV, listening to the radio, and listening, singing, and dancing to music.</li> </ul>

**Table 2** (on next page)

Key Quotes From Each Theme



Theme	Table 2. Key Quotes From Each Theme	
	HIV-Positive Children	HIV-Negative Children
<b>Acceptance of Illness</b>	<p><b>Quote 1</b> HIV-positive girl: [Clicks tongue] I was hopeless, [clicks tongue] I hated myself, [clicks tongue] even I almost lost hope in life... I came to counselling and the counselor taught me how to take medicine, and the consequences [clicks tongue]... I used to cry then after sometime maybe like two months that's when [clicks tongue] I started accepting myself. Now [clicks tongue] I feel just like a normal human being, I just take it like a cold... But I still blame my dad coz he knew he was positive yet he let my mother give birth to me and my mother never knew she had the disease. [Tongue clicks during conversations in Kenya depict discomfort with the topic being discussed].</p>	<p><b>Quote 2</b> HIV-negative girl: [After partial disclosure] I felt relieved because I knew that God will protect her, and maybe she could go on well and get better... I wanted to know of my mother's ailment so that I can assist her in any way that I can, by doing the work that she needs to be done, like working in the house and feeding the chicken.</p>
<b>Stigma and Discrimination</b>	<p><b>Quote 3</b> HIV-positive boy: The way people talk about AIDS sometimes I don't like it, about the medicine, the ARVs! I think when you are thin they say you are positive but when you are fat they say you are not. They say so many things about HIV positive people that I don't like... You see in school when you have HIV status, many people joke, they say if I know about my HIV status, I can kill myself, I don't know what, and then I cannot take those drugs, meaning you feel very badly.</p>	<p><b>Quote 4</b> HIV-negative boy: If you are HIV-positive, then you sometimes are an outcast. They [mother's in-laws] say that you have been witchcrafted, so telling them it will be gossip news, they will be talking about it every time. Even my brother does not know why she [mother] takes the drugs, I don't know if my father knows, but she told me he does not know. They all know that because she was sick with meningitis she takes medicine ever since. I prefer not to tell him, it is not because of hatred or something, it is because if I tell my brother he will go and tell my father.</p>
<b>Medication Consumption</b>	<p><b>Quote 5</b> HIV-positive girl: Sometimes when I have stress as in I am being shouted at, I just sit down and start crying and other stuff. I ask myself questions which I cannot answer by myself; so actually there is nobody who can help me. I usually ask myself why was it supposed to be me? Why is it me who is supposed to take all these drugs all the time? Why is it me I am the only HIV-positive girl in the house? I never used to take drugs, but now I have to stick on them [sighs] until [pauses, hits table], until this world comes to an end. I am a kid, now you know I have stress all the time, thinking I am the only person who has all these diseases, I am taking all these drugs [sighs]. Actually I hate taking drugs all the time, actually it sucks coz usually my brother and sisters just go to bed, me I have to take medicine before I go to bed [sighs], and in the morning the same thing.</p>	<p><b>Quote 6</b> HIV-negative boy: She [mother] got sick and stayed at the hospital for about three months. She is better now, she usually comes here, takes her medicine and then goes back home. Even sometimes when she forgets to take her medicine, because she always takes her medicine at eight am and eight pm, I remind her [laughs].</p>
<b>Sexual Awareness</b>	<p><b>Quote 7</b> HIV-positive boy: [Researcher: Do you have any questions that you have wanted to ask?] Yes, when I am positive and I decide to get married can I get a child who is negative and I cannot transfer the disease to my wife? [Have you asked anybody that question?] Yeah. [Who did you ask?] I asked a psychologist here in the CCC. [Did she answer your question?] She told me, I can't remember exactly what, but your male sperm is taken to the lab and they are treated, then they are taken and transferred to your wife and she gets pregnant without the disease. [Do you feel that she answered your questions completely?] No, it is still in my mind. [Even after she answered your question?] Yeah. [Why is it still in your mind?] What about if it is done physically as in the ordinary way [without a condom]? The way she told me it is very expensive, what about if you cannot afford it, what can you do?</p>	<p><b>Quote 8</b> HIV-negative girl: We are very close, I can just see something or hear something and I ask her [mother]. She never hides anything from me. If it is about sex, she tells me this goes on, and you know about even condoms and not most parents are usually open with their children... My mum disclosed to me and that's a great thing because now I know this AIDS thing is real, it is there, so it's like she is telling me to be careful myself not to end up the way she has. So I think it is best for kids to know about it.</p>
<b>Coping Mechanisms</b>	<p><b>Quote 9</b> HIV-positive boy: I speak to my friends when we come here for our club when the schools are closed. There are many of us, we come and play together and we share experiences like how we felt when we were first told. We discuss about our lives, how we are living,</p>	<p><b>Quote 10</b> HIV-negative boy: When I got to know her status, I told my friend [whose mother is HIV-positive] that my mother is positive. Then he encouraged me that I just take things as normal... I think [HIV-affected] children should be encouraged to get together because if I</p>

how we should live, how we should take our medicine, how we should eat, and how we should control ourselves... [HIV-positive children] need to receive care, be loved, and to be shown they are just like other people, like they be respected not when they come to the hospital they are told you wait because you are HIV. No, they be treated like the other people... They should be encouraged to do their favorite things, you know you can't force me to do something [chores] I don't like, even that one will make me idle.

am a friend then you tell me that your mother is HIV-positive since this age, then I recently know that my father or my mother is HIV-positive, you could help me to know how to take care of him or her or even how to take it positive that she is sick. Some people just see it as a very big sickness that can kill somebody or kill the parent, so it is better to talk to your friend, you speak out what you are feeling.