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A rapid assessment of HIV post-disclosure experiences of urban school-aged children in Kenya

Some HIV affected families in Kenya have a combination of HIV-positive and negative children within the household. HIV-positive and negative children are known to experience variable effects following disclosure of their own and their parents' illnesses respectively. Most studies conducted on the effects of disclosure on children have been with HIV-positive children and mother-child dyads. There has been limited involvement of HIV-negative children in HIV disclosure studies in Sub-Saharan Africa. A larger study was conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya. Seven HIV-positive and five HIV-negative children participated in that study. In the current 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 showing that HIV-positive and negative children have varying post-disclosure experiences revolving around acceptance of illness, stigma and discrimination, medication consumption, sexual awareness, and use of coping mechanisms. HIV-negative children accepted their parents' illnesses faster than HIV-positive children accepted their own illnesses; the later also reported facing more stigma and discrimination. HIV-negative children wanted their parents to take their medications, stay healthy, and pay their school fees; 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. The majority of children coped by speaking about their circumstances to a person close to them and also self-withdrawing to be by themselves when feeling overwhelmed.

Pending further studies conducted with larger sample sizes, the results of this study can be used by healthcare professionals to better facilitate disclosure between HIV-positive parents and their children of mixed HIV statuses.

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

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Introduction

HIV/AIDS remains a public health issue affecting 35.3 million persons globally (UNAIDS, 2013). In 2012, 22% of Kenya's population were children between 10-19 years (UNAIDS, 2013). The HIV prevalence among children aged 18 months to 14 years was 0.9% (National AIDS and STI Control Programme, 2014) and 2.7% among youth aged 15-24 years (UNICEF, 2013). Five percent of Kenyan homes had a HIV-positive head of household (National AIDS and STI Control Programme, 2014) with an adult HIV prevalence of 6% (UNAIDS, 2013). Some families in Kenya have both parent(s) and child(ren) infected with HIV (Gachanja, Burkholder, & Ferraro, 2014a; Gachanja, Burkholder, & Ferraro, 2014b).

Following disclosure, HIV-positive and negative children are known to experience varying effects (Kennedy et al., 2010; Murphy, 2008; Vallerand et al., 2005). After disclosure of their illnesses, HIV-positive teenage children in Puerto Rico went through the five stages of grieving (denial, anger, bargaining, depression, and acceptance) before accepting their illnesses (Blasini et al., 2004). HIV-negative children in studies conducted in the United States using mother-child dyads, were reported to fare no worse after they received disclosure of their mothers' illnesses (Jones et al., 2007; Murphy, Steers, & Stritto, 2001; Shafer et al., 2001). Mothers in South Africa reported their HIV-negative children accepted disclosure of maternal illness calmly, although some were surprised, confused, and emotional (Rochat et al., 2014; Rochat, Mwankazi, & Bland, 2013).

Positive effects of disclosure for HIV-positive and negative children include increased bonding with their parents (Vallerand et al., 2005), fewer behavioral problems and aggression (Lee & Rotheram-Borus, 2002; Murphy, Steers, & Stritto, 2001), and improved resiliency, coping, and perspectives on life (Kennedy et al., 2010; Murphy et

al., 2010). Internalized effects of disclosure include poor functioning, increased stress, sadness, withdrawal, depression, and fear (Asander et al., 2009; Kennedy et al., 2010; Murphy, 2008; Petersen et al., 2010; Vallerand et al., 2005; Wiener et al., 2007). Externalized effects of disclosure include arguing with or ignoring parents, unsafe sexual behavior, and aggression (Lee & Rotheram-Borus, 2002; Murphy, 2008; Nelms & Zeigler, 2008; Vallerand et al., 2005).

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

The stress and coping theory was used as the foundation for this study (Lazarus, 1993). Coping is assessed by how well a person cognitively and behaviorally addresses the stress he or she experiences. The theory posits that stress management involves problem- or emotion-focused coping strategies, and that there is no universal good or bad way to cope with stress. A person's problem-focused coping is enhanced by self-adaption to his or her environment, while emotion-focused coping is improved by avoiding stress or being hyper vigilant and anticipative of which situations lead to stress

(Lazarus, 1993). Assessing a person's thoughts and coping behaviors is important because improved handling of stressors helps him or her understand, cope, and lessen the stress associated with his or her unchangeable circumstances (Lazarus, 1993).

It is not well understood if HIV-positive and negative children experience similar effects following disclosure of their own and their parents' illnesses respectively. Most studies on disclosure to children conducted in Sub-Saharan Africa have reported on the effects of disclosure on HIV-positive children after being told about their own illnesses (Brown et al., 2011; Menon et al., 2007; Petersen et al., 2010; Vaz et al., 2010). A few recent studies have reported mothers' observations on the effects of disclosure of their illnesses on their preadolescent HIV-negative children (Rochat et al., 2014; Rochat, Mwankazi, & Bland, 2013). A larger study was conducted to understand the lived experiences of HIV-positive parents and children in Kenya (Gachanja, Burkholder, Ferraro, 2014a); seven HIV-positive and five HIV-negative children participated in that study. In this current study, data from these 12 children is presented to add to the body of knowledge on the experiences of HIV-positive and negative children after they receive disclosure of their own and their parents' illnesses respectively.

Methods

Recruitment of Participants

Data collection for the larger study was conducted in December 2010 through January 2011 at the Kenyatta National Hospital Comprehensive Care Center located in Nairobi, Kenya. Participant recruitment was continued until interview data saturation was achieved upon which recruitment was halted resulting in a child sample size of seven HIV-positive and five HIV-negative children (Gachanja, Burkholder, & Ferraro, 2014a). HIV-positive and negative children were purposively selected to be in the study because

they were between 8-17 years old, conversant in English, and had already received partial or full disclosure of their own and their parents' illnesses respectively. Ethics approval for the study was received from the Kenyatta National Hospital (KNH) Research Standards and Ethics Committee (Approval # P373/10/2010) and the Walden University Institutional Review Board (Approval # 11-10-10-03904).

HIV-positive parents who had HIV-negative children meeting criteria for study participation were approached during their regularly scheduled clinic visits, provided with an explanation of the study, and requested to bring their HIV-negative children to the clinic at a time convenient to them. HIV-positive children who met criteria to be in the study were approached along with their parents for participation during their regularly scheduled clinic visits, and also provided with an explanation of the study. Children and parents who expressed an interest to participate in the study were escorted by the researcher to a private room in the clinic where consenting and study procedures were performed. Children who agreed to participate provided written assent and their parents provided written informed consent.

Data Collection

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

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

Data Analysis

Recorded interviews were transcribed soon after data collection by the researcher and a local Kenyan university student experienced with transcription. Transcripts were checked twice against the recorded interviews for accuracy and loaded into NVivo8 for analysis. The Van Kaam method (Moustakas, 1994) was used for phenomenological analysis of the transcribed qualitative data. Transcripts were listed, grouped, and scanned repeatedly for emerging codes. Repeating information within the transcripts was clustered into similar codes. The codes and themes were cross-checked by the researcher's supervising research committee for coding reliability and consistency within each emerging theme. The codes were then grouped into five emergent themes describing the children's post-disclosure experiences.

Results

The 12 children's demographic characteristics are displayed in Table 1. Six HIV-positive children had full disclosure of their illnesses, and three HIV-negative children had full disclosure of their parents' illnesses. All HIV-positive children were taking antiretroviral therapy, multivitamins, and cotrimaxazole; all HIV-negative children were

aware that their parents consumed medications on a daily basis. The five themes (acceptance of illness, stigma and discrimination, medication consumption, sexual awareness, and coping mechanisms) that emerged from the data are displayed in Figure 1 and further described below.

Acceptance of Illness

Regardless of the type of disclosure received, 11 of 12 children were shocked at the time of disclosure but expressed they were happy to have been disclosed to. One HIV-positive girl and a HIV-negative boy with full disclosure did not want to be disclosed to again (see Table 2, Quote 1). Following counseling, the six HIV-positive children with full disclosure overcame their shock, accepted their illnesses, and returned to “normal” anywhere from a few weeks up to four months later. Two of these HIV-positive children still expressed blame and anger at their parents for infecting them (see Table 2, Quote 2). HIV-negative children (with partial and full disclosure) overcame their shock and accepted their parents’ illnesses within a few hours to a few weeks later. Most HIV-negative children explained they grew closer to their parents, were empathetic about their illnesses, and helped out more with chores to ease their parents’ burden of illness (see Table 2, Quote 3).

Stigma and Discrimination

Both HIV-positive and negative children were aware of high stigma and discrimination levels prevalent in the community; some expressed their siblings and relatives did not know of theirs and their parents’ illness respectively. HIV-negative children, including those with partial disclosure, were secretive and protective of their parents’ diagnoses. Those with full disclosure expressed awareness of discriminative views held against HIV-positive persons by their extended family and other community

members (see Table 3, Quote 1). HIV-positive children expressed incidences of indirect stigma and discrimination shown them by their HIV-negative peers, and extended family and other community members (see Table 3, Quotes 2 and 3) As a result of stigma, HIV-positive and negative children generally hid theirs and their parents' illnesses respectively from others (see Table 3, Quote 4).

Medication Consumption

Medication consumption was a way of life for all the children. Most HIV-negative children stated they helped their parents remember to take their medications because they had improved their parents' health after prolonged ill health (see Table 4, Quote 1). Four hoped their parents' would remain healthy and pay their school fees so they could finish school and have a better life (see Table 4, Quote 2). Most HIV-positive children were diagnosed after lengthy periods of illness and as such expressed they took their medications as prescribed to stay healthy. All of them were in boarding school and taking their medications there was an additional burden because they had to hide them from their peers (see Table 4, Quote 3). Most disliked taking the medications and some thought they interfered with their regular lives (see Table 4, Quote 4).

Sexual Awareness

All the children expressed they were not sexually active. Although all HIV-positive children had acquired their illnesses through mother-to-child-transmission, three still had questions about the origin of their illnesses (see Table 5, Quote 1). Those who were teenagers stated they received peer pressure from their HIV-negative peers to engage in sexual activity (see Table 5, Quote 2). Three of these HIV-positive teenagers also expressed they had questions about their acceptability as relationship partners, use of condoms, marriage, and childbearing options. All three had spoken with healthcare

professionals about these issues but remained dissatisfied with the answers they were provided (see Table 5, Quotes 3 and 4). Two teenage HIV-negative children with full disclosure suspected their parents acquired the illness through sexual intercourse but were unable to ask them. They stated that their teenage peers were having sex and expressed a wish for children, especially HIV-negative children, to be taught about the illness so they could be more careful about engaging in sex (see Table 5, Quote 5).

Coping Mechanisms

All children except a preadolescent HIV-positive boy with partial disclosure of his illness expressed they had a close trusted person whom they spoke to when feeling down about their circumstances. These persons included their older siblings, cousins, aunts, uncles, grandparents, and friends (see Table 6, Quote 1). All the children including those with partial disclosure expressed that stressful situations, idleness, and periods of unhappiness negatively affected them, causing them to self-withdraw for periods ranging from 30 minutes to two hours. While alone, the children performed a range of activities to help themselves feel better such as thinking about how to improve their lives, praying about their circumstances, watching TV, listening to the radio, and listening, singing and dancing to music (see Table 6, Quotes 2 and 3).

HIV-positive children with full disclosure expressed they gained extra support from their HIV-positive peers during support group meetings held at the clinic. They considered these peers as their only true friends and exchanged cell phone numbers so they could keep in touch when back in school. All HIV-positive children expressed a need to be understood, respected, educated on self-care by healthcare professionals, and loved by their parents, relatives, and peers. They especially wanted their HIV-positive peers to care about and look out for each other. Two of them expressed they did not want to be forced to do chores at home (see Table 6, Quote 4). HIV-negative

children expressed a need for healthcare professionals to educate them about the illness and how best to support their parents. Those with full disclosure of their parents' illnesses expressed a desire to be brought together with other affected children so they could share their experiences and learn from each other (see Table 6, Quote 5).

Discussion

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

HIV-negative children accepted and recovered from disclosure of their parents' illnesses faster than HIV-positive children recovered from disclosure of their own illnesses. Some HIV-negative children also expressed they became closer to their parents and were able to speak with them about difficult subjects such as sex. Unlike prior studies that reported increased bonding post-disclosure between parents and their HIV-positive and negative children (Kennedy et al., 2010; Petersen et al., 2010), HIV-positive children in this study did not report increased closeness with their parents.

Teenage HIV-positive children also experienced similar grieving reactions as those seen in HIV-positive Puerto Rican children following disclosure of their illnesses (Blasini et al., 2004). These differences in post-disclosure experiences of HIV-positive and negative children need to be studied further.

HIV-negative children did not report incidences of direct stigma and discrimination but all hid their parents' illnesses from others. HIV-positive children experienced externalized and internalized stigma through actions shown them by their peers, family, and community members. Prior researchers have reported high levels of depression, discrimination, self-stigma, and self-isolation in HIV-positive children after disclosure of their illnesses (Biadgilign et al., 2011; Ishikawa et al., 2010; Petersen et al., 2010; Vaz et al., 2010; Vreeman et al., 2014). Given the high prevalence of stigma in Kenya, it appears that both HIV-positive and negative children might benefit from disclosure services and public education programs aimed at counteracting stigma, discrimination, and misconceptions held by community members (Kouyoumdjian et al., 2005; Murphy & Marelich, 2008; Vaz et al., 2010).

The majority of HIV-negative children wanted their parents to stay healthy and pay their school fees so they could have a better life for themselves in the future. This was unlike findings reported by Kennedy et al. (2010) who found that following disclosure of their parents' illnesses, some children in that study were so distressed that they could not function for a long time. In this study, HIV-positive children disliked taking their medications but appreciated their role in helping them stay healthy. Additional studies are necessary to further understand and describe the post-disclosure experiences and desires of HIV-negative children in relation to medication consumption by their parents. It also appears that programs and services need to be created to assist HIV-positive children take their medications and maintain adherence.

The 2012 Kenya AIDS Indicator Survey found that despite high awareness of the illness, children were initiating sex as early as 10 years; some had multiple partners with low or no condom use (National AIDS and STI Control Programme, 2014). Teenage HIV-positive and negative children in this study confirmed that their peers were having sex. Some HIV-negative children advocated for children to be taught about the disease and HIV-positive children had many questions about condoms, relationships, marriage, and childbearing. This study's results appear to indicate that teenage children have a desire to speak about and be taught about sexual-related matters. The utility of innovative programs such as Marie Stopes International SMS 4 SRH program (Williamson, 2013), which used text messages to disseminate sexual and reproductive information to adolescents, should be investigated in their capability to provide sexual-related information to children. Additionally, it appears that HIV-positive children might benefit from counseling programs and services that regularly apprise them on emerging research findings such as the use of pre-exposure prophylaxis (PrEP) for conception (Chadwick et al., 2011; Lampe et al., 2011; Savasi et al., 2013; Vernazza, Graf, & Sonnenberg-Schwan, 2011) and post-exposure prophylaxis (Palmer, 2014; Sultan, Benn, & Waters, 2014)

Post-disclosure, prior researchers have called for parents to provide a safe person for their children to speak with (Murphy, 2008; Murphy et al., 2011). In this study, most children had self-identified a person to provide them with social support; HIV-positive children gained additional support within peer groups. Support groups are known to help HIV-positive children cope with their illnesses (Mawn, 2011; Petersen et al., 2010). Some HIV-negative children in this study wanted to be educated on how to support their parents and also wanted to be brought together with other similarly

affected. More studies need to be conducted to understand the post-disclosure needs of HIV-negative children and if peer support groups are beneficial for them.

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

This study's limitations include a small purposively selected sample of mostly teenage children who were conversant in English and were recruited from an urban area. Due to the small sample size, the results may not be generalizable to other children who have undergone disclosure of their own and their parents' illnesses. Future studies should include larger sample sizes, use local languages, and recruit children of different ages from diverse neighborhoods. Future studies should also seek to fill the knowledge gap on post-disclosure experiences of a child's and parent's illness to HIV-positive and negative siblings within the same family.

Conclusion

Many HIV affected families in highly prevalent communities have both HIV-positive and negative children. This study's results are important because they begin to

fill the knowledge gap on post-disclosure experiences of HIV-positive and negative children. Pending further larger studies, these results have the potential to assist healthcare professionals provide targeted disclosure advice to HIV-positive parents who wish to disclose to their children of mixed HIV statuses.

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Figure 1: HIV-Positive and Negative Children's Post-Disclosure Themes and Their Associated Key Experiences

Acceptance of Illness

- HIV-negative children accepted their parents' illnesses within a few hours to a few weeks.
- HIV-positive children accepted their own illnesses within a few weeks up to 4 months later.

Stigma and Discrimination

- HIV-negative children knew of stigmatizing views held by their extended family and community members but reported no direct incidences of stigma and discrimination.
- HIV-positive children reported incidences of indirect stigma and discrimination from their extended family members, HIV-negative peers, and other community members.

Medication Consumption

- 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.
- HIV-positive children disliked taking medications and viewed it as a necessary ordeal to help them stay healthy.

Sexual Awareness

- HIV-negative children had questions about sex and their parents' source of illness, and expressed a wish for parents to speak to them about sexual-related matters.
- HIV-positive children had questions about their source of illness, sex, condom use, and future relationships, marriage, and childbearing options.

Coping Mechanisms

- When feeling down about their circumstances, children coped by speaking with a close trusted person such as older siblings, cousins, aunts, uncles, grandparents, and friends.
- Children also self-withdrew to perform positive activities. 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.

Table 1: Sample Demographic Characteristics

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

Table 2: Quotes From the Acceptance of Illness Theme

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Quote 1

HIV-positive girl: *Because I know my status they are not supposed to be telling me all the time.*

Quote 2

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, 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].

Quote 3

HIV-negative boy: *I felt bad [at the time of disclosure] because I started thinking what will happen next but [clicks tongue] that was at first. Then I took a positive attitude that it is just something that she will live with but I will still be seeing her for the time being. I started now getting close to my mother too much and I was not used to being open with her. Nowadays I am very, very open with her, I can talk about anything and I can tell her everything.*

Table 3: Quotes From the Stigma and Discrimination Theme

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Quote 1

HIV-negative boy: *If you are HIV-positive then you sometimes are an outcast. They [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.*

Quote 2

HIV-positive boy: *When you are thin they [community members] say you are positive but when you are fat they say you are not.*

Quote 3

HIV-positive boy: *If you are HIV-positive and you have greeted someone who is negative, that negative person thinks that you have already transmitted the disease to him or her. If you get this HIV, they [HIV-negative peers] think that when you get it, just like that you are going to die right now, right now.*

Quote 4

HIV-positive boy: *I don't have the courage to face them [friends] to tell them because it's hard to explain because sometimes even you go and lack words on how to say it. You know you don't know the mind of a person, others can reject you.*

Table 4: Quotes From the Medication Consumption Theme

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Quote 1

HIV-negative boy: She [mother] got sick with meningitis and she 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, we remind her me and my brother [laughs].

Quote 2

HIV-negative girl: You know every kid wants everything from their parents, and the best thing a parent can give to his or her child is their education, so children should also focus on their studies. Children should not give up since they have a brighter future ahead of them, for me I am looking forward to a brighter future

Quote 3

HIV-positive boy: When I am travelling [to school] I have to carry my medicine, people ask me what is the medicine for and it becomes very hard for me to answer the questions. I tell them they are for a cold... The way people talk about AIDS sometimes I don't like it, about the medicine, the ARVs. You see in school many people joke and 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.

Quote 4

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.

Table 5: Quotes From the Sexual Awareness Theme

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Quote 1

HIV-positive girl: [After disclosure] *I thought how can I have this disease and I hear that most likely the people who get this disease are the people who are prostitutes and the biggest majority of the people who have AIDS get it from sexual transmitted intercourse? I said wow, so I am a virgin how can I have mmm HIV [clicks tongue]? That's what I asked myself.*

Quote 2

HIV-positive boy: *You know when you are age mates you do so many things because of peer pressure, some which are reasonable and some which are not. In secondary [high] school, people usually have girlfriends and boyfriends and they have sex. They [HIV-negative peers] have nothing to worry about since they are not HIV-positive, they cannot be able to infect the other person but for the infected they will. Even if they are given the news, the news cannot contradict their lives.*

Quote 3

HIV-positive girl: *One of the questions that I asked him [doctor] was like umm in the future like getting umm a husband who can get married to me. So how can I get married to a HIV-negative guy while me I am a HIV-positive girl? Coz you may find a guy who is a HIV-negative person but he don't want to understand, he doesn't want to listen coz you know some men? [Do feel you as though the doctor addressed that question for you?] No actually I don't think so. [Are you going to ask him again?] Yes, if he is there.*

Quote 4

HIV-positive boy: [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? The way she told me it is very expensive, what about if you cannot afford it, what can you do?*

Quote 5

HIV-positive boy: [Do you have a question you have wanted to ask and didn't ask?] *Mine is just once someone is affected with HIV, you are affected too yes, and you are married together now if you have sex and you want to get a child will you just use a condom or just do like that? People say that someone might use a condom, and a condom how can it help and you want to get a child? [Did you ask the doctor that question?] No I was afraid to ask that question [in a support group meeting] because I felt like people will laugh because that's just not a good question to ask.*

Quote 6

HIV-negative boy: *She [mother] has never told me where she contracted it. It really concerns me where she contracted it. I keep the questions to myself because I just know it from my heart that she has it, I don't even care of talking to her about it coz I think that sometimes it is hurting to remind her of that fact... There is this thing of teenagers having sex, so when a parent tells his teenage girl or boy that let's say he [parent] is positive, he [child] will not be engaging in any sex, he might even be helping in abstinence from it.*

Table 6: Quotes From the Coping Mechanisms Theme

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Quote 1

HIV-negative girl: *I always tell my cousin that my mother has suffered a lot, paying for us school fees and feeding us. Sometimes I also tell her when my mother is sick, we go somewhere and we pray and ask God to take care of my mother and help her in everything that it is. I know that she [cousin] is a strong Christian and I am very close to her and I trust her not to spread it around. She tells me that I can tell her my problems.*

Quote 2

HIV-negative boy: *I like to sit down and listen to the radio, some music, or just go and watch TV. I also take a walk, I just relax myself, and try to forget everything.*

Quote 3

HIV-positive boy: *I sing gospel songs and I pray for my body, for the sickness to move outside.*

Quote 4

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 discuss about our lives, how we are living, how we should live, how we should take our medicine, how we should eat, and how we should control ourselves... HIV-positive children 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.*

Quote 5

HIV-negative boy: *I think [affected] children should be encouraged to get together because if I 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.*