

## A Couple's Marital Disharmony and its Psychological Effects on Their Children during the HIV Disclosure Process in Kenya

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## Abstract

Limited published data exists on how HIV-positive couples perform disclosure of their illnesses to all their children. An HIV-positive couple's disclosure experience to all their five children is presented. They participated in a larger study conducted to understand the lived experiences of HIV-positive parents and their children during the disclosure process in Kenya. Each underwent an individualized in-depth semi-structured interview. Their interviews were transcribed and transferred into NVivo 8 for analysis using the Van Kaam method. Three themes emerged which included HIV testing, full disclosure delivery to children accompanied by marital disharmony, and negative post-disclosure psychological effects on the family. Marital disharmony and non-involvement of the father in disclosure-related activities caused the mother to fully disclose their illnesses to their four oldest children. The children were affected by disclosure; one had a delayed emotional outburst directed at her father and another was still angry and withdrawn eight years later. As a result, the couple and their four oldest children were hesitant to fully disclose to the youngest son/brother. HIV-positive couples with poor relationships within their families, need intense counseling and support pre, during, and post-disclosure to improve outcomes in all family members.

**Keywords:** *HIV/AIDS; HIV disclosure; psychological effects of HIV disclosure; parental HIV status disclosure; resource-poor nation; Kenya*

# A Couple's Marital Disharmony and its Psychological Effects on Their Children during the HIV Disclosure Process in Kenya

G. Gachanja

## I. Introduction

HIV/AIDS remains a big public health challenge in the world today. As of 2013, there were 35 million infected persons in the world; more than 25 million of them lived in Sub-Saharan Africa (UNAIDS, 2014). Kenya, a country located in Sub-Saharan Africa, has 1.2 million infected adults aged 15-64 years (NACC & NASCOP, 2014). The adult prevalence of the disease in Sub-Saharan Africa is 4.7% among those aged 15-49 years (UNAIDS, 2013), and 5.6% in Kenya among those aged 15-64 years (NACC & NASCOP, 2014). The prevalence of the illness in Kenya is expected to keep rising in the decades to come, as infected persons live longer due to increased availability of antiretroviral therapy (ART: NACC & NASCOP, 2012). Therefore, the country will see an increased need for HIV-positive couples to disclose their illnesses to their children for many years to come.

HIV-positive parents consider disclosure to their children as being important, but are very challenged by it (Blasini et al., 2004; Gachanja, Burkholder, & Ferraro, 2014a; Gachanja, Burkholder, & Ferraro, 2014b; Kallem, Renner, Ghebremichael, & Paintsil, 2011; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana, 2005; Vallerand, Hough, Pittiglio, & Marvicsin, 2005). This is more so when there are many family members infected, who may include both parents (Republic of Kenya, 2009). When parents delay disclosure, children sense secrets within their households and ask persistent questions in a bid to elicit disclosure (Brown et al., 2011; Gachanja, 2015; Gachanja et al., 2014a; Gachanja et al., 2014b; Kallem et al., 2011; Kouyoumdjian et al., 2005; Petersen et al., 2010; Vaz, Maman, Eng, Barbarin, Tshikandu, & Behets, 2011). Disclosure is a process that moves children from a state where they have no disclosure or no knowledge of their parents' illnesses (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Oberdorfer et al., 2006; Vaz et al., 2011), to partial disclosure where they know that their parents have a chronic illness or are taking medications (Bikaako-Kajura et al., 2006; Rochat, Mkwanazi, & Bland, 2013; Vaz et al., 2011), and finally to full disclosure when the children are told that their parents are infected with HIV (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Oberdorfer et al., 2006; Rochat et al., 2013).

HIV disclosure results in mixed effects in children. Some studies have shown no psychological impact on children (Jones, Foster, Zalot, Chester, & King, 2007; Murphy, Steers, & Stritto, 2001; Shafer, Jones, Kotchick, Forehand, & The Family Health Project Research Group, 2001). Other studies have shown positive effects such as improved parent-child closeness (Gachanja, 2015; Gachanja et al., 2014a; Vallerand et al., 2005), fewer behaviour problems and aggression (Lee & Rotheram-Borus, 2002; Murphy et al., 2001), and an improved outlook on life and the illness (Gachanja, 2015; Gachanja et al., 2014a; Kennedy et al., 2010). Negative effects of full disclosure in

children include externalized acting out behaviour problems such as ignoring or arguing with parents (Gachanja, 2015; Murphy, 2008; Vallerand et al., 2005); or internalized problems such as sadness, depression, and withdrawal (Gachanja, 2015; Gachanja et al., 2014a; Kennedy et al., 2010; Petersen et al., 2010; Vallerand et al., 2005).

The Disclosure Process Model is composed of three main components; these include decision making, the disclosure event, and disclosure outcomes (Chaudoir, Fisher, & Simoni, 2011; Chaudoir & Fisher, 2010; Qiao, Li, & Stanton, 2013). In the decision making stage, the HIV-positive parent considers positive approach goals which can be achieved through full disclosure against avoidance goals which seek to prevent the negative outcomes associated with disclosure (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013). Consideration of the disclosure event takes into account how full disclosure will be delivered by the parent and received emotionally by the child (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013). Disclosure outcomes involve considering the positive (improved clinic attendance for parent) and/or negative individual effects that may occur for the disclosing parent (rejection by child) and/or the child (poor functioning) receiving disclosure; positive (improved closeness between parent and child) and/or negative (depression in parent and child) dyadic outcomes that may occur in both the parent and child; and the positive (increased awareness of the disease) and negative (exposure to stigma/discrimination) sociocultural community aspects associated with full disclosure (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013).

It is not well understood how HIV-positive parents approach full disclosure of their illnesses to all their children in the household. A larger study was performed to understand the lived experiences of HIV-positive parents and their biological children during the disclosure process in Kenya (Gachanja et al., 2014a). To increase the body of knowledge on how HIV-positive couples fully disclose their own illnesses to all their children in the household, the experience of disclosure and its psychological impact on the family of a married couple who participated in the larger study are presented in this case report. This couple's experience is especially presented because their disclosure experience and the impact of disclosure on their family differed greatly from those of the other 14 parents interviewed in the larger study. It is important to communicate the couple's experience to healthcare professionals in order to convey how marital disharmony can lead to negative outcomes within a family during the HIV disclosure process.

## II. Methods

### Study design

Phenomenological interpretive qualitative data was collected between December 2010 to January 2011 at the Comprehensive Care Center located at the Kenyatta National Hospital which is situated a few kilometers from downtown Nairobi, Kenya. The couple was purposively selected to participate in the study because they had performed partial and full disclosure of their own illnesses to all their children. They were approached for participation in the clinic's waiting room during their regularly scheduled clinic visit. Through the informed consent process, the purpose of the study was explained to them, and they were both invited to participate. They both agreed and provided written informed consent for study participation and verbal consent for recording of their interview sessions. Ethics approval for the study was received from the Walden University's Institution Review Board (Approval # 11-10-10-03904), and the Kenyatta National Hospital Research Standards and Ethics Committee (Approval # P373/10/2010).

## Data collection and analysis

Both husband and wife underwent individualized in-depth semi-structured interviews conducted by the author in English, a language they were both fluent in. Interviews were recorded using a digital recorder. Interview guide questions revolved around how they had prepared themselves and their children for full disclosure, how and who among them had told their children they were both HIV-positive, their reasons for and against telling their children about their illnesses, and their children's reaction to full disclosure of their illnesses. The husband's interview lasted for 45 minutes and his wife's 78 minutes.

Following the interviews, the recorded data was transcribed by the author and a local Kenyan university student familiar with transcription. Both cross-checked the transcripts twice against the recorded interviews to ensure that the data was accurately transcribed. Transcribed data was transferred into NVivo 8 for data analysis using the Van Kaam method (Moustakas, 1994). Transcripts were read and reread looking for codes, which were then grouped into emergent themes on the couple's disclosure experience to their children. The codes and themes were cross-checked by members of the research team. Three themes emerged spanning the disclosure process; these included HIV testing, full disclosure delivery to children accompanied by marital disharmony, and negative post-disclosure psychological effects on the family. These themes are further described below.

## III. Results

At the time of their interviews, John (54 years: pseudonym) and Jane (49 years: pseudonym) had three sons aged 25, 24, and 15; and two daughters aged 22 and 20 years. The couple had been diagnosed 10 years before their interviews but only the husband was on ART; the wife was on cotrimoxazole and multivitamins. They both had completed college and owned a business. All their children were living at home. The three oldest children had finished college, the fourth was still in college, and the youngest was in high/secondary school. The four oldest children had full disclosure of both parents' illnesses. The youngest son was unaware of his father's illness but thought his mother consumed medications for a back problem. During their interviews, John and Jane's descriptions of their diagnoses, their disclosure experience to each other and their children, and how their family was faring post-disclosure were noticeably different as described below. In fact, John ended his interview by saying "now talk to my wife you get the opposite."

The three themes that emerged from the data are displayed in Figure 1. The family's HIV testing circumstances, their disclosure process timeline, and the psychological effects of disclosure on the family are displayed in Figure 2.

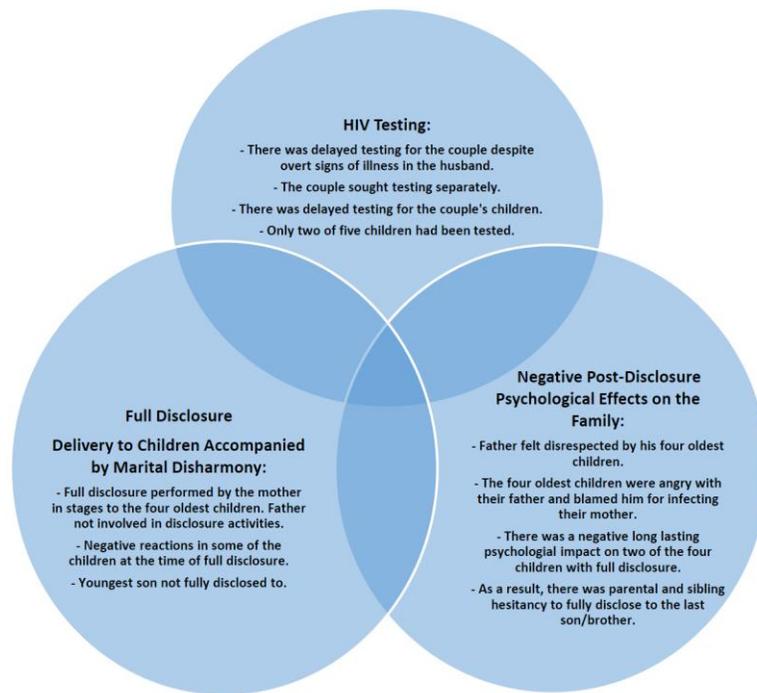


Figure 1: HIV disclosure themes in a HIV-positive couple's disharmonious marriage

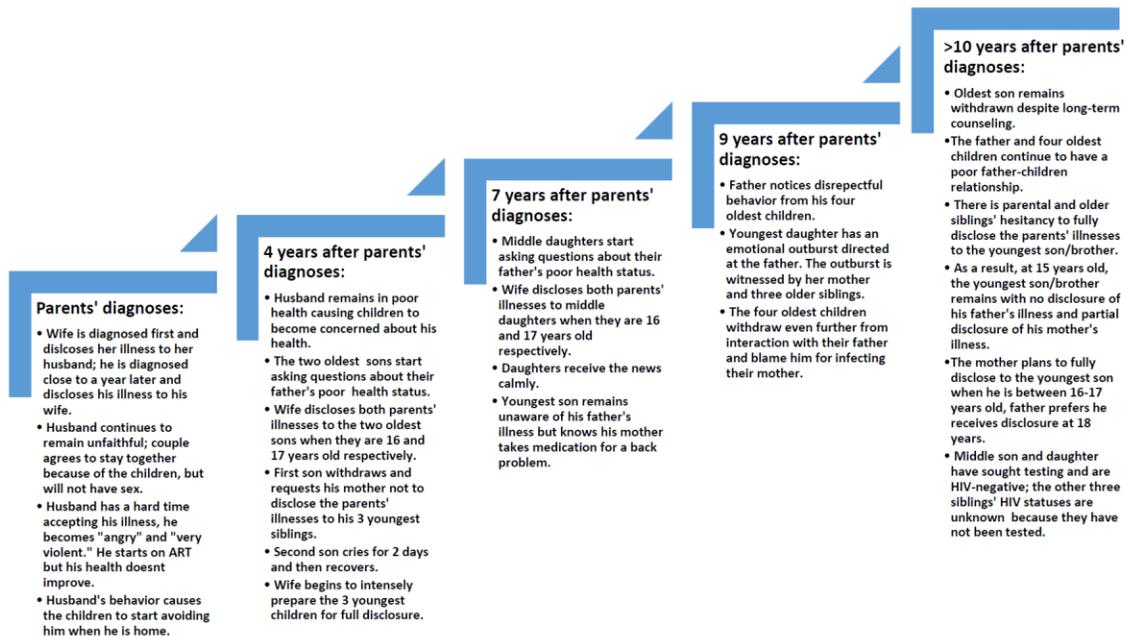


Figure 2: Disclosure timeline and the negative impact of disclosure on the family

## **HIV testing**

John was interviewed first and his responses to questions were succinct without further elaboration to prompting questions. He explained his illness started when he was admitted to the hospital with a groin swelling which was subsequently diagnosed as tuberculosis. He was very sick, vomiting persistently, and losing weight rapidly. John explained:

I was quite sick, I had a swelling in my groin area and that's the one that was tested and they found that I had TB [...] The doctor suggested I go for a HIV test, uh just to check to make sure that everything was okay because there was actually nothing wrong with me though I used to have coughs here and there. But all the tests were not producing anything until I had that swelling. So that's when I found out I was positive, but they said I go and check with my wife as well [...] In fact we tested the same time, she suggested we go together and the results came out the same time [...] It was very, very, thundering to find out that was the condition we were in but later we talked together and we said let's journey from there.

John expressed that none of their children were tested for HIV, although testing had been strongly recommended by healthcare professionals for their youngest son who was born a few years before their diagnoses. John did not want this son to suspect his parents' illnesses if testing were to be performed.

Jane was interviewed next and her recollection of their diagnoses circumstances was different. She relayed that before his diagnosis, John was chronically ill for a long time with what she recognized as signs of HIV infection, while she remained healthy. He constantly refused HIV testing whenever she suggested it. Finally he fell severely ill, was admitted to the hospital, and diagnosed with tuberculosis. She explained:

My husband was always sickly, sickly, me I was okay. When he was in hospital, I approached our family doctor and said I really want to get the guy tested, but he [John] resisted so he couldn't do it. So I suggested then do it on me first, so when he did it, we found it was positive [...] My husband was not so faithful, we had issues with that, so I was not so shocked but okay it comes as a shock anyway (laughs) [...] He [John] was so shocked and it was like he couldn't talk, I don't know why he was so shocked (laughs), we were even surprised [...] After he had left hospital, he was not comfortable and he was a bit resistant [to seek HIV testing] but now that I had tested positive he had you know now curiosity (laughs) [...] He was tested close to a year later. The doctor called him, and then he called me and said he has agreed to be tested, he has given in, but that I make sure he goes. I said if he agreed we will go, so we just went, and he was tested. I said well you were tested? He said it's just like yours (laughs), like that it's just like (laughs) like yours. (Clicks tongue) I said fine, now that you know our situation, now what next? He said nothing, we will just work it out, then I left it like that because he was very moody, he had these mood swings which were very bad.

Jane expressed she had asked the four oldest children to seek testing. The two oldest children had refused but the middle son and daughter were HIV-negative. Although undergoing regular care for a heart condition, the youngest son had not been tested because she did not think it was necessary.

## **Full disclosure delivery to children accompanied by marital disharmony**

After their diagnoses, Jane accepted her illness but relayed John had a harder time. He took many years to accept his own illness and his post-diagnosis behavior greatly affected their family. Jane explained:

He was so quiet, so quiet that we had to talk to him. He was unusually quiet, the kids were like what's wrong, is dad more sick or what? Then I went back to the doctor I said your person is breaking down but he is quiet I don't know what is going on in his mind. So he called him and talked to him again and slowly, then slowly he started opening up. Then he became so violent, so annoyed with everything, everybody, when he comes home the kids just leave the room. So that was the most difficult thing we have gone through. I think he gave up at a certain stage, he didn't care what happened you know? [...] He wasn't taking care of himself; he could still drink the way he used to drink with friends. He didn't change his lifestyle so I think he was re-infecting himself because he started to become very sick. So I told him, you know this situation we cannot reverse it now, you have to change your lifestyle if you are to actually stay stable, but if it is difficult for you then I have to make a decision and very fast. So we talked and he said it is not easy, you know men can be arrogant, it is not easy to leave his [girl] friends mmm. If he had one, he cannot just say I have dropped you as a friend. It was easier on my side because I have children, we cannot all perish, and somebody has to remain mmm. I have to be there for them, at least I will try coz the kids, only two were in secondary [high] school [at the time], and the other three were still in primary [elementary] school. I said now we will just have to agree, you continue with your life, me you just have to let me be. I will be total abstinence, I will be your wife, I will stay, I will take care of you, everything, I vowed to do it, so we agreed (laughs).

Jane relayed that although they were still married, they remained abstinent from sexual relations with each other since that conversation. In addition, John's anger and violent behavior affected their children who started avoiding him when he was home. Jane sought intervention from his family and John's behavior improved. John was started on ART but his health did not improve causing concern among the four oldest children. With time, they started asking their mother questions about his health. Four years after their diagnoses, Jane was prompted to fully disclose to the two oldest sons when they were 16 and 17 years old respectively. She explained:

I did it [full disclosure] myself but I did it in stages. The first time, the children were in secondary school, one was in form four [12<sup>th</sup> grade], the other was in form three [11<sup>th</sup> grade], was it? No, form three, form two [10<sup>th</sup> grade] around there, I can't remember exactly but the father was sick. They are very inquisitive my children. They were like what is it with dad? What is happening? What is the doctor saying? What is it you are not telling us? Why is it that he gets attacks so often? I said okay you have been taught about HIV [in school] because now they had been sensitized they knew. I told them the situation, their reaction was unbelievable! The second born cried, I have never seen a boy cry the way that one cried, he cried and cried for two days. The elder one just looked at me clicked and walked off.

Jane expressed she informed John she had fully disclosed their illnesses to their two oldest sons and he did not express disapproval. Their oldest son requested she not tell his younger siblings in order to protect them from the effects of full disclosure. Due to the sons' reactions and this request, Jane decided to intensively prepare the three remaining children for full disclosure. She explained that John did not want to participate in HIV or disclosure-related discussions with the children, so she prepared them herself. Jane started giving their three youngest children HIV-related pamphlets to read, and also taught them about the illness whenever an HIV/AIDS show or Ad was played on TV and radio. She sought counseling and attended peer support group meetings held at the children's schools and in church to speak with other infected parents. Three years after disclosing to their sons, the daughters also started asking questions about their father's health. This time around, Jane felt she and the girls were adequately prepared and fully disclosed to them when they were also 16 and 17 years old respectively. She explained:

The elder girl was like what is it with dad mmm? There is something you are not saying, someone cannot just be sick, sick, sick, sick and he's losing weight, what is it? They were seeing and also you know they were older now they could understand [...] So when I told them, they kept quiet, then they didn't react violently [like their brothers] so for some time I thought they were stronger, but they were also like the elder ones [...] One asked me does Jeremiah [youngest brother: pseudonym] know? I said no and I am not telling him now, they said okay. Then they asked does Jack [oldest brother: pseudonym] and Jacob [middle brother: pseudonym] know? I said yes. They were like, you know you could see the expression, if they knew why haven't they said anything (laughs). So I knew the older ones had not told them.

Soon after, Jane notified John and their two oldest sons that she had fully disclosed to the girls. The four oldest children agreed not to tell their youngest brother about their parents' illnesses. During his interview, John agreed he did not participate in disclosure-related activities and full disclosure sessions with his four oldest children. He expressed he had discussed full disclosure to the children with his wife, but they did not agree on a definite time when they should be told. John expressed he had been against telling the children "at that particular time" because he did not want them to be psychologically and academically affected. Additionally, he had needed more time to prepare himself, obtain counseling, and accept his illness. He explained:

I don't know maybe I feel the way my wife went about it is right, but somebody may say it is not right you see? Because we never discussed at what time we are going to tell them but she came back and told me I have already told them and I took it as she said. Maybe she makes more decisions than me in the family so it may not have been a surprise you see maybe? So it depends on the relationship between the father and the mother and that will determine how that information will be released, whether they are going to do both or individually or whether if one does, the other one feels annoyed.

Jane on the other hand explained John had visible signs of illness long before his diagnosis which caused concern in the children, and he also took too long to accept his illness. She explained that John had never been close to their children while they were growing up, because he usually worked late and left early in the morning. When he would not participate in disclosure-related activities, she was forced to take matters into her own hands. She explained:

It was difficult, I didn't know what to do, so the decision I made myself [...] I tried [talking to him] before telling the first ones he resisted, he was so violent [...] The second time he was like postponing, but he always knows when I am going to tell them, that one I am sure coz I tell them but he's never there [...] He doesn't want to be part of it so I assume he doesn't want to face the children. Otherwise if he had another reason he would say this is why I don't want you to say, but he doesn't come up with that so I just assume its ok [...] I think he doesn't want to face them because he feels guilty. That one I know he can't face them, he feels he has let them down in a way uh, and he is responsible, because that man has told me he is responsible. He knows, because there is a [girl] friend of his who passed on, so he knows he is the one responsible, he has admitted that.

### **Negative post-disclosure psychological effects on the family**

John and Jane were asked how their four oldest children were faring after full disclosure. John was not quite sure when Jane had fully disclosed to their four oldest children, but thought all of them had received full disclosure within the last two years of his interview. After disclosure, John expressed he noticed these children's

behavior towards him changing and decided to hold a family meeting with them and his wife. According to John, the youngest son was left out of the meeting because he was too young to participate. He explained:

The mother had talked to them and they decided they wanted to hear from me, that's how it came about. It didn't take long; maybe it was two weeks later [after full disclosure]. You know you see signs; they were saying why is daddy not telling us himself? I was questioning why when I talk to them; they were throwing words at me. Some of them were not respecting me. When we were in the meeting they were saying you know daddy you are the result of this and that, and we said okay that could have happened but let us move on, you cannot dwell on what has happened whether it is me or whatever. I said fine that might be the position but now we have gone over that, we have gone over that. My young girl cried and said oh you have crucified the person I love most. I said to her I am sorry.

John further explained that the children “were looking for a chance of talking to me but things are okay now.” However, Jane explained there had been no meeting between the parents and the four oldest children to discuss disclosure. The meeting John made reference to was an altercation that occurred between him and their youngest daughter about two years after she received full disclosure. One day, this daughter arrived home late from school due to a traffic jam; John was displeased, and told her that she should have called. Jane expounded:

She [youngest daughter] stood and said who are you to tell me what to do, since when eh? You shouldn't give examples you are not supposed to! You don't have any right telling me how to live my life, what about yours, what have you done? I was trying to stop her, and she was no mum he has to be told. You don't tell him, you pamper him, he thinks it is okay, now he's put your life into danger blah, blah, blah, she was uncontrollable. The brothers were catching her, I told them no let her be, let her finish saying what she has to say, she will be fine. She quarreled, the dad went to the bedroom, she followed him, she said everything that she was holding back, and then she cried and cried and cried until she slept. When she woke up the following morning (laughs) that's when I knew these people, everybody reacts differently. But after that they have never talked about it but you can see the closeness is not much there with the girls, they keep their distance. It is obvious you can see it, but it is improving.

Additionally, Jane explained that their oldest son was still not back to normal eight years after full disclosure and long-term counseling:

They [children] dealt with the news differently, you see the elder one I still believe he has not let go [...] that one is affected up to now, he's always annoyed, he doesn't talk to his father except if he is asked something he will answer and go. Sometimes the father comes, sits there, he walks away up to now, so he is still angry and he is holding it in [...] He's growing older and it is not breaking but the second one who cried him that was it. He's dealing with it, he's accepted it, he's the one who can confront dad and tell him you know you are not supposed to be drinking eh! You have this flu now for a week go and see a doctor. So they are taking it differently [...] we have really talked to him, we have talked to some counsellors who have talked to him. He is opening up, but it is too slow for me. Maybe I am expecting too much because our characters are different in the way we react, so maybe he is improving. The counselor we were using said he will get over it, it is not bad, but being a parent and knowing how he was, I am always a bit worried. Maybe I am comparing with the rest how they have bounced back to their normal lives.

Given their four oldest children's reactions to full disclosure, their youngest daughter's emotional outburst directed at her father, and the lasting impact of full disclosure on their oldest son, Jane was very hesitant and unsure

about how to fully disclose to their youngest son. Previously, she had used opportunities created by the four oldest children's questions about their father's poor health status to fully disclose hers and John's illnesses. At the time of their interviews, John's health was much better and their youngest son was unaware his father was sick. She was therefore confused on how to approach disclosure to him. This son was also very close to her and had a temper, so she worried about how he would handle the news. However, like his older siblings, Jane planned to disclose to him within the next year when he was between 16-17 years old. She preferred this age for full disclosure because by then children had gone through the tumultuous adolescent years. John agreed their last son was close to Jane but preferred he receive disclosure at 18 years after finishing secondary/high school, so his education was not affected.

## IV. Discussion

This case report begins to address the gap on how HIV-positive married couples approach full disclosure of their illnesses to each other and all their children in their households. Before their diagnoses, this couple had a poor marital relationship marred with infidelity, and HIV testing was delayed even when visible signs of illness were present in the husband. Infidelity has been cited as one of the main reasons why HIV spreads among married and cohabiting couples in Kenya (Republic of Kenya, 2009). Additionally post-disclosure, only two of the couple's children knew their own HIV statuses. The poor relationship between the parents affected how they relayed their diagnoses to each other and their four oldest children. The mother proceeded to fully disclose to the four oldest children without their father's involvement because she felt it was necessary to answer their questions. Persistent child questions have been found to prompt disclosure from parents to children (Brown et al., 2011; Kallem et al., 2011; Gachanja et al., 2014a; Kouyoumdjian et al., 2005; Petersen et al., 2010; Vaz et al., 2011). The effects of disclosure on the family were mainly negative, mostly in the children, and affected family cohesion. The reactions (crying, sadness) and negative effects of disclosure (emotional outburst, acting out behaviors, withdrawal, and depression) that occurred in these children have also been seen in prior studies (Gachanja, 2015; Gachanja et al., 2014a; Kennedy et al., 2010; Murphy, 2008; Petersen et al., 2010; Vallerand et al., 2005). Negative disclosure outcomes are known to improve over time (Kennedy et al., 2010; Murphy, 2008; Nostlinger, Bartolib, Gordilloc, Roberfroid, & Colebunders, 2006). However, in this study, the oldest child had not yet recovered fully from the effects of full disclosure eight years later. Children with lingering negative post-disclosure effects need additional long-term counseling and follow-up until they have returned to baseline normalcy.

As seen in prior research (Blasini et al., 2004; Gachanja et al., 2014a; Gachanja et al., 2014b; Kallem et al., 2011; Kennedy et al., 2010; Kouyoumdjian et al., 2005; Vallerand et al., 2005), this case report adds to the body of knowledge that parents are challenged by full disclosure to their children, and it appears more so when they have many children in the household in need of disclosure. It took 4-7 years for the four oldest children to receive full disclosure of their parents' illnesses and 10 years post-diagnosis, the couple was yet to fully disclose to their youngest son. As seen in this case report, prior researchers have also found that parents who delay full disclosure of their illnesses to their children have poor family dynamics and handling of family problems (Lee & Rotheram-Borus, 2002). Some researchers have recommended that parents with poor pre-disclosure parent-child relationships be helped to improve these relationships before disclosure occurs (Jones et al., 2007; Petersen et al., 2010), and that full disclosure be delivered before children are teenagers to limit negative outcomes (American Academy of Pediatrics, 1999; Kennedy et al., 2010; Lee & Rotheram-Borus, 2002; Murphy, 2008; Vallerand et al., 2005; WHO, 2011). Pre-disclosure, this couple's children already had a poor relationship with their father. It is likely that the poor disclosure outcomes seen in the children were a result of the poor father-children relationship, as well as

receiving full disclosure in their teenage years. Unlike other men in the larger study (Gachanja et al., 2014b), the father in this study did not take a lead in disclosure-related activities in his home. In some cultures, it may be harder for some men to lead or participate in disclosure-related activities within their families (Gachanja et al., 2014b; Oberdorfer et al., 2006). These men may need targeted counseling to accept their illnesses and also to improve their willingness and capability to fully disclose to their children. Additionally, HIV-positive married or cohabiting parents with poor relationships among themselves and many children needing disclosure may benefit from support programs that help them repair parent-parent and parent-child(ren) relationships, as well as prepare for, and fully disclose to all their children in a structured, culturally-appropriate and timely manner, preferably before their children reach adolescence.

In support of the Disclosure Process Model, the mother in this study fully disclosed to the four oldest children to allay their anxiety over their father's health status (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013). However, since the father engaged in avoidance behaviors and disengaged himself from the disclosure process, the mother was forced to take charge of disclosure-related activities. As a result, the family mostly experienced negative dyadic effects of disclosure. The father felt disrespected by his four oldest children, while they were unhappy with him and blamed him for infecting their mother. Therefore, this case report appears to suggest that children may prefer to receive full disclosure of their parents' illnesses from both parents at the same time. Maintenance of the family's secret among the parents and four oldest children likely increased stress levels within the home. The negative child reactions and long-lasting impact of disclosure on the family led to parental and older siblings' hesitancy to fully disclose to the youngest son/brother. To ease disclosure facilitation and delivery, healthcare professionals working with HIV-affected families should receive training on HIV disclosure models so that they are able to assess each married/cohabiting couple's family circumstances, their willingness to perform disclosure to their children, and the stage of disclosure of each child within the family. Additional useful models that can be used to facilitate and ease disclosure from parent to child include the Four Phase Model (Gachanja et al., 2014b; Tasker, 1992; Qiao et al., 2013), the Disease Progression Theory and Consequences Theory of HIV Disclosure (Gachanja et al., 2014a; Serovich, 2001), The Stress and Coping Theory (Gachanja, 2015; Lazarus, 1993), and the Disclosure Decision-Making Model (Omarzu, 2000; Qiao et al., 2013).

Qualitative research is conducted with a small group of participants to study a phenomenon that is not well understood (Creswell, 2009). HIV disclosure of married/cohabiting couples' illnesses to all their children is currently not well described in the literature. Data on an HIV-positive married couple's experience on fully disclosing their illnesses to all their children is presented in this case report to start addressing this gap. However, the couple's experience may be dissimilar from other married or cohabiting HIV-positive couples. Therefore, larger studies are needed to provide additional data on the HIV disclosure process from parent to parent and subsequently to all their children in the household. These studies should enroll married and/or cohabiting couples with HIV-positive and negative biological and/or stepchildren to seek a detailed understanding of the lived experiences of HIV disclosure within these complex family situations. Local national or dialect languages should be used in these studies in order to include participants who may not be fluent in English. Further testing of HIV disclosure models and theories within the studies would help uncover which are best suited for disclosure in different cultures, communities, and family circumstances.

## V. Conclusion

This case report appears to suggest that HIV-positive married couples may not necessarily be in agreement on if, when, and how to fully disclose to their children; and that children may prefer to receive disclosure of their parents' illnesses from both parents at the same time. Unresolved differences among married couples may delay disclosure to their children, and also lead to negative prolonged post-disclosure outcomes within their families. A few recommendations emerge from this case report. HIV-positive parents with many children need programs and services to help guide them through the steps it takes to move all their children from a state of no disclosure to full disclosure. Post-disclosure, children of HIV-positive parents need programs to help them accept and cope with their parents' illnesses, especially where the source of illness is infidelity in one of their parents. HIV-positive parents need programs to help them improve acceptance of illness and lessening of the guilt associated with bringing the infection into the home, so they are eventually able to fully disclose to their children. Finally, programs aimed at improving harmony, resiliency, relationships, and communication patterns among HIV-affected family members before, during, and after full disclosure are urgently needed. As more countries create or update their HIV disclosure guidelines, manuals, and programs, these recommendations should be added into them. Stakeholders should continually be on the lookout for new research findings to incorporate into and update the services provided to HIV-affected families.

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## References

- American Academy of Pediatrics. (1999). Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*, 103(1), 164-166. doi:10.1542/peds.103.1.164
- Bikaako-Kajura, W., Luyirka, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., Bunnell, R. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS and Behavior*, 10(Suppl 1), S85-S93. doi:10.1007/s10461-006-9141-3
- Blasini, I., Chantry, C., Cruz, C., Ortiz, L., Salabarria, I., Scalley, N., Diaz, C. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and evaluation. *Developmental and Behavioral Pediatrics*, 25(3), 181-189. doi:0196-206X/00/2503-0181
- Brown, B. J., Oladokun, R. E., Osinusi, K., Ochigbo, S., Adewole, F., & Kanki, P. (2011). Disclosure of HIV status to infected children in a Nigerian HIV Care Programme. *AIDS Care*, 23(9), 1053-1058. doi:10.1080/09540121.2011.554523
- Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). The disclosure process model: A review and application of the disclosure processes model. *Social Science and Medicine*, 72(10), 1618-1629. doi:10.1016/j.socscimed.2011.03.028

- Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: Understanding disclosure decision-making and post-disclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin*, 136(2), 236-256. doi:10.1037/a0018193
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Gachanja G. (2015). A rapid assessment of post-disclosure experiences of urban HIV-positive and HIV-negative school-aged children in Kenya. *PeerJ* 3, e956. doi: <https://dx.doi.org/10.7717/peerj.956>
- Gachanja, G., Burkholder, G. J., & Ferraro, A. (2014a). HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya. *PeerJ*, 2, e486. doi:10.7717/peerj.486
- Gachanja, G., Burkholder, G. J., & Ferraro, A. (2014b). HIV-positive parents' accounts on disclosure preparation activities in Kenya. *Journal of Social, Behavioral, and Health Sciences*, 8(1), 18-37. doi: 10.5590/JSBHS.2014.08.1.02
- Jones, D. J., Foster, S. E., Zalot, A. A., Chester, C., & King, A. (2007). Knowledge of maternal HIV/AIDS and child adjustment: The moderating role of children's relationships with their mothers. *AIDS and Behavior*, 11(3), 409-420. doi:10.1007/s10461-006-9188-1
- Kallem, S., Renner, L., Ghebremichael, M., & Paintsil, E. (2011). Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS and Behavior*, 15(6), 1121-1127. doi: 10.1007/s10461-010-9741-9
- Kennedy, D. P., Cowgill, B. O., Bogart, L. M., Corona, R., Ryan, G. W., Murphy, D. A., ... Schuster, M. A. (2010). Parents' disclosure of their HIV infection to their children in the context of the family. *AIDS and Behavior*, 14(5), 1095-1105. doi: 10.1007/s10461-010-9715-y
- Kouyoumdjian, F. G., Meyers, T., & Mtshizana, S. (2005). Barriers to disclosure to children with HIV. *Journal of Tropical Pediatrics*, 51(5), 285-287. doi:10.1093/tropej/fmi014
- Lazarus, R. E. 1993. Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55(1993), 234-247.
- Lee, M. B. & Rotheram-Borus, M. J. (2002). Parents' disclosure of HIV to their children. *AIDS*, 16(16), 2201-2207. Retrieved from <http://journals.lww.com/aidsonline/pages/default.aspx>
- Moustakas, C. (1994). *Phenomenological research methods*. London, England: Sage Publications
- Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: A review. *Clinical Child Psychology Psychiatry*, 13(1), 105-122. doi:10.1177/1359104507087464
- Murphy, D. A., Steers, W. N., & Stritto, M. E. D. (2001). Maternal disclosure of mothers' HIV serostatus to their young children. *Journal of Family Psychology*, 15(3), 441-450. doi:10.1037//0893-3200.15.3.441
- NACC and NASCOP (2014). Kenya AIDS Indicator Survey 2012. Retrieved from [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)

- NACC and NASCOP (2012). The Kenya AIDS Epidemic Update 2011. Retrieved from [http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce\\_KE\\_Narrative\\_Report.pdf](http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_KE_Narrative_Report.pdf)
- Nostlinger, C., Bartolib, G., Gordilloc, M., Roberfroid, D., & Colebunders, R. (2006). Children and adolescents living with HIV positive parents: Emotional and behavioural problems. *Vulnerable Children and Youth Studies*, 1(1), 1-15. doi: 10.1080/17450120600659036
- Oberdorfer, P., Puthanakit, T., Louthrenoo, O., Charnsil, C., Sirisanthana, V., & Sisanthana, T. (2006). Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *Journal of Paediatrics and Child Health*, 42(5), 283-288. doi:10.1111/j.1440-1754.2006.00855.x
- Omarzu, J. (2000). A disclosure decision model: Determining how and when individuals will self-disclose. *Personality and Social Psychology Review*, 42(2), 174-185. doi: 10.1207/S15327957PSPR0402\_05
- Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. *AIDS Care*, 22(8), 970-978. doi: 10.1080/09540121003623693
- Republic of Kenya. (2009). Kenya AIDS Indicator Survey 2007. Retrieved from [http://www.wofak.or.ke/Publications/kais\\_preliminary\\_report\\_july\\_29.pdf](http://www.wofak.or.ke/Publications/kais_preliminary_report_july_29.pdf) [KAIS Report 2009.pdf](#)
- Rochat, J. R., Mkwanzazi, N., & Bland, R. (2013). Maternal HIV disclosure to HIV-uninfected children in rural South Africa: A pilot study of a family-based intervention. *BMC Public Health*, 13(147), 1-16. doi:10.1186/1471-2458-13-147
- Serovich, J. M. (2001). A test of two HIV disclosure theories. *AIDS Education and Prevention*, 13(4), 355-364. doi:10.1521/aeap.13.4.355.21424
- Shafer, A., Jones, D. J., Kotchick, B. A., Forehand, R., & The Family Health Project Research Group. (2001). Telling the children: Disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *Journal of Child and Family Studies*, 10(3), 301-313. doi:10.1023/A:1012502527457
- Tasker, M. (1992). *How can I tell you? Secrecy and disclosure with children when a family member has AIDS*. Bethesda, MD: Association for the Care of Children's Health.
- UNAIDS. (2014). World AIDS Day 2014 Report: Fact sheet. Retrieved from: <http://www.unaids.org/en/resources/campaigns/World-AIDS-Day-Report-2014/factsheet>
- UNAIDS. (2013). Core Epidemiology Slides. Retrieved from: [http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309\\_epi\\_core\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309_epi_core_en.pdf)
- Vallerand, A. H., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care and STDs*, 19(2), 100-109. doi:10.1089/apc.2005.19.100.

Vaz, L. M. E., Maman, S., Eng, E., Barbarin, O. A., Tshikandu, T., & Behets, F. (2011). Patterns of disclosure of HIV status to infected children in a Sub-Saharan African setting. *Journal of Developmental & Behavioral Pediatrics*, 32(4), 307-315. doi: 10.1097/DBP.0b013e31820f7a47

WHO. (2011). Guideline on HIV disclosure counselling for children up to 12 years of age. Retrieved from [http://www.who.int/hiv/pub/hiv\\_disclosure/en/](http://www.who.int/hiv/pub/hiv_disclosure/en/)