A couple's marital disharmony and its psychological effects on their children during the HIV disclosure process in Kenya

Grace Gachanja
Walden University
g_gachanja@hotmail.com

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Abstract

HIV-positive parents are challenged with disclosure to their children. Limited published data exists on how HIV-positive parents perform disclosure to all their children in the household. To start addressing this gap, data is presented on a couple's HIV disclosure experiences to all their children. The couple 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 including HIV testing, full disclosure delivery accompanied by marital disharmony, and post-disclosure psychological effects on the family. The couple's narration of their diagnoses, and disclosure experiences to their children differed significantly. Ongoing poor paternal health caused persistent inquisitive questions from children. A poor paternal-children relationship, accompanied with his avoidance and non-involvement in disclosure matters caused the mother to fully disclose both parents' illnesses to the four oldest children. These children were affected by disclosure and held animosity towards their father. One had an emotional outburst directed at the father, while another still displayed anger and withdrawal years later. Therefore, the couple was hesitant to fully disclose their illnesses to their youngest son and differed in how they wanted to disclose to him. HIV-positive parents with poor relationships among family members before HIV testing and/or disclosure should be provided with intense counseling aimed at increasing family cohesion. Extra support before, during, and after disclosure may be required for these families to increase positive outcomes.

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

Introduction

HIV/AIDS remains a big public health challenge in the world today. By 2012, there were over 35 million infected persons in the world of which 25 million lived in Sub-Saharan Africa (SSA: UNAIDS, 2013). Kenya a country located in SSA, has 1.4 million infected adults aged 15-64 years (NACC & NASCOP, 2012; UNAIDS, 2013). The adult prevalence of the disease in SSA is 4.7% among those aged 15-49 years (UNAIDS, 2013), and 5.6% in Kenya among those aged 15-64 years (National AIDS and STI Control Programme, 2013). The disease's prevalence 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). The country will see an increased need for HIV-positive parents to disclose their illnesses to their children in the years to come.

HIV-positive parents consider disclosure to children important but are very challenged by it (Blasini et al., 2004; Kallem et al., 2011; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana, 2005; Vallerand et al., 2005). This is more so when there are many family members including both parents infected (Republic of Kenya, 2009). When parents delay disclosure, children sense secrets within the household and ask persistent questions in a bid to elicit disclosure (Brown et al., 2011; Kallem et al., 2011; Kouyoumdjian et al., 2005; Petersen et al., 2010; Vaz et al., 2011). Disclosure is a process that moves children from a state where they have non-disclosure or no knowledge of their parents' infection (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Oberdorfer et al., 2006; Vaz et al., 2011), to partial disclosure where they know 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 their parents are infected with HIV (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Oberdorfer et al., 2006; Rochat et al., 2013).

The Disclosure Process Model has three main components which include decision making, disclosure event, and 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 from fully disclosing against avoidance goals which seek to prevent negative outcomes associated with disclosure (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013). The disclosure event takes into account how disclosure is delivered by the parent and received emotionally by the child (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013). Post-disclosure outcomes involve positive (ability to take ART without hiding) and/or negative (rejection) individual outcomes in the disclosing parent; positive (improved closeness between parent and child) and/or negative (depression in parent and child) dyadic outcomes in both the parent and the child; and positive (increased awareness of the disease) and negative (exposure to stigma/discrimination) sociocultural aspects associated with social characteristics of disclosure delivery (Chaudoir et al., 2011; Chaudoir & Fisher, 2010; Qiao et al., 2013).

HIV disclosure results in mixed effects in children. Some studies have shown no psychological impact on children (Jones et al., 2007; Murphy, Steers, & Stritto, 2001; Shafer et al., 2001). Other studies have shown positive effects such as improved parent-child closeness (Vallerand et al., 2005), fewer behavior problems and aggression (Lee & Rotheram-Borus, 2002; Murphy et al., 2001), and an improved outlook on life (Kennedy et al., 2010). Negative effects of full disclosure on children include externalized acting out behavior problems such as ignoring or arguing with parents (Murphy, 2008; Vallerand et al., 2005); or internalized problems such as

sadness, depression, and withdrawal (Kennedy et al., 2010; Petersen et al., 2010; Vallerand et al., 2005).

There are limited published details on how HIV-positive parents disclose their illnesses to all their children within the household. Additionally at this time, there are no reported studies on parental HIV infection status disclosure to children in Kenya. It is therefore not well known how HIV-positive parents approach full disclosure of their illnesses to their children. A larger study was performed to understand the lived experiences of HIV-positive parents and their biological children during the disclosure process in Kenya [unpublished data, G. Gachanja, G. Burkholder, & A. Ferraro, 2014]. To start addressing the gap on how HIV-positive parents perform full disclosure of their own illnesses to all their children, data is presented here on a married couple's disclosure experiences to their five children and disclosure effects on their family. This couple's experience is especially presented in this study because their disclosure experiences and disclosure impact on their family differed from those of the other 14 parents interviewed in the larger study. It is important to communicate their experiences to healthcare professionals (HCPs) to show how martial disharmony can lead to negative outcomes within a family after HIV disclosure.

Methods

Study Design

Phenomenological interpretive qualitative data was collected at the HIV comprehensive care center (CCC) located at the Kenyatta National Hospital (KNH) 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 Institution Review Board (Approval # 11-10-10-03904), and the KNH 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 were 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 performed full disclosure, their reasons for and against performing full disclosure to their children, and their children's reaction to full disclosure. The husband's interview lasted for 45 minutes and the wife's 78 minutes. Following the interviews, recorded data was transcribed by the author and a local university student familiar with transcription. Both cross-checked the transcript twice against the recorded interviews to ensure 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 grouped into emergent themes on the couple's disclosure experiences to their children. The codes and themes were cross-checked by members of the supervising committee. Three themes emerged spanning the disclosure process. These included HIV testing, full disclosure delivery to children accompanied with marital disharmony, and post-disclosure psychological effects on the family. These subthemes are further described below.

Results

At the time of their interviews, John (54 years) and Jane (49 years: pseudonyms) had three sons aged 25, 24, and 15; and two daughters aged 22 and 20 years. The couple was diagnosed 10 years before their interviews but only the husband was on ART. 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 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 and disclosure experiences to their children were noticeably different as described below.

HIV Testing

John was interviewed first and his responses to questions were brief without further elaboration to prompting questions. He explained his illness started when he was admitted to hospital with a groin swelling which was subsequently diagnosed as tuberculosis (TB). He was very sick, vomiting persistently, and losing weight rapidly. His doctor suggested HIV testing for him and his wife. Both were tested and found to be infected. John explained:

> *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 although testing had been strongly recommended by HCPs for their youngest son born a few years before their diagnoses. John did not want this son to suspect his parents' illnesses if testing was to be performed.

Jane was interviewed next and her recollection of their diagnoses circumstances was different. She relayed before his diagnosis, John was chronically ill 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, and diagnosed with TB. During his admission, she sought HIV testing for herself and was found to be infected. She explained:

> *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).*

Jane disclosed her status to John, he was shocked to find out she was infected, but still refused to get tested until almost a year later. Jane expressed he finally decided to get tested because he was "curious" to see if he was also infected. After his diagnosis, John disclosed his illness to Jane by telling her "it's just like yours." Jane expressed she had asked the four oldest children to seek testing. The two oldest refused but the middle son and daughter were HIV-negative. The youngest son was untested because she did not think it was necessary.

Full Disclosure Delivery to Children Accompanied with Marital Disharmony

After their diagnoses, Jane accepted her illness but relayed John had a harder time. He withdrew and had mood swings during which he would become "violent and so annoyed with everything and everybody." This 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. They started asking their mother questions. Four years after their diagnoses, Jane was prompted to fully disclose to the two oldest sons when they were 16 and 17 years respectively:

> *Their father was sick and 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, the reaction was unbelievable! The second born he 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 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 disease whenever an HIV/AIDS show or Ad was played on TV and radio. She attended counseling and peer support meetings to speak with other parents. Three years after disclosing to her sons, her 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 16 and 17 years 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, them they didn't react violently [like the brothers] so for some time I thought they were stronger, but they were also like the elder ones.*

The daughters were surprised to know their brothers were aware of their parent' illnesses and had not told them. Soon after, Jane notified John and the two oldest sons she had fully disclosed to their sisters. These four oldest children were aware their youngest brother had no knowledge of their parents' illnesses and agreed not to tell him.

During his interview, John agreed he did not participate in 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 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:

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?

John was not quite sure when Jane had fully disclosed to the four oldest children, but thought all received disclosure within the last two years of his interview. After disclosure John expressed he noticed these children's behavior changing, and decided to hold a family meeting with them and his wife. 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.

Jane on the other hand explained John had visible signs of illness long before his diagnosis, and took too long to accept his illness. She explained he had never been close to the children while they were growing up because he usually worked late and left early in the morning. Additionally, Jane explained John avoided disclosure to the children because he felt "guilty" as "he was the one responsible" for her infection. When he would not participate in disclosure, she was forced to take matters into her own hands. She explained:

It was difficult I didn't know what to do, 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 him 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.

Post-Disclosure Psychological Effects on the Family

John and Jane were asked how the four oldest children were faring post-disclosure. John explained since the meeting things were better between him and the children adding "they 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 children to discuss disclosure. The meeting John made reference to was an altercation that occurred between him and their youngest daughter two years after she received full disclosure. She arrived home late from school due to a traffic jam; John was displeased and told her 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 mom 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 so not much there with the girls, they keep their distance. It is obvious you can see it but it is improving.*

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

> *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 in a world of his own, he doesn't talk much you don't know what he is thinking but he was okay just before the news so I really don't understand what's going on… 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 life.*

Given the four oldest children's reactions to full disclosure, her middle daughter's emotional outburst directed at her father, and the lasting post-disclosure impact on their oldest son; Jane was very hesitant to fully disclose to their youngest son. He was very close to her and had a temper, so she worried how he would handle the news. Like all the other children, she planned to disclose to him at 17 years after he had gone through the tumultuous adolescent years. John agreed this last son was close to Jane but preferred he receive disclosure at 18 years after finishing high school.

Discussion

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

As seen in prior research, this study revealed parents are challenged by full disclosure to their children (Blasini et al., 2004; Kallem et al., 2011; Kennedy et al., 2010; Kouyoumdjian et al., 2005; Vallerand et al., 2005), especially when there are many children in the household in

need of disclosure. It took 4-7years 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. Prior researchers have found parents who delay full disclosure of their illnesses to their children have poor family dynamics and handling of family problems (Lee & Rotheram-Borus, 2002). Other researchers have recommended parents with poor pre-disclosure parent-child relationships be helped to improve these relationships before disclosure (Jones et al., 2007; Petersen et al., 2010); and that 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). In this study, the father already had a poor father-children relationship which further deteriorated upon disclosure. Unlike other men in the larger study (unpublished data, G. Gachanja, G. Burkholder, & A. Ferraro, 2014), he did not take a lead in disclosure events in his home. In some cultures, it may be harder for some men to participate in disclosure events within their families (Oberdorfer et al., 2006; unpublished data, G. Gachanja, G. Burkholder, & A. Ferraro, 2014); they may need targeted counseling to accept their illnesses and to improve willingness to fully disclose to their children. Additionally, HIV-positive parents with poor relationships and many children needing disclosure may benefit from support programs which help them repair parent-parent and/or parent-child relationships, prepare for, and fully disclose to all their children in a structured, culturally appropriate, and timely manner preferably before 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 was not involved with disclosure delivery, these children were unhappy with him and blamed him for infecting their

mother. The family mostly experienced negative dyadic effects of disclosure. All four children were affected by full disclosure of their parents' illnesses; one had a delayed emotional outburst directed at her father, and another was still angry and withdrawn. The mother was forced to take charge of disclosure activities while the father felt disrespected by the children. There was parental and sibling hesitancy to disclose to the youngest son/brother. Maintenance of the family's secret among the parents and four oldest children likely increased stress levels within the home. This study's results reveal children may prefer to receive full disclosure from both parents at the same time. To ease disclosure facilitation and delivery, HCPs working with HIV-positive parents should receive training on HIV disclosure models so they can assess the parents' circumstances, willingness to perform disclosure, and stage of disclosure. Models that should be used by HCPs during facilitation of HIV disclosure from parent to child include the Four Phase model (Tasker, 1992; Qiao et al., 2013; unpublished data); the Disease Progression Theory and Consequences of HIV Disclosure Theory (Serovich, 2001; unpublished data, G. Gachanja, G. Burkholder, & A. Ferraro, 2014), 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 a married couple's illnesses to all their children is currently not well described in the literature. Data on a HIV-positive couple's experiences on fully disclosing their HIV illnesses to all their children is presented here to start addressing this gap. The couple's experiences may be dissimilar from other married HIV-positive parents. 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 understand the lived experiences of disclosure within these diverse families. Local national or dialect languages should be used to include participants who very fluent in English. Further testing of disclosure models and theories in these studies would help uncover which is best suited for disclosure within different cultures, communities, or family circumstances.

Conclusion

This study reveals that married couples may not necessarily be in agreement on if and how to fully disclose to their children. These unresolved differences may lead to negative and prolonged post-disclosure outcomes within their families. A few recommendations emerge from this study. HIV-positive parents with many children need programs and services that guide them through the steps it takes to move their children from a state of non-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 acceptance of illness, lessening of guilt associated with the guilt of bringing the infection into the home, and improving family harmony, resiliency, relationships, and communication patterns before and after full disclosure. As more countries create or update their HIV disclosure guidelines, manuals, and programs, they should add these recommendations and continually also be on the lookout for new research findings to incorporate and update them.

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