

Marital disharmony in a couple's marriage and its psychological effects on their children during the HIV disclosure process in Kenya

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Walden University

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Research Brief

Grace Gachanja,
PhD, MPH, RN
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A Couple's Marital Disharmony and its Psychological Effects on Their Children during the HIV Disclosure Process in Kenya

Grace Gachanja, PhD, MPH, RN

College of Health Sciences, Walden University,

Minneapolis, MN, USA

g_gachanja@hotmail.com

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AIM

The aim of this research brief is to summarize a case report study that described an HIV-positive married couple's poor disclosure experience of their illnesses to all their children in the household. It is important to communicate this couple's HIV disclosure experience to healthcare professionals (HCPs) so that they are aware of the problems that can occur if married or cohabiting couples do not collaborate with each other during the disclosure process. The data presented in the case report study and in this research brief should be used to provide targeted counseling to HIV-positive parents or cohabiting couples considering disclosure to their children.

BACKGROUND

In Kenya as of 2012, there were 1.2 million HIV-infected adults aged 15-64 years with a HIV prevalence of 5.6% (NACC & NASCOP, 2014). The prevalence of the illness is expected to keep rising in the decades to come as infected persons live longer due to ART availability (NACC & NASCOP, 2012). Therefore, the need to address HIV disclosure within these families will continue for many years to come.

HIV-positive parents are challenged by disclosure (Gachanja, Burkholder, & Ferraro, 2014a; Gachanja, Burkholder, & Ferraro, 2014b; Kallem, Renner, Ghebremichael, & Paintsil, 2011; Kennedy et al., 2010) especially if there are many family members infected (Republic of Kenya, 2009). Disclosure progresses from a state where children have no knowledge of their parents' illnesses, to partial disclosure when they know that their parents are sick or taking medications, and

Key Aspects of The Married Couple's HIV Disclosure Experience to Their Children:

1. This HIV-positive married couple's description of their disclosure experiences (i.e., HIV testing, disclosure process, and effects of disclosure on their children) differed greatly from each other's.
2. The couple was tested a year apart; two of their children were tested later and found to be HIV-negative. At the time of study participation, three remained untested.
3. The couple never reached an agreement on if, when, and how to disclose to their children. When the husband kept postponing disclosure, the wife was prompted to disclose to their four oldest children over a period of years by herself because they were asking persistent questions about their father's poor health status.
4. Some of the children received disclosure emotionally, others were calm. Post-disclosure, two of the children were badly affected; one had an emotional outburst directed at her father, the other remained angry and withdrawn eight years later.
5. As a result of these poor post-disclosure outcomes, the couple and their four oldest children were hesitant to disclose to their youngest son/brother.
6. To ensure good outcomes within HIV-affected families, HIV-affected couples need services and programs that guide them through HIV testing and the disclosure process until all their fully children are disclosed to.

finally to full disclosure when they are told that their parents are HIV-positive (Bikaako-Kajura et al., 2006; Kallem et al., 2011; Vaz et al., 2011). Disclosure results in mixed effects in children; these may be positive or negative and be displayed internally or externally (Gachanja, 2015; Gachanja et al., 2014a; Kennedy et al., 2010; Vallerand et al., 2005).

A larger study was conducted to understand the lived experiences of HIV-positive parents and their biological children during the HIV disclosure process

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in Kenya (Gachanja et al., 2014a; Gachanja et al., 2014b); a married couple participated in that larger study. This couple's data was published in a case report study because their disclosure experience and its impact on their family differed greatly from the other 14 parents in the larger study. This research brief summarizes their disclosure experience.

PROCESS

Qualitative phenomenological data was collected at the Kenyatta National Hospital Comprehensive Care Center located in Nairobi, Kenya. The couple was selected and approached to participate in the study because they had performed partial and full disclosure of their own illnesses to all their children. Both agreed to participate, provided informed consent, and were interviewed separately. Their interview data was transcribed and analyzed with NVivo8 using the Van Kaam method (Moustakas, 1994).

FINDINGS

At the time of study participation, John (husband, 54 years) and Jane (wife, 49 years: pseudonyms) had three sons aged 25, 24, and 15 years; and two daughters aged 22 and 20 years. All their children were living at home. 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 how they were diagnosed, how they disclosed to each other and their children, and the impact of disclosure of their children differed from each other. Three themes emerged from their interview data; these are displayed in Figure 1 and further described below. The couple's HIV disclosure timeline to their children is displayed in Figure 2.

1. **HIV Testing:** During her interview, Jane relayed that John had been chronically ill with signs of HIV

infection for a long time, but refused HIV testing whenever she suggested it. She was aware that John was having extramarital affairs and decided to get tested when he was admitted to the hospital with tuberculosis. Her diagnosis came as a surprise to both of them. After much urging from Jane and their doctor; John was finally tested close to a year later. Jane explained that the oldest son and daughter had refused HIV testing but the middle son and daughter were HIV-negative. Although he was born a few years before their diagnoses, both John and Jane did not want their youngest son to be tested. For his part, John relayed that the couple was tested at the same time and that none of their children had been tested.

Recommendations: Programs and services are highly needed to counteract HIV-positive parents' resistance to HIV testing for spouses and children. HCPs should counsel couples to seek regular HIV testing to prevent the spread of the illness from infected spouses to their uninfected partners; appropriate healthcare should be offered to spouses found to be infected. Additionally after parental diagnoses, HCPs should counsel and encourage HIV-positive parents to take all their children for testing so that all their HIV statuses are known and healthcare is initiated for those found to be infected.

2. **Full Disclosure Delivery to Children Accompanied by Marital Disharmony:** After their diagnoses, Jane relayed that she accepted her illness quickly; John however, had a harder time. He became depressed, violent, and had mood swings which affected the family, forcing her to seek intervention from his family until his behavior improved. John's poor health continued causing worry and concern in their children; they started asking her many questions about his health. Jane wished to disclose to their children to allay their anxiety, but John kept

Figure 1. HIV Disclosure Themes in the HIV-positive Couple's Disharmonious Marriage

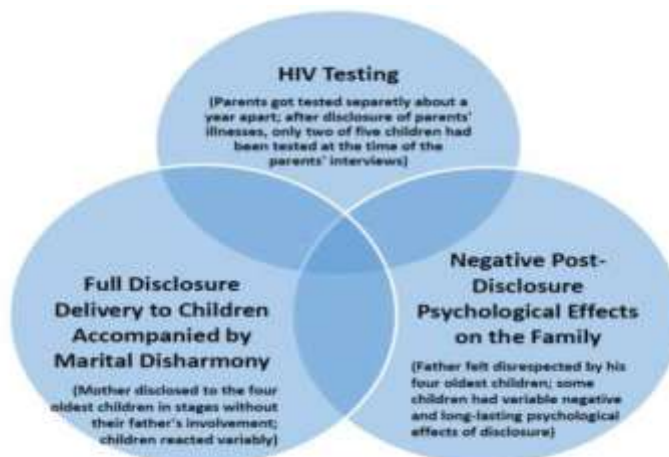
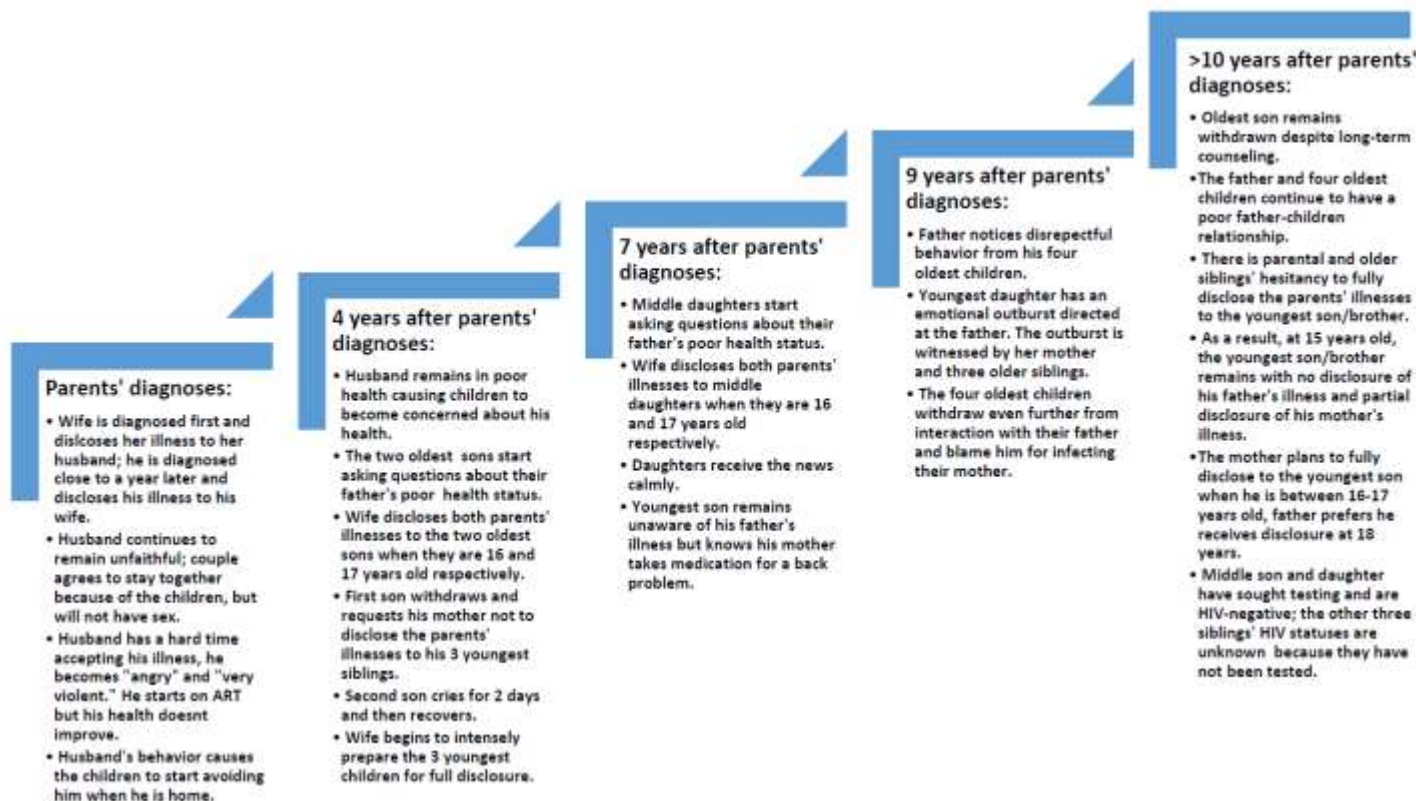


Figure 2. Disclosure Timeline and the Negative Impact of Disclosure on the Family



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postponing disclosure. When the children's questions became unbearable, Jane prepared and disclosed to their four oldest children over a period of years without John's help when each child was between 16-17 years old. The sons were emotional at the time of disclosure but the daughters appeared to receive the news calmly. John relayed that he had wished to delay disclosure to avoid affecting the children psychologically and also to avoid affecting their education. However, Jane relayed that John was unable to participate in disclosure activities because he "felt guilty" about infecting her and he also had never been close to their children.

Recommendations: HIV-positive parents (especially men) need programs to help them with acceptance of their illnesses and lessening of the guilt associated with bringing the infection into the family. As part of the disclosure process, programs and services should be offered to HIV-affected families to help improve parent-parent and/or parent-children disagreements, and also to improve family harmony, resiliency, relationships, and communication patterns before, during, and after full disclosure.

3. **Negative Post-disclosure Psychological Effects on the Family:** John and Jane were asked how their children were faring post-disclosure. John explained he noticed the four oldest children being disrespectful towards him and he held a meeting with them to discuss disclosure. After the meeting, the children were faring better. Jane however, explained that there had been no meeting between the parents and the children to discuss disclosure. Rather, what occurred was an emotional outburst by their middle daughter directed at John and witnessed by the other three siblings with full disclosure. During the altercation, these children expressed anger and blamed their father for infecting their mother. Additionally, Jane added that their oldest son remained angry and withdrawn eight years post-disclosure despite receiving long-

term counseling. Given these negative effects of disclosure on their family, the couple and their four oldest children were very hesitant to disclose to the youngest son/brother. John and Jane still differed on when and how to disclose to him. John wanted to wait until the son had finished high school, Jane wanted to disclose to him when he also reached the age of 16-17 years old.

Recommendations: It appears that children prefer to receive disclosure of their parents' illnesses from both parents at the same time. HIV-positive parents or cohabiting couples should receive counseling on the merits of preparing and disclosing to their children together as a unit. To avoid negative effects of disclosure, it is preferable that children receive disclosure before they are teenagers (Kennedy et al., 2010; Vallerand et al., 2005). Therefore, HCPs should encourage married and cohabiting couples to prepare for and disclose to their children before they reach adolescence. Counseling services should be offered to all HIV-affected families to help overcome negative post-disclosure effects.

POLICY IMPLICATIONS

The following policy implications emerge from this case report study:

- HIV-positive parents or cohabiting couples need programs and services that assist and guide them in moving all their children from a state of no to full disclosure.
- Following disclosure, children of HIV-positive parents need services and programs to help them with acceptance of parental illnesses especially when they receive disclosure in their teenage years, and if they are aware that the source of illness was infidelity by one of their parents.
- Some children may take a long time to recover from the effects of disclosure. These children need additional counseling and follow up until they have returned to baseline normalcy.

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- HCPs working with HIV-positive parents should receive disclosure training on HIV disclosure models so that they are able to provide appropriately targeted HIV disclosure services and programs to HIV-affected families during the disclosure process.

FUTURE RESEARCH

Future researchers should focus on:

- Performing larger studies that lead to a greater understanding of the disclosure process from parent to parent and subsequently to all their children in the household.
- Conducting studies on married and/or cohabiting couples who have both HIV-positive and negative biological and/or stepchildren in order to understand the lived experiences of disclosure within these diverse families.
- Conducting studies that test HIV disclosure models and theories in order to help uncover which are best suited for facilitating disclosure in different cultures, communities, and family circumstances.

CONCLUSION

Marital infidelity and disharmony adversely affects the HIV disclosure process and may lead to poor outcomes in a family. Although the data provided in this case report study details one couple's HIV disclosure experience, the results are important because they begin to lend an insight into how HIV-positive parents approach disclosure to each other and all their children in the household. Pending further larger studies, HCPs should use these results to offer targeted advice to HIV-positive parents or cohabiting couples who wish to disclose their illnesses to their children.

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