

HIV-positive parents disclosure-related preparation activities in Kenya

Grace Gachanja, PhD, MPH, RN; Gary J. Burkholder, PhD; Aimee Ferraro, PhD

ABSTRACT

The HIV disclosure process is not well understood in Kenya. There are no guidelines to assist parents and healthcare professionals (HCPs) in the preparation and performance of disclosure. Some families have multiple infected persons thereby complicating disclosure delivery further as parents grapple for years with why, when, where, how, and which of their children to prepare for disclosure. Two theoretical models of HIV disclosure were tested during the conduct of this study.

PROBLEM

Most HIV-infected persons live in Sub-Saharan Africa (SSA) where HIV disclosure guidelines are limited or non-existent in some countries. In some families both the parent(s) and some or all the children are infected. More HIV disclosure studies are being conducted in SSA but the knowledge of how parents prepare for disclosure to their children remains limited. Additionally, it is not known what resources parents require or have available to them during the preparation stage of disclosure in SSA.

PURPOSE

This qualitative phenomenological study was conducted to describe the lived experiences of HIV-positive parents and their children (infected and /or uninfected) during the HIV disclosure process in Kenya.

RELEVANT LITERATURE

Prior studies have found that parents wait to accept their illnesses prior to preparing for disclosure. Parents are known to formulate future vague disclosure plans; and they make/remake their minds many times before deciding when to start preparing. In the U.S., Tasker found that HIV-positive parents go through four phases (secrecy, exploratory, readiness, and full disclosure) during the disclosure process of their own illnesses to their children. The disease progression theory stipulates that as a HIV-infected person's illness progresses, it becomes more difficult to keep the disease a secret making him/her start disclosure preparations. The consequence theory of HIV disclosure stipulates that infected persons weigh the risks of performing disclosure to others versus the benefits that can be achieved, proceeding with disclosure preparation only when the benefits outweigh the risks.

RESEARCH QUESTIONS

What are the lived experiences of HIV-infected parents and their children before, during, and after disclosure of a parent's and child's HIV infection status to their children?

- How do HIV-infected parents, their children, and healthcare professionals think that HIV-infected parents should perform disclosure of a parent's and child's HIV infection status to their children?
- What do HIV-infected parents, their children, and healthcare professionals think are the perceived benefits and costs of HIV-infected parents disclosing a parent's and child's HIV infection status to their children?
- How should HIV-infected parents approach disclosure of a parent's and child's HIV infection status to their children?
- What support services do HIV-infected parents and their children require before, during, and after disclosure of a parent's and child's HIV infection status to their children?

PROCEDURES

Sixteen HIV-positive parents, 7 HIV-positive children, 5 HIV-negative children, and 6 HCPs (34 total) were interviewed using in-depth, individualized, semi-structured questionnaires. Interviews were digitally recorded. Ethics approval was obtained from Walden university's IRB (Approval # 11-10-10-03904), and the Kenyatta National Hospital (KNH) Research Standards and Ethics Committee (Approval # P373/10/2010).

DATA ANALYSIS

Transcribed interviews transcripts were cross-checked for accuracy against the audio files. Verification of transcripts accuracy was also conducted with 15% of participants. NVivo Version 8 was used for coding. The Van Kaam method was used for data analysis along predetermined themes obtained from prior HIV disclosure research. Over 300 codes emerged that led to seven themes spanning the HIV disclosure process. Codes and themes were cross checked by two other experienced qualitative researchers. Data presented here is from the theme on parents' preparation efforts during the disclosure process.

FINDINGS

Parents take years to prepare for disclosure, proceeding when they perceive themselves capable and ready, and their children are receptive to the news. Preparation activities include thinking about and making disclosure plans, reading information, teaching children about the disease without disclosure while improving the parent-child relationship, praying regularly and attending religious activities, seeking counseling, and attending support group meetings.



LIMITATIONS

The sample for this study was purposively chosen and may not completely represent HIV infected parents' disclosure preparation activities in Kenya. The results may therefore not be generalizable to the study population. Interviews were conducted in English and this may have limited participants to those fluent in English. These participants may therefore not be representative of the target population.

CONCLUSIONS

Parents perform a number of activities to get themselves and their children ready for disclosure. These activities are crucial in the timely delivery of disclosure. Understanding the importance of these activities helps HCPs assist parents to deliver disclosure faster after diagnosis of illness.

SOCIAL CHANGE IMPLICATIONS

This study's results revealed how parents prepare for disclosure in Kenya and the resources available to them locally. The results are valuable for HCPs to better guide and facilitate disclosure delivery from parent to child. As more SSA countries create HIV disclosure guidelines, these results can be incorporated into culturally sensitive guidelines, manuals, and programs in countries that closely mirror the Kenyan population. When ready, the use of these materials can better facilitate disclosure delivery while improving disclosure rates.

ACKNOWLEDGMENTS

We would like to thank KNH staff Dr. Charles Kabetu, Dr. James Kiarie, Ms. Mugambi, Ms. Gacheri, Nelly Opiyo, Godfrey Mureithi, David Mutabari, and other staff for their assistance during the data collection procedures; and Purity Kibino for her assistance with data transcription.