HIV-positive parents disclosure-related preparation activities in Kenya

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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.

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 # P379/10/2010).

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.

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