

Child, Parent, and Healthcare Professionals' Perspectives on HIV Infection Status Disclosure to Children

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ABSTRACT

HIV disclosure is a challenging process for parents and healthcare professionals (HCPs). HIV disclosure guidelines are lacking in Kenya, and parents are especially challenged with disclosure when there are multiple affected family members. While there are two theoretical models of HIV disclosure, their utility in explaining disclosure in African cultures is largely unknown.

PROBLEM

The majority of HIV-infected persons live in Sub-Saharan Africa (SSA) where HIV disclosure guidelines for a parent's and a child's illness are virtually nonexistent. HIV can affect many family members including both the parent(s) and/or children. Most studies on HIV disclosure have been conducted in resource-rich countries. Little is known about how disclosure is performed in resource-poor/SSA nations and what resources are required or accessed by parents and their families during the disclosure process.

PURPOSE

The purpose of this qualitative phenomenological study was to describe the lived experiences of HIV-positive parents and their infected and uninfected children during the HIV disclosure process in Kenya.

RELEVANT LITERATURE

The HIV disease process and ART consumption make disclosure necessary at some point. The study was based on the disease progression theory and the consequence theory of HIV disclosure. Disclosure rates are affected by stigma and discrimination in resource-poor nations. Improved disclosure rates can lead to reduced stigma/discrimination, improved ART adherence and self-care, increased utilization of PMTCT services, improved family dynamics, and designation of future caregivers for children of infected parents. Parental barriers to disclosure include guilt; and fears of rejection, isolation, violence, causation of psychological harm to children, and leakage of family secrets by young children. Benefits for disclosure include catharsis; and improved family dynamics, communication, social support access, psychological health, and attendance of healthcare appointments and ART consumption without fear.

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?

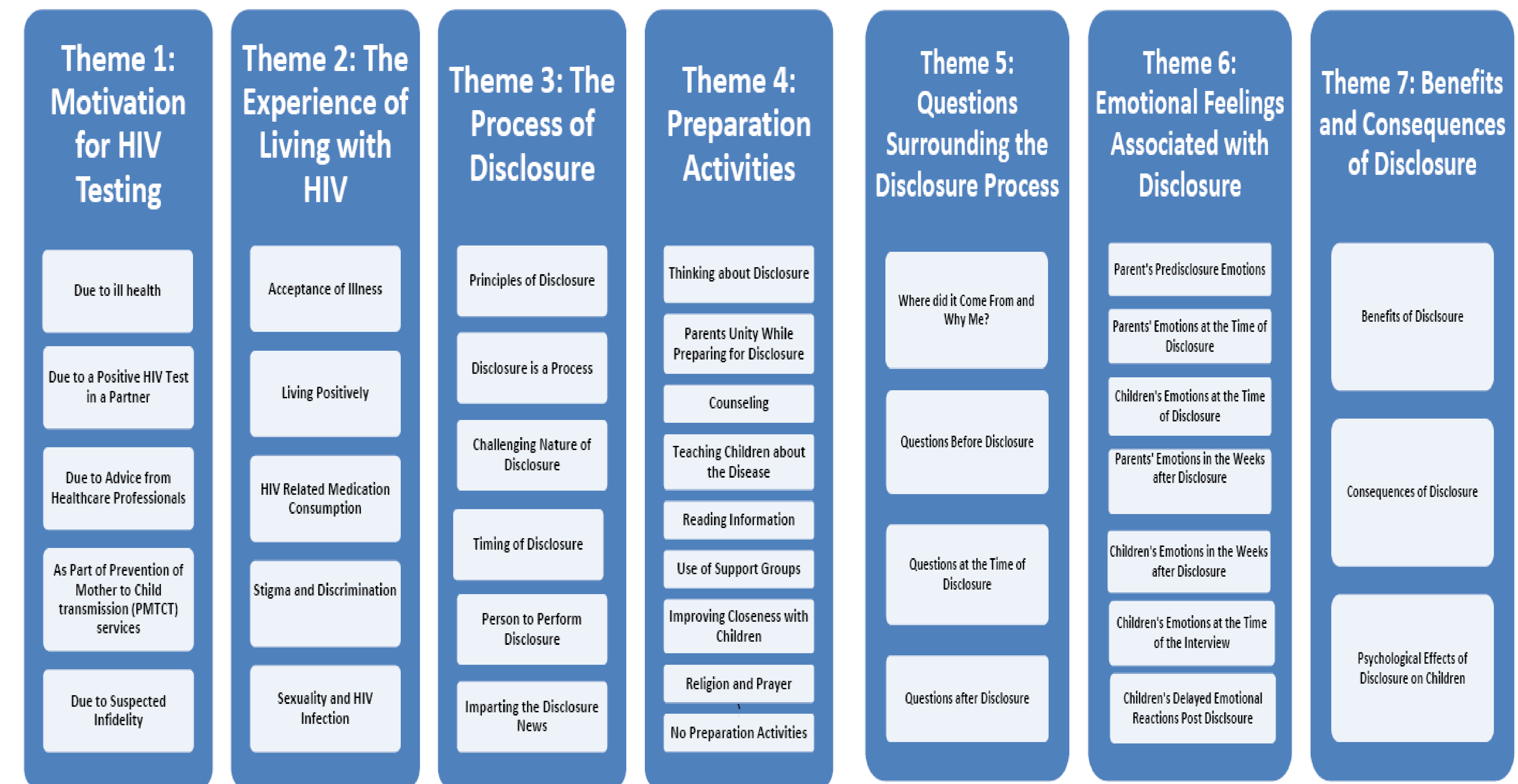
PROCEDURES

34 participants consisting of 16 HIV-positive parents, 7 HIV-positive children, 5 HIV-negative children, and 6 HCPs underwent in-depth, individualized, semi-structured digitally recorded interviews. Participants signed informed consent forms for study participation and provided verbal consent for digital recording of their interviews. Ethics approval was obtained from the university's IRB (Approval # 11-10-10-03904), and the Kenyatta National Hospital Research Standards and Ethics Committee (Approval # P373/10/2010).

DATA ANALYSIS

Interviews were transcribed and transcripts cross checked for accuracy against the audio files. Transcripts were sent to and verified by 15% of participants as being accurate. Coding was performed with NVivo Version 8 using the Van Kaam method along predetermined themes obtained from prior HIV disclosure research. 327 codes emerged that led to a grouping of 7 themes spanning the HIV disclosure process. Codes and themes were cross checked by two other experienced qualitative researchers.

FINDINGS



LIMITATIONS

This purposively chosen sample may not provide a complete picture of the HIV disclosure experience in Kenya and as such the results may not be generalizable to the study population. The conduct of interviews in English may have limited participants who participated to those fluent in English and may therefore not be representative of the target population

CONCLUSIONS

HIV disclosure is challenging, and each disclosure session performed is planned for the needs of the particular child receiving disclosure. Parents and HCPs are challenged by disclosure and can benefit from creation of HIV disclosure guidelines accompanied by culturally sensitive manuals and training programs aimed at parents and HCPs to ease the process of disclosure in Kenya and other resource-poor nations with high HIV prevalence.

SOCIAL CHANGE IMPLICATIONS

This study's results led to a revelation of how disclosure of a parent's and child's illness is performed in Kenya especially where there are multiple infected family members. These results will be valuable for HCPs who assist parents/guardians with disclosure; and can be used to create culturally sensitive HIV disclosure guidelines, manuals, and programs in countries that closely mirror the Kenyan population. These guidelines, manuals, and programs when created will prove valuable in the facilitation of disclosure and may result in increased disclosure rates.

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