

# Parents' Phases and Children's Stages of HIV Disclosure

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## ABSTRACT

Many HIV-affected families have one or more HIV-positive family members. HIV-positive parents are challenged with HIV testing and disclosure to their children. Some test all their children, others test none of their children, and yet others test only those children with signs of infection. Delayed testing leads to late HIV diagnosis and further complicates the disclosure process within these families. Even after finding out which of their children are HIV-positive, some HIV-positive parents do not disclose at all, others disclose to some children, and full disclosure to all their children may take many years.

## PROBLEM

The HIV disclosure process is not well understood in Kenya. A lack of HIV disclosure guidelines in Kenya impedes HIV disclosure to children. Many HIV-positive parents are unable to disclose to their children, and need the help of healthcare professionals to prepare for and disclose to their children. Unfortunately, guiding parents through the HIV disclosure process is challenging for healthcare professionals.

## PURPOSE

This qualitative phenomenological study was conducted to understand the lived experiences of HIV-positive parents and their HIV-positive, HIV-negative, and untested children during the HIV disclosure process in Kenya.

## RELEVANT LITERATURE

Prior studies have found that HIV-positive parents take a long time to disclose their own and/or their children's illnesses to their HIV-negative and positive children, respectively (Gachanja, Burkholder, Ferraro, 2014a; Gachanja, Burkholder, Ferraro, 2014b; Tasker, 1992). Parents are known to go through four disclosure phases (secrecy, exploratory, readiness, and full disclosure) before disclosing their own and their children's illnesses to their children. During these phases, parents provide increasing bits of information about the illness to their children, thereby taking them from a state where the children have no knowledge of the illness, to knowing that a chronic illness is present (partial disclosure), and finally to full disclosure when they are told the illness in question is HIV. Along this disclosure journey, parents take none, some, or all their children for HIV testing so that they are aware which of these children are also HIV-positive and need disclosure of their illnesses.

## RESEARCH QUESTIONS

What are the lived experiences of HIV-positive parents and their HIV-positive, HIV-negative, and untested children before, during, and after disclosure of a parent's and/or a child's HIV infection status?

- How do HIV-positive parents navigate the disclosure phases when preparing to disclose to their children?
- What are the stages of HIV disclosure for children?
- How do parents decide if, when, and how to take their children for HIV testing?

## PROCEDURES

Sixteen HIV-positive parents were purposively selected because they were in the process of HIV disclosure to their children. They were approached for participation during regular clinic hours at the Kenyatta National Comprehensive Care Center located in Nairobi, Kenya. Those who agreed to participate signed a written informed consent form. Each parent was engaged in an in-depth, individualized, semi-structured interview. 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

The first author and a local Kenyan university student transcribed the interviews. The transcripts were cross-checked for accuracy against the audio files. Verification of the transcription accuracy was also conducted with 15% of the participants. NVivo Version 8 was used for qualitative coding. The Van Kaam method was used for data analysis along predetermined themes obtained from prior HIV disclosure research. Emerging codes and themes were cross-checked by the last two authors of the study. Data presented here is from three themes, which emerged about the HIV-positive parents' disclosure preparation efforts, and how they approached HIV testing and disclosure to their children.

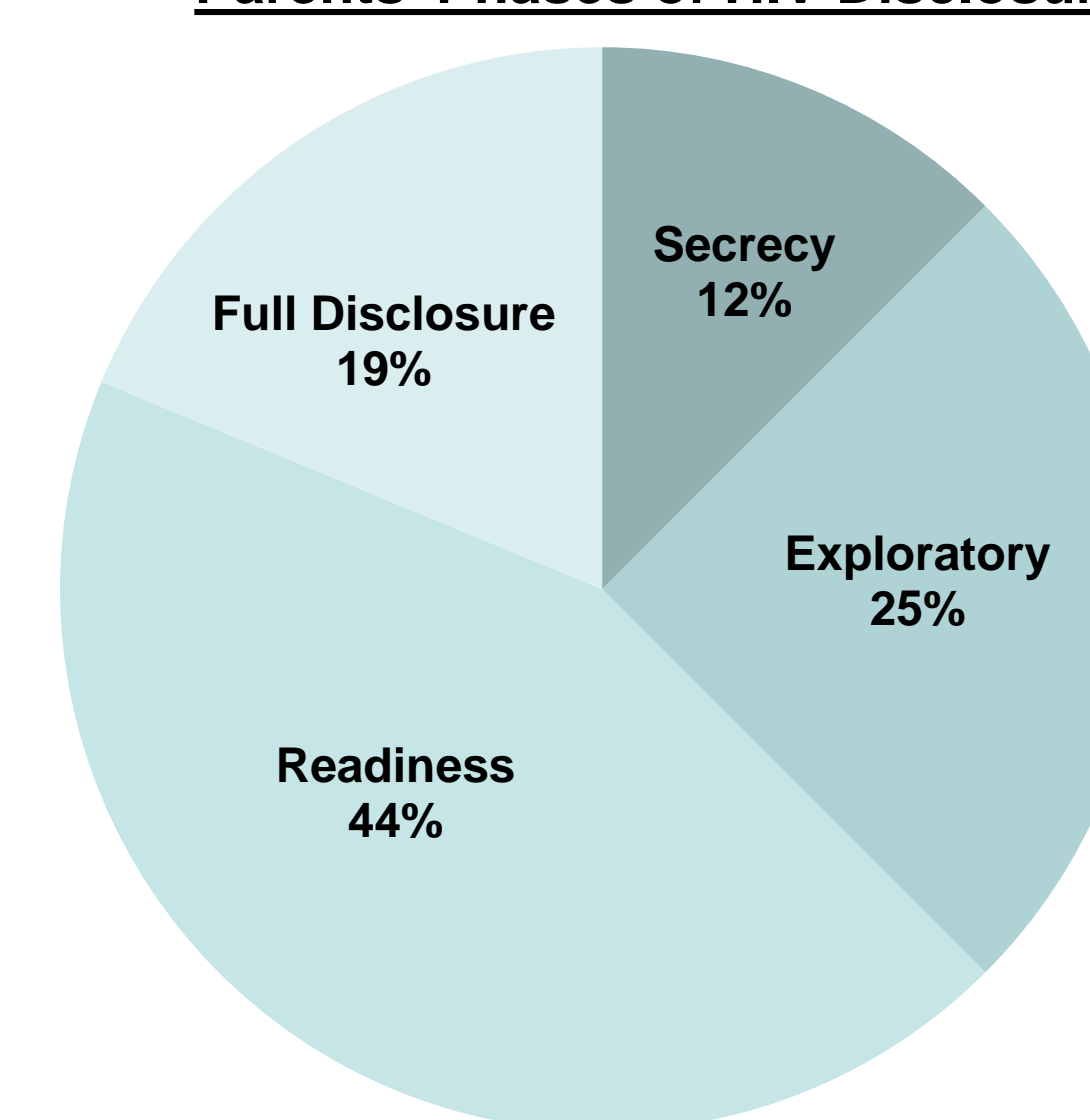
## LIMITATIONS

The study sample was purposively selected and may not represent other HIV-positive parents' disclosure experiences in Kenya. Study interviews were conducted in English; this possibly limited the participants to those fluent in English. The results of this study may therefore not be generalizable to the study population.

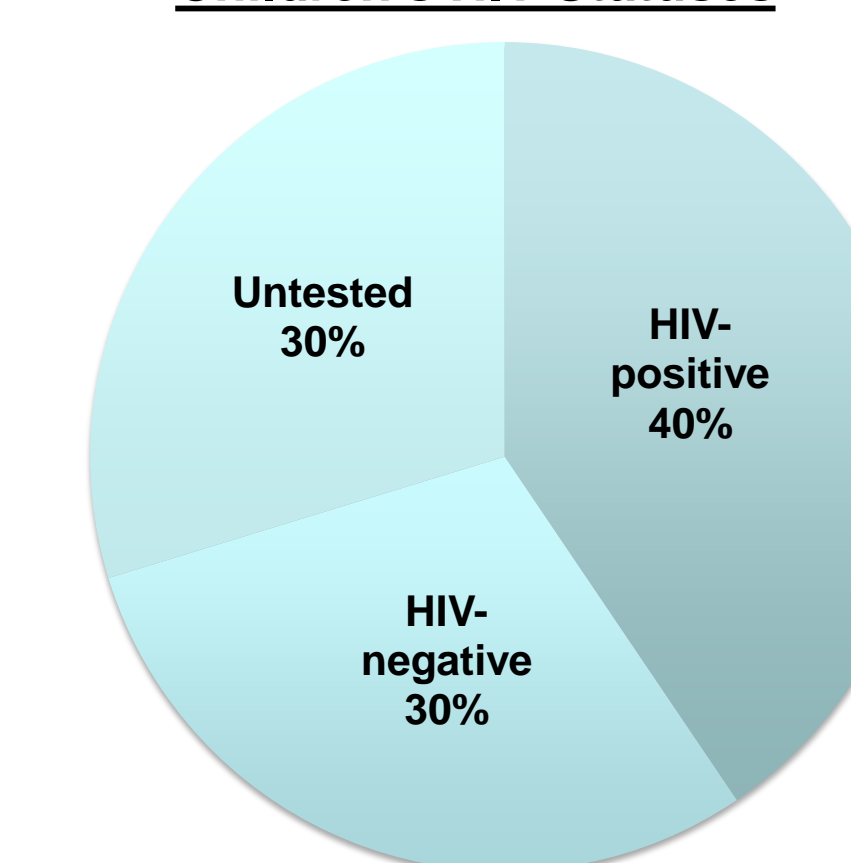
## FINDINGS

HIV-positive parents in the study had a total of 37 living children. Twenty-six of the children had been tested (15 HIV-positive and 11 HIV-negative) while 11 were of unknown HIV status. Parents were noted to go through four phases (secrecy, exploratory, readiness, full disclosure) of disclosure. Counseling provided by healthcare professionals' over a period of many years was instrumental in helping parents move their children through the three child stages (no, partial, full) of disclosure. However, most parents were "stuck" in between the exploratory and full disclosure phases; they had fully disclosed to their oldest children but were still preparing younger children for full disclosure. Twelve children (HIV-negative and unknown status) had full disclosure of their parents' illnesses, nine HIV-positive children had full disclosure of their own and their parents' illnesses, and 10 children (five HIV-positive, four unknown status, and one HIV-negative) had partial disclosure of their own and/or their parents' illnesses. Parents had indefinite plans to disclose to the six children with no knowledge of any illnesses in the family.

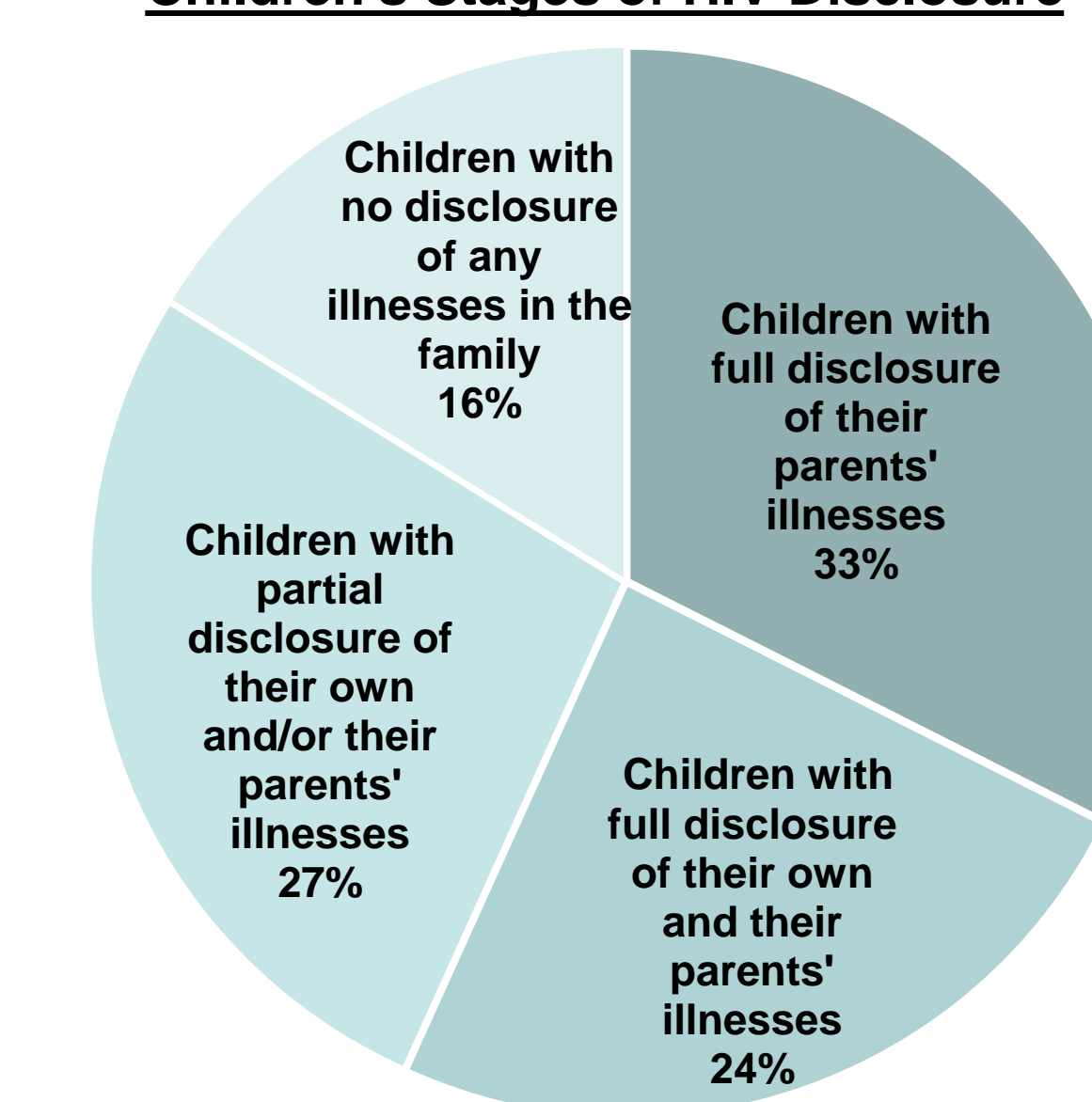
Parents' Phases of HIV Disclosure



Children's HIV Statuses



Children's Stages of HIV Disclosure



## CONCLUSIONS

Through the help of healthcare professionals, parents are able to navigate the four disclosure phases and fully disclose to their oldest children. However, many parents remain in HIV disclosure preparation mode as they continue to prepare their middle to youngest children for full disclosure. In order for timely HIV disclosure to occur to children, healthcare professionals need to continuously assist HIV-positive parents with disclosure preparation activities by providing them with regular targeted advice on how to move each child in the family towards full disclosure of illness.

## REFERENCES

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## POLICY IMPLICATIONS

This study's results reaffirmed that HIV-positive parents are challenged with HIV testing and disclosure to their children. It takes a long time before all children in HIV-affected families receive full disclosure of all HIV-positive family members' illnesses. Researchers and policy makers need to determine improved techniques that hasten the time it takes to fully disclose to each child. Achieving full disclosure status for all children within HIV-affected families should assist these families to have improved psychological health, family functioning, relationships, antiretroviral therapy adherence, and healthcare access.

## ACKNOWLEDGMENTS

Many thanks to Kenyatta National Hospital Comprehensive Care Center staff, Dr. Charles Kabetu, Dr. James Kiarie, Ms. Mugambi, Ms. Gacheri, Nelly Opiyo, Godfrey Mureithi, and David Mutabari for their assistance during planning and data collection procedures for this study. A big thank you to Purity Kibino for her assistance with data transcription and Opeyemi Fasina for his assistance with copy editing of the poster.