HIV-positive parents' accounts on disclosure preparation activities for a parent's and/or a child's illness in Kenya

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The aim of this research brief is to describe a study that examined how HIV-positive parents prepared themselves and their children for HIV disclosure in Kenya. This is the first study from Sub-Saharan Africa (SSA) that provides comprehensive data on how HIV-positive parents prepare themselves and their HIV-positive and negative children for disclosure of a parent's and/or a child's illness. Prior studies in SSA have provided limited details about the activities performed by parents to prepare for disclosure of a parent's or a child's illness. Key aspects of preparing for disclosure to children: **1.** Most parents take years to prepare for disclosure, proceeding when they judge themselves ready to impart the news and their children receptive to receive the news. **2.** Parents' preparation activities for disclosure proceed through four major phases which include secrecy, exploration, readiness, and finally full disclosure of illness. **3.** In the secrecy phase parents do not disclose; in the exploration phase they plan how they will disclose; in the readiness phase they seek activities that will help them to fully disclose; finally when ready they fully disclose to their children based on birth order. **4.** Parents who have many children remain simultaneously within the different preparation phases as they move their children from a state where none are disclosed to, to a state when all of them have been fully disclosed to. The original research article is located at: http://scholarworks.waldenu.edu/jsbhs/vol8/iss1/1/

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Research Brief

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HIV-Positive Parents' Accounts on Disclosure Preparation Activities for a Parent's and/or a Child's Illness in Kenya

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AIM

The aim of this research brief is to describe a study that examined how HIV-positive parents prepared themselves and their children for HIV disclosure in Kenya. This is the first study from Sub-Saharan Africa (SSA) that provides comprehensive data on how HIV-positive parents prepare themselves and their HIV-positive and negative children for disclosure of a parent's and/or a child's illness. Prior studies in SSA have provided limited details about the activities performed by parents to prepare for disclosure of a parent's or a child's illness.

BACKGROUND

As of 2012, there were 35 million persons infected with human immunodeficiency virus (HIV) globally (UNAIDS, 2013), the majority (90%) of whom lived in SSA. In Kenya as of 2012, there were 1.4 million adults and 200,000 children who are living with the illness (NACC & NASCOP, 2012). The prevalence of the disease is expected to increase because infected persons are living longer due to increased access to antiretroviral therapy (NACC & NASCOP, 2012).

HIV disclosure of a parent's and/or a child's illness is widely known to be challenging for parents (Gachanja, Burkholder, & Ferraro, 2014; Vaz et al., 2008). HIV disclosure is a process which evolves with time and should address local cultural norms and practices (Kallem, Renner, Ghebremichael, & Paintsil, 2011; Vaz et al., 2008).

With the exception of isolated studies in Congo (Vaz et al., 2010; 2008) and Botswana (Nam et al., 2009), there has been limited published details on how parents prepare (teaching children about disease, cooking child's favorite food, and offering love and gifts) their children for disclosure in resource-poor nations. The Four Phase Model (FPM; Tasker, 1992) of HIV disclosure formed the

Key Aspects of Preparing for Disclosure to Children:

1. *Most parents take years to prepare for disclosure, proceeding when they judge themselves ready to impart the news and their children receptive to receive the news.*
2. *Parents' preparation activities for disclosure proceed through four major phases which include secrecy, exploration, readiness, and finally full disclosure of illness.*
3. *In the secrecy phase parents do not disclose; in the exploration phase they plan how they will disclose; in the readiness phase they seek activities that will help them to fully disclose; finally when ready they fully disclose to their children based on birth order.*
4. *Parents who have many children remain simultaneously within the different preparation phases as they move their children from a state where none are disclosed to, to a state when all of them have been fully disclosed to.*

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theoretical basis of our study. The four phases include secrecy, exploration, readiness, and full disclosure. The FPM has not been extensively tested for disclosure of a parent's and/or a child's illness in resource-poor nations.

PROCESS

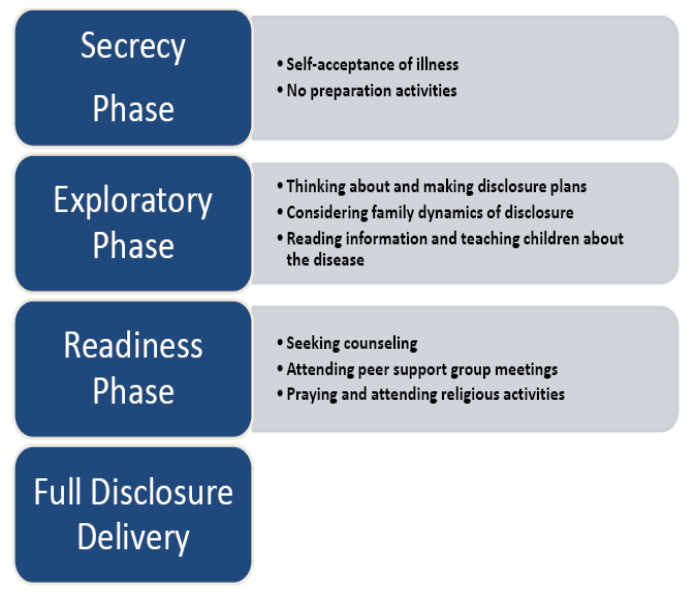
HIV-positive parents were recruited at the Comprehensive Care Center located within Kenyatta National Hospital in Nairobi, Kenya. Sixteen HIV-positive parents including a married couple were interviewed between December 2011 and January 2012. Parents were purposively selected because they had biological HIV-positive and negative children aged 8-17 years to whom they had performed no, partial (child was told limited details), and full (child was told the illness in question was HIV) disclosure of a parent's and/or a child's illness. During their interviews, those parents who had fully disclosed to their children were asked how they had prepared; others with no or partial disclosure, were asked how they were planning to prepare for full disclosure to their children.

FINDINGS

There were 15 families (including a married couple) represented in our sample comprising a diverse mix of HIV infected and uninfected parents and children. Children within these families had varied HIV disclosure statuses of parent(s) and child[ren]'s illnesses. Parents prepared and fully disclosed to their children based on birth order. The majority of parents (10) had 1-2 children, and the remaining 6 had between 3-6 children. The parents' demographic characteristics are displayed in the following table:

HIV-positive Parents' Social-demographic Profiles	
Variable	**Frequency**
Age	
31-40	*8*
41-50	*7*
51-60	*1*
Gender	
Female	*11*
Male	*5*
Employment Status	
Employed	*16*
Unemployed	*0*
Educational Status	
Primary	*2*
Secondary	*7*
College	*7*
Marital Status	
Single	*1*
Divorced	*1*
Widowed	*4*
Married	*10*
Religion	
Catholic	*6*
Protestant	*9*
Muslim	*1*
Years Since Diagnosis	
<1	*2*
2-5	*6*
6-10	*6*
10+	*2*
No. who had Performed Full Disclosure to at Least one Child in the Household	
Parental HIV infection status	*9*
Child HIV infection status	*8*
Both parent and child HIV infection statuses	*6*

The Figure below displays the activities performed by parents in preparation for full disclosure; these activities are further described below.



Secrecy Phase

Parents began the disclosure process in the secrecy phase:

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1. **Self-acceptance of illness:** Parents were initially shocked at their diagnoses and went through a time period when they did not tell their children anything. A few fathers (one parent and two spouses of married women in the sample) diagnosed many years before the study remained in this phase and had not disclosed to their children by the time of data collection.

Recommendations: Some fathers may need intensive counseling to help them accept their illnesses so they are able to disclose to their children. Counseling should preferably be provided at the time of diagnosis and periodically as deemed necessary.

2. **No Preparation Activities:** Two mothers tested their teenage children at a testing center, and opted to disclose theirs and these children's diagnoses immediately without preparing them. One of these children was in poor health and had a profound suicidal reaction to disclosure of hers and her mother's illnesses. A third mother disclosed her son's illness out of choice without preparation and was also planning to disclose her own illness to him by leaving her medication next to his.

Recommendations: HCPs should caution parents against immediate full disclosure of a child's illness (especially if the child is unwell and/or a teenager). All parents should be encouraged to prepare themselves and their children before disclosure regardless of whose illness is being disclosed.

Exploratory Phase

Parents began to explore how they would disclose to their children:

1. **Thinking about and making disclosure plans:** A newly diagnosed parent had not yet thought of disclosure. Other parents had thought of it but put it off to the future. Some parents whose older children reacted poorly to prior disclosure carefully deliberated how to disclose to younger siblings. Although actively thinking about disclosure, some reported they delayed disclosure for years because of contradictory advice provided by HCPs on if and when to proceed.

Recommendations: Newly diagnosed parents need to be advised on the need for disclosure to their children at some point in the near future. Parents whose older children react poorly to disclosure need services (e.g., counseling, support groups, decision-making skills, and role playing and disclosure practice sessions) that help them address and overcome their hesitancy to disclose to younger siblings. HCPs need disclosure-related training so they can better facilitate disclosure from parent to child.

2. **Considering the family dynamics of disclosure:** Kenya is a society based in patriarchy, and involvement of men in disclosure varied. Most men in the sample led disclosure preparation efforts in their homes; however, three of five married women prepared and disclosed to their children because their husbands were unable or unwilling to participate due to guilt associated with bringing the illness into the home. Close family members helped widowed, single, and divorced women prepare or plan for disclosure.

Recommendations: Targeted counseling should be given to married couples noted not to be preparing their children for disclosure together. Additionally, some fathers may need additional counseling so they can accept their illnesses and assist their

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spouses in preparing and disclosing to their children. Single, divorced, and widowed women appear to need assistance to disclose to their children. As part of disclosure preparation, they should be assisted to identify persons who can support them before, during, and after disclosure.

3. Reading information and teaching children about the disease without disclosing: Parents increased their HIV knowledge by reading HIV-related materials (e.g., books, brochures, and magazines). With the knowledge gained they prepared their children for disclosure by regularly teaching them about the illness; and also clearing any misconceptions and stigmatizing views their children held towards infected persons. Parents expressed children were sexually active and needed to be taught regularly about the illness.

Recommendations: Provide parents with targeted disease and disclosure-related materials to help them prepare for and disclose to their children. Provide community-wide education services using locally available resources (e.g., TV/radio ads, drama/music skits, and lectures from respected community leaders) to address early sex initiation among children; and to reduce stigma and discrimination levels in high prevalence countries.

Readiness Phase

Once parents perceived themselves as being capable of disclosing and their children ready to receive the news favorably, they sought out activities that would help them fully disclose:

1. Seeking counseling: Parents sought disclosure-related advice from HCPs or by making appointments with psychologists during clinic visits. HCPs helped parents identify HIV-positive children who were ready for disclosure and advised them to bring these children to the clinic for counseling. HIV-negative children were not brought to the clinic for counseling. Parents attributed counseling as being instrumental in their ability (especially words to use) to disclose to their children.

Recommendations: Counseling appears to be beneficial in helping parents disclose to their children and may also help HIV-positive children receive the news well. HIV clinics should increase the number of counselors on staff or provide additional disclosure-related training to current staff. Clinics should make an effort to include HIV-negative children in disclosure-related counseling to increase their resiliency to receive the news well.

2. Attending peer support group meetings: High stigma and discrimination levels compelled parents to seek disclosure-related help from peers within support group meetings. Parents also advised each other in the waiting rooms. Some parents brought their HIV-positive children to the clinic for support group sessions and explained it helped these children gain support from other similarly infected children. Support group services were not available for HIV-negative children.

Recommendations: Peer support group meetings benefit HIV-positive parents and children. HCPs should offer more sessions outside of clinic hours so more families can benefit from them. Since parents are advising each other in waiting rooms, clinics should have trained peer educators mingle with parents and provide then with disclosure advice. This may lead to better engagement with parents as opposed to one-sided lectures provided

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by HCPs to parents within reception and waiting rooms. HIV-negative children should be provided with support group sessions of their own as they may benefit from them as well.

3. Praying and attending religious activities: Parents sought out religious activities to assist them to fully disclose. These included prayer sessions, masses, and fellowship meetings held at religious facilities or in their homes. They prayed for strength, courage, and the words to use during disclosure; and also encouraged or planned to encourage their children to increase their faith in God as a way to cope with disclosure.

Recommendations: Parents should be encouraged to engage in religious activities because they appear to be helpful in disclosure delivery. HIV clinics should consider adding religious activities (e.g., chaplain services, and peer-led prayer and counseling sessions) as part of services provided to parents and children during the disclosure process.

Full Disclosure Phase and the FPM

Our study results indicate that the FPM is suitable for use in disclosing a parent's, a child's, or both a parent's and a child's illness in families where both parent(s) and child(ren) are infected in resource-poor nations. Most parents took years to negotiate the four phases of the FPM. Nine parents had disclosed a parent's illness, eight had disclosed a child's illness, and six had disclosed both a parent's and a child's illness to at least one child in the household.

However, while a few parents disclosed without preparing their children, many were yet to fully disclose to all their children. Therefore, HCPs should be aware that parents with many children sequentially straddle the different phases of the FPM as they move their children based on birth order from a state of no to full disclosure. These parents would benefit from targeted family-oriented disclosure plans that assist them to negotiate the four phases of disclosure as well as move all their children from no to full disclosure status.

POLICY IMPLICATIONS

Families represented in our study had diverse mixes of infected and uninfected family members; and children at different ages and disclosure levels. The following policy implications emerge from our study:

1. There are guidelines available from WHO (2011) to disclose HIV-positive children's illnesses for those aged up to 12 years. However, parents in resource-poor nations with children diagnosed as HIV-positive after 12 years, HIV-positive children who have not received disclosure by 12 years of age, or those with only HIV-negative children, are in need of disclosure guidelines.
2. There are also no guidelines for disclosure of a parent's illness to HIV-positive and negative children in resource-poor nations.
3. HCPs need training on HIV disclosure. We recommend that the FPM be incorporated into disclosure training programs so HCPs are better able to serve HIV-positive parents (and HIV-positive children) with their disclosure needs.
4. Efforts should be made to include HIV-negative children in research so their disclosure-related needs can be ascertained as they may be different from those of HIV-positive children. HIV Clinics should create and extend disclosure-

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related services (e.g., counseling and peer support groups) to HIV-negative children.

5. Global HIV infection rates among 10-19 year olds are increasing (UNICEF, 2014) and children are initiating sexual activity at early ages. Policymakers and governments of countries with high HIV prevalence should create sexual-related programs and services with the help of adolescents aimed at counteracting these rising rates.

FUTURE RESEARCH

Future researchers should focus on:

1. Identifying the best way for parents to prepare for and disclose a parent's and a child's illness to all HIV-positive and negative children in their households.
2. Performing larger quantitative studies using national or local languages to test the FPM's effectiveness in disclosing a parent's, a child's, or both a parent's and a child's illness in families where both parent(s) and child(ren) are infected.
3. Investigating services available to HIV-positive parents during the disclosure process in resource-poor nations so that they can be reported and added into disclosure guidelines.
4. Creating effective disclosure programs and services grounded in the FPM for use in resource-poor nations. These programs and services should use local culturally and religiously acceptable/appropriate resources.
5. Creating disclosure-related training programs based on the FPM for HCPs who work with HIV-positive parents and their families. This training will benefit parents, children, and HCPs.

CONCLUSION

Parents are challenged with disclosure; many take years to prepare and disclose to all their children based on birth order. There are four main phases of disclosure which include secrecy, exploration, readiness, and full disclosure. Some fathers are unable to move past the secrecy phase. During disclosure preparation, parents with many children are simultaneously in different phases of the FPM. Conflicting advice provided by HCPs on if and when to fully disclose to children may cause parents to remain within the exploration and readiness phase for long periods. Therefore, HCPs would benefit from disclosure-related training programs so they can better facilitate disclosure from parent to child.

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