

Parents' and Children's Emotions Spanning the HIV Disclosure Process in Kenya

**2014 APHA Annual Conference
Tuesday, November 18, 2014
New Orleans, LA**

**Grace Gachanja, PhD, MPH, RN*¹
Gary Burkholder, PhD^{1,2,3}
Aimee Ferraro, PhD, MPH¹**

[*g_gachanja@hotmail.com](mailto:g_gachanja@hotmail.com)

Walden University
¹College of Health Sciences

²College of Social and Behavioral Sciences
100 Washington Avenue, Suite 900
Minneapolis, MN, 55401
USA

³Laureate Education, Inc.
650 S. Exeter Street
Baltimore, Maryland 21202
USA

**WALDEN
UNIVERSITY**

A higher degree. A higher purpose.

296655 Parents' and children's emotions spanning the HIV disclosure process in Kenya

Tuesday, November 18, 2014

Grace Gachanja, PhD, MPH, RN , College of Health Sciences, Walden University, Minneapolis, MN

Gary J. Burkholder, PhD , Senior Research Scholar, Center for Research Quality, Walden University, Minneapolis, MN

Aimee Ferraro, PhD, MPH , College of Health Sciences, Walden University, Minneapolis, MN

Background: HIV disclosure from parent to child is challenging. While disclosure is expected to be emotional for parents and children, the total disclosure experience has not been described. The purpose of this study was to understand the lived experiences of HIV-positive parents and their children in Kenya during the disclosure process.

Methods: Phenomenological qualitative data were collected using in-depth semistructured interviews. Thirty four participants consisting of HIV-positive parents, their children (infected and uninfected), and healthcare professionals (HCPs) were enrolled. Data analysis was performed using NVivo 8 and the Van Kaam method.

Results: Pre-disclosure, parents were plagued with fear/worry of stigma, judgment, rejection, blame; and the reaction/consequences of disclosure on their children. Guilt and shame for bringing the illness into the home abounded. Children sensed, wondered, and worried about secrets within their homes. During disclosure, parents experienced catharsis, guilt, confusion, and panic when children reacted negatively. Children experienced shock, disbelief, anger, sadness, worry, depression, confusion, and catharsis from finally knowing what was wrong. Post-disclosure parents alternated between relief, guilt, and depression as their children's behavior changed due to disclosure. Children experienced unhappiness, depression, hopelessness, self-hate, and withdrawal. Recovery time varied lasting from a few hours to four months later; some children ultimately felt relief and self-acceptance. However, stress exposure caused disclosure emotions to reappear.

Conclusion: HIV disclosure process is accompanied by alternating negative and positive feelings for both parents and children. To ease the process, HCPs should provide support services such as disclosure practice sessions/trainings, counseling, peer support groups, and stress management.

HIV Statistics

- **As of 2012, 35 millions people were infected globally with HIV, 90% live in Sub-Saharan Africa (UNAIDS, 2013).**
- **In Kenya there are 1.4 million adults living with the disease with a prevalence of 5.6% among 15-64 year olds (NACC & NASCOP, 2012).**
- **There are 200,000 children aged 18 months to 14 years living with the disease with a prevalence of 0.9% (National AIDS and STI Control Programme, 2013).**
- **Prevalence is expected to keep rising in the decades to come due to increased accessibility to ART (NACC & NASCOP, 2012).**

Background

- Parents and children experience both positive and negative emotions before, during, and after disclosure (Kennedy et al., 2010; Murphy, 2008).
- Prior to disclosure, parents are psychologically challenged by the decision on if and when to disclose (Kallem, Renner, Ghebrenichael, & Paintsil, 2011; Kennedy et al., 2010; Kouyoumdjian, Meyers, & Mtshizana, 2005); for some this elicits as strong emotions as the time they were first diagnosed (Vaz et al., 2008; Wiener, Battles, & Heilman, 1998).
- During and after disclosure, parents' reactions can range from relief at finally disclosing to guilt and pain if their children react negatively to disclosure (Kennedy et al., 2010; Wiener et al., 1998).

Background

- Both HIV-positive and negative children are affected by disclosure of their own (Oberdorfer et al., 2006; Petersen et al., 2010; Vaz et al., 2008) and their parents' (Delaney, Serovich, & Lim, 2008; Kennedy et al., 2010; Vallerand et al., 2005) illnesses respectively.
- Younger children show little to no reaction to disclosure (Kennedy et al., 2010; Weiner et al., 1998); teenagers tend to have more profound reactions (Blasini et al., 2004; Ledlie, 2001; Lester et al., 2002).

Methods

- The study was conducted at the Kenyatta National Hospital Comprehensive Care Center located in Nairobi, Kenya.
- HIV-positive parents and children were recruited in the waiting areas of the clinic and also referred by healthcare professionals.
- A different set of HIV-positive parents were requested to bring their HIV-negative children to the clinic for participation in the study.
- Parents and children were not parent–child dyads because we wanted to obtain rich data on disclosure from the perspectives of parents and children in different families.

Methods

- **Participants were purposively selected:**
 - Parents had biological children aged 8-17 years to whom they had performed no, partial (limited details of illness), or full (complete details of illness) disclosure of a parent and/or a child's illness.
 - HIV-positive and negative children were selected because they were between 8-17 years old; and had partial or full disclosure of their own and their parents' illnesses respectively.
- **Parents provided written informed consent; children provided written assent and their parents provided written informed consent. All participants verbally consented to digital recording of their interviews.**
- **The study was approved by the University's Institution Review Board and the Kenyatta National Hospital Research Standards and Ethics Committee.**

Data Collection

- All participants underwent in-depth semi-structured interviews.
- Children with partial disclosure were interviewed based on the illness (e.g., TB, backache) they knew they or their parents were suffering from.
- Due to the sensitive nature of the research topic, a psychologist remained on hand throughout the data collection period to provide counseling as needed.
- One HIV-negative child was provided with counseling.
- Participants were encouraged to visit with her at anytime after the study ended should a need arise.

Data Collection

- Interviews were conducted in English and lasted from 30-90 minutes.
- HIV-positive parents' interview guide questions explored various facets of the HIV disclosure process including how they and their children felt before, during, and after disclosure of a parent's and/or a child's illness.
- HIV-positive and negative children's interview guides explored various facets of the HIV disclosure process including how they had felt during and after disclosure of their own and their parents' illnesses respectively.

Data Analysis

- Interviews were transcribed soon after the interviews.
- Transcripts were checked twice against the recorded interviews for accuracy.
- Transcripts were sent to five participants to verify transcription accuracy; interviews were verified as being accurate.
- Transcripts were transferred into NVivo 8 for data analysis.
- Data analysis was performed using the modified Van Kaam method (Moustakas, 1994).

Data Analysis

- Transcripts were checked and cross-checked for codes.
- Codes were grouped into seven themes that emerged spanning the HIV disclosure process.
- Codes and themes were cross-checked by members of the research team.
- This presentation covers one of those seven themes, and describes the emotions experienced by parents and children during the disclosure process.

Sample Description

Table 1 Participants' social demographic characteristics.

Variable	HIV-positive parents	HIV-positive children	HIV-negative children
Age			
Children 12–13		2	1
14–15		1	3
16–17		4	1
Parents 31–40	8		
41–50	7		
51–60	1		
Gender			
Female	11	3	3
Male	5	4	2
Educational status			
Primary	2	2	3
Secondary	7	5	2
College	7	NA	NA
Marital status			
Single	1		
Divorced	1		
Widowed	4		
Married	10		

Notes.

NA, Not applicable.

Source: Gachanja, G., Burkholder, G. J., & Ferraro, A. (2014). HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya. *PeerJ*, 2, e486.

<http://dx.doi.org/10.7717/peerj.486>

Sample Description

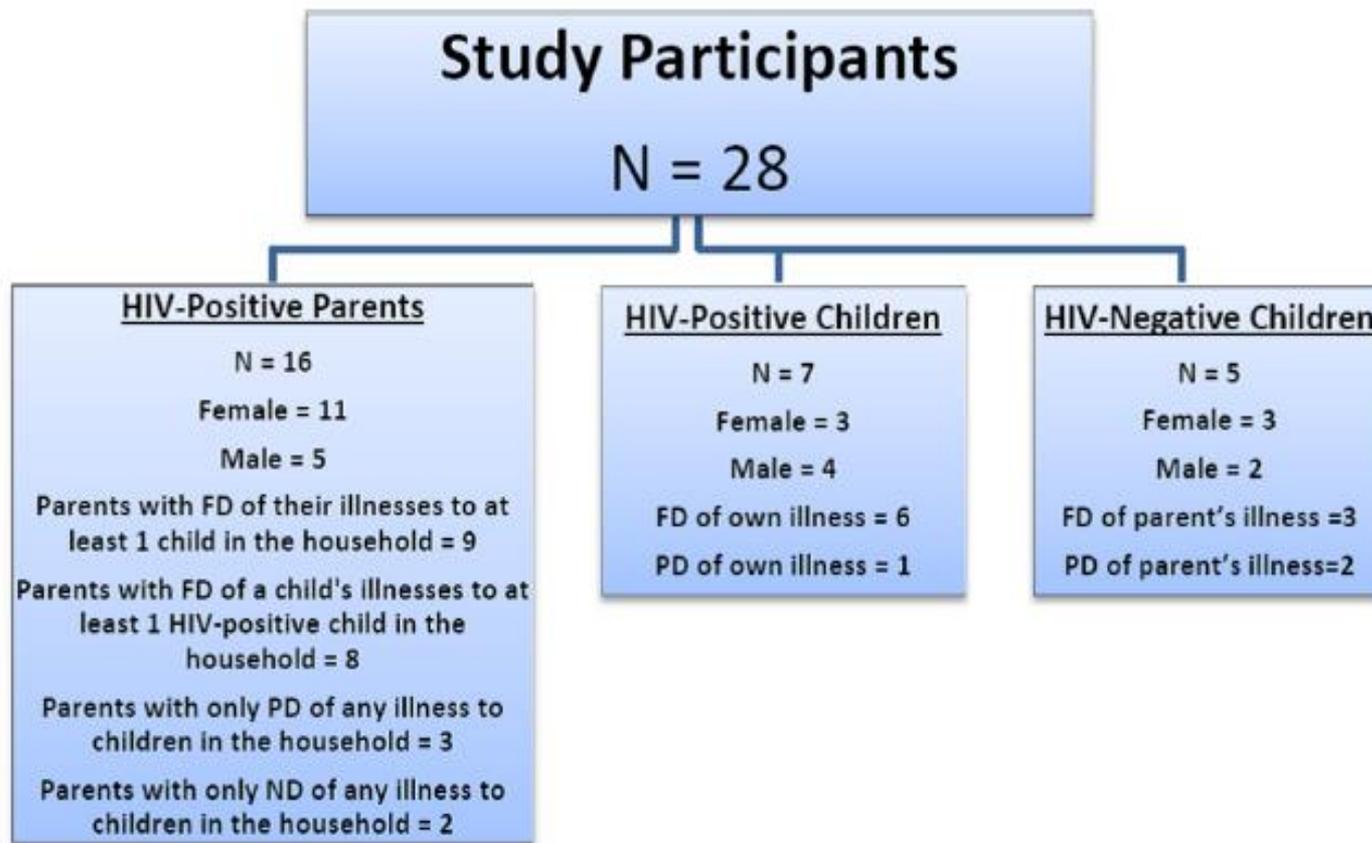


Figure 1 Sample description. FD, full disclosure; ND, nondisclosure; PD, partial disclosure.

Source: Gachanja, G., Burkholder, G. J., & Ferraro, A. (2014). HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya. *PeerJ*, 2, e486

<http://dx.doi.org/10.7717/peerj.486>

Results: Pre-disclosure Emotions

- **Parents and children experienced mostly negative emotions before disclosure.**
- **Parents feared and worried about how their children would react at the time of disclosure and what impact full disclosure would have on their children thereafter.**
- **Children suspected there were secrets within their families, wondered about them, and worried about theirs or their parents' health statuses.**

Results: Pre-disclosure Emotions

Pre-disclosure Emotions

HIV-Positive Parents

Fear of: Judgment; Rejection; Blame; Hatred; Child's reaction; Child's emotional/psychological state post-disclosure

Worry
Shame
Guilt

Children

HIV-Positive

Worry/Wonder/Suspicion about:

Own or parent(s)' health statuses and/or prior deaths

People's behavior around them

Reason for clinic attendance

Medication consumption

Blood draws/HIV testing

HIV-Negative

Worry/Wonder/Suspicion about parent(s)' health status

Participants' Quotes Related to Pre-disclosure Emotions

HIV-positive mother: *“You know sometimes people take HIV like a disease which you got it in a bad way, so that’s sex, that’s why we are ashamed to tell them [children].”*

HIV-positive boy: *“My brother always tells me when I was a baby I didn’t like to breastfeed... I was always just sick, sick, sick.”*

HIV-negative girl: *“Father had died, she [HIV-positive mother] had an illness because she had carried a baby in her stomach, my last sister, she did not use bad words but she was stressed.”*

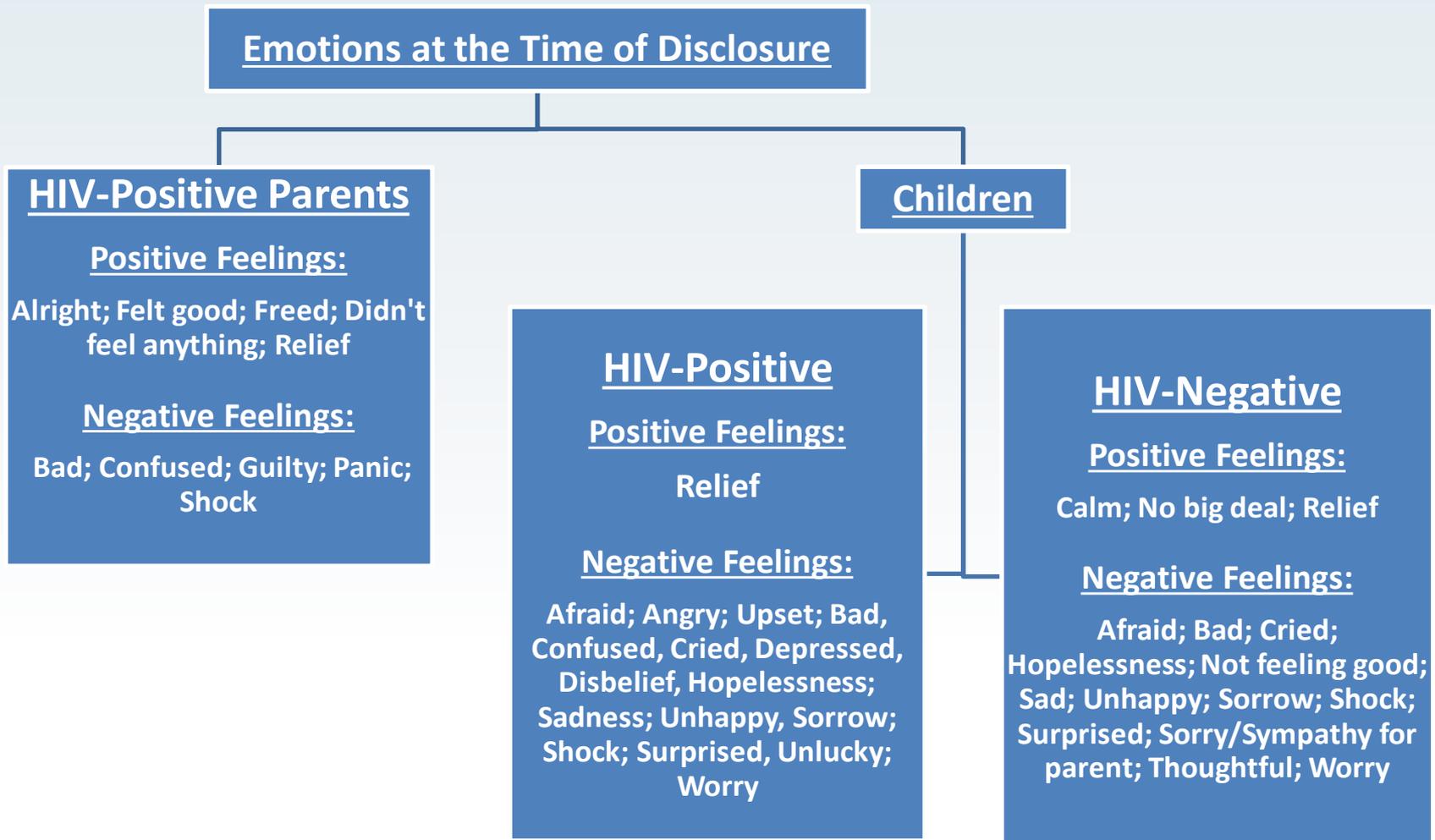
Results: Emotions at the Time of Disclosure

- At the time of full disclosure, parents were relieved to pass on the news but also experienced confusion, guilt, shock, and panic when their children reacted negatively.
- Some children were relieved to know why they or their parents had been unwell for a long time, but they also experienced a wide array of negative emotions including anger, confusion, disbelief, crying, unhappiness, hopelessness, and worry.
- Both HIV-positive and negative children experienced these range of emotions.

Results: Emotions at the Time of Disclosure

- Children who received partial disclosure (aged 8-9 years at time of disclosure) experienced little impact to the news regardless of their HIV statuses.
- Younger children who received full disclosure below 10 years of age showed little to no emotion.
- HIV-positive teenagers (14-17 years) had more profound reactions following full disclosure.
- HIV-negative children showed less emotional impact than HIV-positive children following full disclosure.
- Boys showed fewer emotions than girls; girls were more expressive.

Results: Emotions at the Time of Disclosure



Participants' Quotes Related to Emotions at the Time of Disclosure

HIV-positive mother: *"I think (clicks tongue) he [HIV-positive son] was not surprised rather he was so sad, he was depressed... For me because I had already taken some time, I was relieved, mmm, the burden (laughs) that I was carrying, I think I was relieved."*

HIV-positive boy: *"I was shocked and I couldn't believe it. I was angry with my mother. I was somehow confused because now I was wondering what to do to next."*

HIV-negative girl: *"When she [HIV-positive mother] told me, at first I was shocked, then she talked to me and told me that it's not like it is the end since she is going to be taking some medicines which will like prolong her life. I was relieved since now I know there were no more secrets."*

Results: Emotions in the Weeks After Disclosure

- Parents continued to experience the same emotions they felt during disclosure, but some also developed new feelings of guilt and depression when the implications of disclosure downed on them.
- Parents also alternated between relief at having disclosed and guilt as their children's behavior changed due to disclosure.
- HIV-negative children were mostly relieved; however, HIV-positive children experienced the same negative emotions as the time of disclosure and new ones (withdrawal, self-hate).
- Parents' and children's return to "normal" varied from a few hours to months later.

Results: Emotions in the Weeks After Disclosure

Emotions in the Weeks After Disclosure

HIV-Positive Parents

Intermittent Positive and Negative Feelings

Positive: Felt good; Happy; Normal; Relief

Negative: Bad; Depressed; Guilty; Unsure

Children

HIV-Positive

Intermittent Positive and Negative Feelings

Positive: Acceptance; Feeling better

Negative: Cried; Depressed; Down; Hopelessness; Low; Sad; Unhappy, Self-hate; Withdrawal; Wonder where illness came from

HIV-Negative

Intermittent Positive and Negative Feelings

Positive: Feeling better; Normal; Okay

Negative: Bad

Participants' Quotes Related to Emotions in the Weeks After Disclosure

HIV-positive father: *“You know you have some innocence [that full disclosure will go well], you have to feel guilty, you have that perception of guiltiness. How did it come, how did it happen, why me?”*

HIV-positive mother: *“Somehow (clicks tongue) it is difficult, it is 50/50, either you are relieved, sometimes it also disturbs you (laughs), now maybe you tell your child but you don't know whether she has received it well.”*

HIV-positive boy: *“I was depressed, I felt sad and most of the time I wanted to be lonely but after sometime I saw that I am not different from the ordinary person... I learnt to live positively and that's why I am here.”*

HIV-negative girl: *“I felt relieved because I knew that God will protect her [HIV-positive mother], and maybe she could go on well and get better.”*

Results: Emotions at the Time of Participants' Interviews

- Parents and children were back to “normal” and had adapted to their situations.
- However exposure to stress caused negative emotions to reappear in both parents and children.
- The impact of the illness and disclosure caused parents to have on and off feelings of guilt and shame for having brought the illness into the home.
- Children also experienced negative emotions when they were bored/idle because it caused them time to think about their circumstances.
- Parents and children did not speak to each other about these feelings.

Results: Emotions at the Time of the Interviews

Emotions at the Time of the Interview

HIV-Positive Parents

Intermittent Positive and Negative Feelings

Positive: Hope (cure, children aren't infected); Acceptance; Courageous; Increased closeness with children

Negative: Fear of stigma if child tells others; Hurt; Depression; Guilty; Discomfort from children's questions; Shame; Worry about disclosure to remaining children; Non-acceptance of illness

Children

HIV-Positive

Intermittent Positive and Negative Feelings

Positive: Comfortable; Happy; Normal; Okay; Hope for cure; Increased closeness with parents

Negative: Crying; Nervousness; Sadness; Stressed; Upset; Worry

HIV-Negative

Intermittent Positive and Negative Feelings

Positive: Feeling better; Hopeful; Increased closeness with parents

Negative: Hopelessness; Sadness; Sympathy for parent; Upset; Wonder about origin of parents' illnesses

Participants' Quotes Related to Emotions at the Time of the Interviews

HIV-positive father: *“I feel guilty because as he [HIV-positive son] grows up he will be old and then to marry or have a job, these things will now begin obstructing him because in a job you are told you must be tested for HIV, if you want to join the forces you will be told you must be HIV-negative. You want to marry you are told, are you positive or negative? You know these things will be hindering him, now you know you cut his life short.”*

HIV-positive girl: *“(Clicks tongue) sometimes maybe when I am bored, you know taking this medicine is not fun coz (clicks tongue) it’s not... So sometimes (clicks tongue) you just feel sad and ask even God why do you want me now to take these medicines forever?”*

HIV-negative boy: *“I get sad and upset when I recall that she [HIV-positive mother] has HIV, at times I just feel hopeless, sometimes but not for a long time. Sometimes she tells me that she is not feeling well, I just start to wonder what is wrong? How can I help? Then I just don’t know what to do.”*

Policy Implications

- **Parents and children are in need of services and programs that help them cope with their emotions during the disclosure process.**
- **These services and programs should include disclosure related-training and role playing for parents, and counseling and peer support group meetings for parents and children.**
- **Parents and children should be followed up post disclosure until it is ascertained they are doing well.**
- **Parents should be encouraged to disclose to someone close to them who can support them emotionally before, during, and after disclosure.**

Policy Implications

- Encourage full disclosure as early as possible because younger children absorb the news better.
- Children's resiliency to absorb the news should be increased prior to full disclosure occurring. This can be done through counseling, peer support, and pre-disclosure related camps.
- Children should be provided with someone safe to speak/confide with after disclosure so they can share their emotions with that person.
- Preferably that person (e.g., older sibling, aunt, grandparent) should be close to the child and be present at the time of full disclosure
- Parents and children should be encouraged to support each other after disclosure.

Conclusion

- **Parents and children experience a variety of emotions during the HIV disclosure process.**
- **Following full disclosure, their emotions gravitate back and forth between positive and negative feelings.**
- **When things are going well, parents and children have positive feelings.**
- **Life stressors cause the reoccurrence of negative emotions for both parents and children.**
- **Parents and children would benefit from services and programs that help them cope with the emotions associated with the HIV disclosure process.**

Questions



References

- Blasini, I., Chantry, C., Cruz, C., Ortiz, L., Salabarria, I., Scalley, N., ... Diaz, C. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico: Design, implementation, and evaluation. *Developmental and Behavioral Pediatrics, 25*(3), 181-189. doi:0196-206X/00/2503-0181
- Delaney, R. O., Serovich, J. M., & Lim, J. (2009). Psychological differences between HIV-positive mothers who disclose to all, some, or none of their biological children. *Journal of Marital and Family Therapy, 35*(2), 175-180.
- Gachanja, G., Burkholder, G., & Ferraro, A. (2014). HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya. *PeerJ, 2*, e486. <http://dx.doi.org/10.7717/peerj.486>
- Kallem, S., Renner, L., Ghebremichael, M., & Paintsil, E. (2011). Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS and Behavior, 15*(6), 1121-1127. doi: 10.1007/s10461-010-9741-9.
- Kennedy, D. P., Cowgill, B. O., Bogart, L. M., Corona, R., Ryan, G. W., Murphy, DA, ... Schuster, M. A. (2010). Parents' disclosure of their HIV infection to their children in the context of the family. *AIDS and Behavior, 14*(5), 1095–1105. doi: 10.1007/s10461-010-9715-y.
- Kouyoumdjian, F. G., Meyers, T., & Mtshizana, S. (2005). Barriers to disclosure to children with HIV. *Journal of Tropical Pediatrics, 51*(5), 285-287. doi: 10.1093/tropej/fmi014.

References

- Ledlie, S. W. (2001). The psychosocial issues of children with perinatally acquired HIV disease becoming adolescents: A growing challenge for providers. *AIDS Patient Care and STDs*, 15(5), 231-236. doi:10.1089/10872910152050748
- Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B., ... Wara, D. (2002). When the time comes to talk about HIV: factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *Journal of Acquired Immune Deficiency Syndromes*, 31(3), 309-317. doi: 10.1097/00126334-200211010-00006.
- Moustakas, C. (1994). *Phenomenological research methods*. London, England: Sage Publications.
- Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: A review. *Clinical Child Psychology Psychiatry*, 13(1), 105-122. doi: 10.1177/1359104507087464
- NACC and NASCOP. (2012). The Kenya AIDS Epidemic Update 2011. Available at http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_KE_Narrative_Report.pdf
- National AIDS and STI Control Programme. (2013). Kenya AIDS Indicator Survey 2012: preliminary report. Available at <http://reliefweb.int/sites/reliefweb.int/files/resources/167580994-Preliminary-Report-for-Kenya-AIDS-indicator-survey-2012-pdf0.pdf>

References

- Oberdorfer, P., Puthanakit, T., Louthrenoo, O., Charmsil, C., Sirisanthana, V., & Sisanthana, T. (2006). Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *Journal of Paediatrics and Child Health, 42*(2006), 283-288. doi:10.1111/j.1440-1754.2006.00855.x
- Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., ... Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. *AIDS Care, 22*(8), 970-978. doi: 10.1080/09540121003623693
- UNAIDS. (2013). Core epidemiology slides. Available at <http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/201309epicoreen.pdf>.
- Vallerand, A. H., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care and STDs, 19*(2), 100-109. doi:10.1089/apc.2005.19.100.
- Vaz, L., Corneli, A., Dulyx, J., Rennie, S., Omba, S., Kitetele, F., ... Behets, F. (2008). The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care, 20*(7), 842-852. doi:10.1080/09540120701742276
- Wiener, L. S., Battles, H. B., & Heilman, N. E. (1998). Factors associated with parents' decision to disclose their HIV diagnosis to their children. *Child Welfare, 77*(2), 115-135.