

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

Grace Gachanja, PhD, MPH, RN^{a*}

Gary Burkholder, PhD^a

Aimee Ferraro, PhD^a

^aWalden University

College of Health Sciences

155 Fifth Avenue South, Suite 100

Minneapolis, MN, 55401

USA

*Corresponding author email: g_gachanja@hotmail.com

Abstract

HIV disclosure is a challenging process for parents and healthcare professionals. 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 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.

Relevant Literature

The HIV disease process and ART consumption make disclosure necessary at some point. Improved disclosure 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 healthcare appointments and ART consumption without fear. The study was based on two HIV disclosure theories; the disease progression theory and the consequence theory of HIV disclosure (Serovich, 2001) as depicted in the figure below.

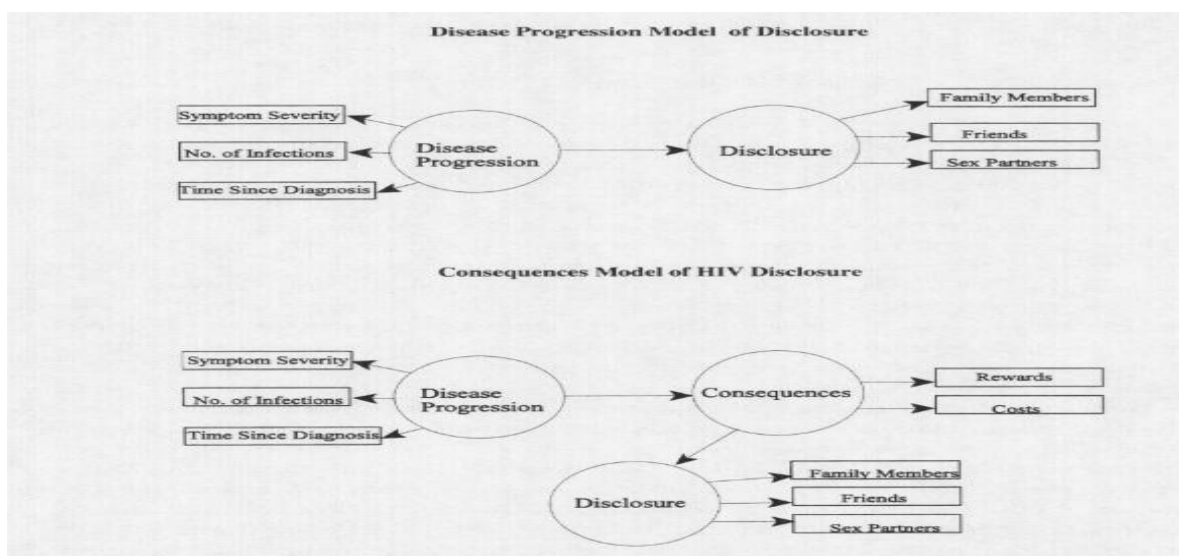


Figure 1. HIV disclosure theories. Adapted from "A test of two HIV disclosure theories," by J. M. Serovich, 2001, *AIDS Education and Prevention*, 13, p. 358. Copyright 2001 by Guilford Press. Reprinted with permission.

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.

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? Sub-questions include:

- 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?

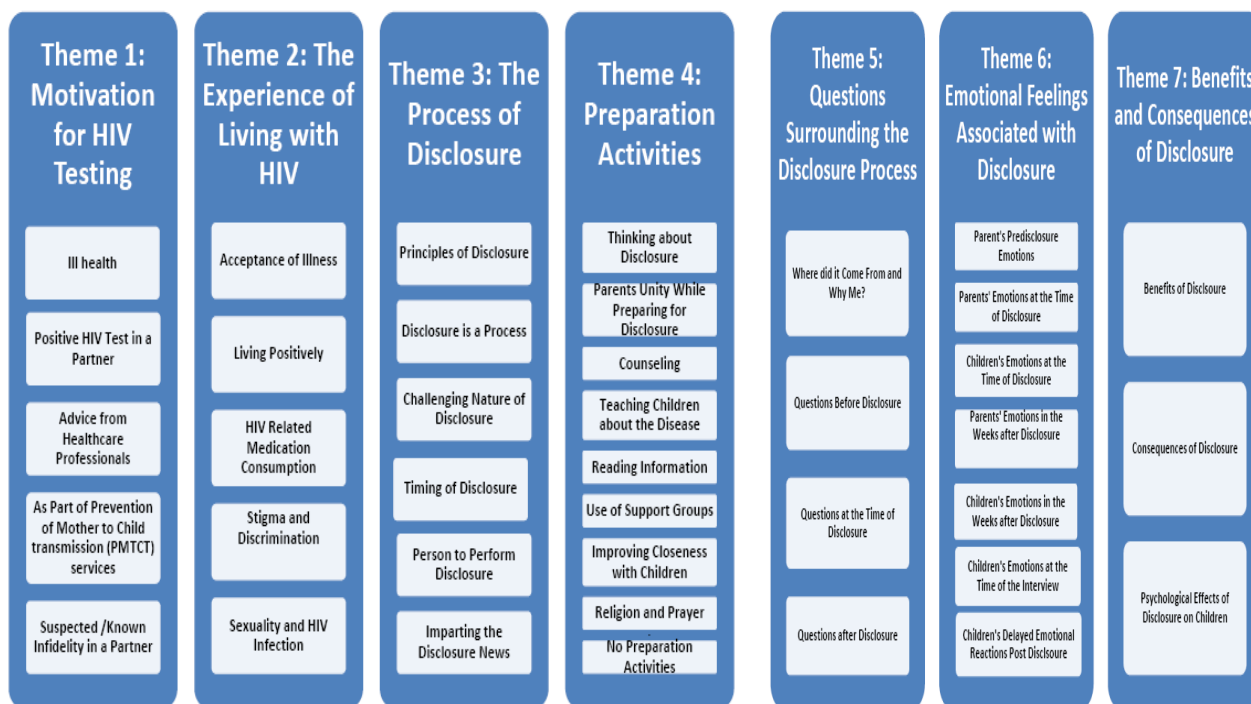
Procedures

34 participants consisting of 16 HIV-positive parents, 7 HIV-positive children, 5 HIV-negative children, and 6 healthcare professionals (HCPs) underwent in-depth, individualized, semi-structured digitally recorded 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 V8 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.

Results



Conclusions

HIV disclosure is challenging and each disclosure session performed is planned and geared to the particular child receiving disclosure. Parents and healthcare professionals 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.

Social Change Implications and Future Research

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 Kenya and countries that closely mirror the study population. Future research can include:

- The time it takes HIV-positive parents to take all their children for testing and finally deliver disclosure to them.
- How disclosure is approached until **all** infected and uninfected children are informed of all illnesses in the family.
- How HIV serodiscordant parents perform disclosure to their children.
- How vertically infected children are prepared to have children of their own while preventing infections in their partners and unborn children.

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. However, the conduct of semi-structured in-depth interviews garnered rich data on HIV disclosure in Kenya. 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.

Acknowledgments

We would like to thank KNH staff Dr. Charles Kabetu, Dr James Kiarie, Ms Mugambi, Ms Gacheri, Nelly Opiyo, Godfrey Mureithi, David Mutabari, and other staff for their assistance during data collection procedures; and Purity Kibino for her assistance with data transcription. No conflicts of interest to declare.

References

- Bairan, A., Taylor, G. A. J., Blake, B. J., Akers, T., Sowell, R., & Mendiola, R. (2007). A model of HIV disclosure: Disclosure and types of social relationships. *Journal of the American Academy of Nurse Practitioners, 19*(2007), 242-250. doi:10.1111/j.1745-7599.2007.00221.x
- Bikaako-Kajura, W., Luyirka, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., ... Bunnell, R. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS and Behavior, 10*, S85-S93. doi:10.1007/s10461-006-9141-3
- Blasini, I., Chantry, C., Cruz, C., Ortiz, L., Salabarría, 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
- Brown, B. J., Oladokun, R. E., Osinusi, K., Ochigbo, S., Adewole, F., & Kanki, P. (2011). Disclosure of HIV status to infected children in a Nigerian HIV Care Programme. *AIDS Care, 23*(9), 1053-1058. doi: 10.1080/09540121.2011.554523
- Delaney, R. O., Serovich, J. M., & Lim, J. (2008). Reasons for and against maternal disclosure to children and perceived child reaction. *AIDS Care, 20*(7), 876-880. doi:10.1080/09540120701767158
- Kallem, S., Renner, L., Ghebremichael, M., & Paintsil, E. (2011). Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana. *AIDS 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, D. A., ... 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
- Kirshenbaum, S. B., & Nevid, J. S. (2002). The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education and Prevention, 14*(1), 1-16. doi:10.1521/aeap.14.1.1.24331
- 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
- Miller, A. N., & Rubin, D. L. (2007). Motivations and methods of self-disclosure of HIV seropositivity in Nairobi, Kenya. *AIDS Behavior, 11*(2007), 687-697. doi:10.1007/s10461-006-9198-z
- Mitchell, M. M., & Knowlton, A. (2009). Stigma, disclosure, and depressive symptoms among informal caregivers of

- people living with HIV/AIDS. *AIDS Patient Care and STDs*, 23(8), 611-617. doi:10.1089/apc.2008.0279
- 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
- Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., & Herbeck, D. M. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: The TRACK program. *Journal of Consulting and Clinical Psychology*, 79(2), 203-214. doi: 10.1037/a0022896
- Nam, S. L., Fielding, K., Avalos, A., Gaolathe, T., Dickinson, D., & Geissler, P. W. (2009). Discussing matters of sexual health with children: What issues relating to disclosure of parental HIV status reveal. *AIDS Care*, 21(3), 389-395. doi:10.1080/09540120802270276
- Nelms, T. P., & Zeigler, V. L. (2008). A study to develop a disclosure to children intervention for HIV-infected women. *Journal of the Association of Nurses in AIDS Care*, 19(6), 461-469. doi:10.1016/j.jana.2008.05.005
- Njosing, B. N., Edin, K. E., Sebastián, M. S., & Hurtig, A. (2011). "If the patients decide not to tell what can we do?": TB/HIV counsellors' dilemma on partner notification for HIV. *BMC International Health and Human Right*, 11(6), 1-11. doi: 10.1186/1472-698X-11-6
- Norman, A., Chopra, M., & Kadiyala, S. (2007). Factors related to HIV disclosure in 2 South African Communities. *American Journal of Public Health*, 97(10), 1775-1781. doi:10.2105/AJPH.2005.082511
- Nostlinger, C., Jonckheer, T., De Belder, E., van Wingaerden, E., Wylock, C., Pelgrom, J., & Colebunders, R. (2004). Families affected by HIV: parents' and children's characteristics and disclosure to the children. *AIDS Care*, 16(5), 641-648. doi: 10.1080/09540120410001716432
- Republic of Kenya. (2009). *Kenya AIDS Indicator Survey 2007*. Retrieved from http://www.aidskenya.org/public_site/webroot/cache/article/file/Official_KAIS_Report_2009.pdf
- Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). 'What if they ask how I got it?': Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy and Planning*, 28, 36-42. doi:10.1093/heapol/czm040
- UNAIDS. (2010). *UNAIDS Report on the global AIDS epidemic 2010: Epidemic update*. Retrieved from http://www.unaids.org/documents/20101123_GlobalReport_Chap2_em.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. M. E., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in Sub-Saharan Africa. *AIDS Patient Care STDs*, 24(4), 247-256. doi: 10.1089/apc.2009.0217
- 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