



Disclosing HIV to Infected Children in South Africa in the Era of HAART: A Grounded Theory Study on the Process, Reasons and Outcomes of Disclosure

PDF (Size: 130KB) PP. 319-329 DOI: 10.4236/wja.2012.24043

Author(s)

Sphiwe Madiba

ABSTRACT

South Africa has seen an increasing population of children and adolescents accessing antiretroviral treatment (ART) in the past seven years. Many of these children are at the age when they should know their HIV diagnosis. We used grounded theory to explore the process, reasons and outcomes of HIV disclosure to children accessing ART from a paediatric HIV clinic in South Africa. Twenty seven caregivers of children aged 6 - 13 years who were receiving ART participated in four focus group interviews. Four main themes, disclosure occurring as a process, asking HIV related questions, the right age to tell, and the child's reaction to the diagnosis emerged. Biological caregivers approached disclosure as a process; they planned and prepared for the disclosure event for a long time. Full disclosure occurred when the caregivers had dealt with their own personal fears over the child's diagnosis, resulting in disclosure being delayed to older age and adolescence. Non-biological caregivers disclosed impulsively to children and employed partial disclosure. Caregivers disclosed because of the child's refusal to continue taking medication or the child repeatedly questioned the reasons for taking medication. Caregivers also disclosed because it was the right time to disclose, and the right time was often when the child reaches adolescence. After learning about their HIV diagnosis children became more adherent to medication, they also ensured that their HIV infected biological caregivers were adherent too. Children kept their diagnosis secret from people outside their immediate families. The increased survival of children on ART in South Africa calls for concerted efforts from researchers and health care providers to develop disclosure guidelines to assist caregivers to disclose to children in a manner that promotes the wellbeing of the child.

KEYWORDS

HIV Infected Children; Revealing the Diagnosis; Disclosure Outcomes; South Africa; Reaction to Disclosure; Disclosure Guidelines; Disclosure Process

Cite this paper

S. Madiba, "Disclosing HIV to Infected Children in South Africa in the Era of HAART: A Grounded Theory Study on the Process, Reasons and Outcomes of Disclosure," *World Journal of AIDS*, Vol. 2 No. 4, 2012, pp. 319-329. doi: 10.4236/wja.2012.24043.

References

- [1] WHO, UNAIDS, and UNICEF, "Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access, Progress Report," WHO, Geneva, 2011. http://www.who.int/hiv/pub/progress_report2011/en/index.html
- [2] UNAIDS, "Report on the Global AIDS Epidemic," UNAIDS, Geneva, 2009. http://data.unaids.org/pub/report/2009/jc1700_epi_update_2009_en.pdf
- [3] O. Shisana, T. Rehle, L. C. Simbayi, K. Zuma, J. Jooste, et al., "South African National HIV Prevalence, Incidence, Behaviour and Communication Survey 2008: A Turning Tide among Teenagers? HSRC Press, Cape Town, 2009. <http://www.hsrb.ac.za/Document-3239.phtml>
- [4] J. M. Mahloko and S. Madiba, "Disclosing HIV Diagnosis to Children in Odi District, South Africa: Reasons for Disclosure and Non-Disclosure," *African Journal of Primary Health Care and Family*

[WJA Subscription](#)[Most popular papers in WJA](#)[About WJA News](#)[Frequently Asked Questions](#)[Recommend to Peers](#)[Recommend to Library](#)[Contact Us](#)

Downloads:	27,769
Visits:	81,141

[Sponsors >>](#)

- [5] R. G. Steele, T. D. Nelson and B. P. Cole, " Psychosocial Functioning of Children with AIDS and HIV Infection: Review of the Literature from a Socio-Ecological Framework," *Journal of Developmental & Behavioral Pediatrics*, Vol. 28, No. 1, 2007, pp. 58-69. doi: 10.1097/DBP.0b013e31803084c6
- [6] C. Thorne, M. L. Newell, F. A. Botet, A. B. Bohlin, A. Ferrazin, et al., " Older Children and Adolescents Surviving with Vertically Acquired HIV Infection," *JAIDS Journal of Acquired Immune Deficiency Syndromes*, Vol. 29, No. 4, 2002, pp. 396-401.
- [7] G. J. Domek, " Debunking Common Barriers to Pediatric HIV Disclosure," *Journal of Tropical Pediatrics*, Vol. 56, No. 6, 2010, pp. 440-442. doi:10.1093/tropej/fmq013
- [8] P. Lester, M. Chesney, M. Cooke, R. Weiss, P. Whalley, et al., " When the Time Comes to Talk about HIV: Factors Associated with Diagnostic Disclosure and Emotional Distress in HIV-Infected Children," *JAIDS Journal of Acquired Immune Deficiency Syndromes*, Vol. 31, No. 3, 2002, pp. 309-317. doi: 10.1097/00126334-200211010-00006
- [9] I. Blasini, C. Chantry, C. Cruz, L. Ortiz, I. Salabarría, et al., " Disclosure Model for Pediatric Patients Living with HIV in Puerto Rico: Design, Implementation, and Evaluation," *Journal of Developmental & Behavioral Pediatrics*, Vol. 25, No. 3, 2004, pp. 181-189. doi:10.1097/00004703-200406000-00007
- [10] C. E. Abadía-Barrero and M. D. LaRusso, " The Disclosure Model versus a Developmental Illness Experience Model for Children and Adolescents Living with HIV/ AIDS in Sao Paulo, Brazil," *AIDS Patient Care and STDs*, Vol. 20, No. 1, 2006, pp. 36-43.
- [11] P. J. Bachanas, K. A. Kullgren, K. S. Schwartz, B. Lanier, J. S. McDaniel, et al., " Predictors of Psychological Adjustment in School-Age Children Infected with HIV," *Journal of Pediatric Psychology*, Vol. 26, No. 6, 2001, pp. 343-352. doi:10.1093/jpepsy/26.6.343
- [12] I. Funck-Brentano, D. Costagliola, N. Seibel, E. Straub, M. Tardieu, et al., " Patterns of Disclosure and Perceptions of the Human Immunodeficiency Virus in Infected Elementary School-Age Children," *Archives of Pediatric Adolescence Medicine*, Vol. 151, No. 10, 1997, pp. 978-985. doi:10.1001/archpedi.1997.02170470012002
- [13] S. Biadgilign, A. Deribew, A. Amberbir and K. Deribe, " Barriers and Facilitators to Antiretroviral Medication Adherence among HIV-Infected Paediatric Patients in Ethiopia: A Qualitative Study," *SAHARA J*, Vol. 6, No. 4, 2009, pp. 148-154.
- [14] S. Kallem, L. Renner, M. Ghebremichael and E. Paintsil, " Prevalence and Pattern of Disclosure of HIV Status in HIV-Infected Children in Ghana," *AIDS and Behavior*, Vol. 15, No. 6, 2010, pp. 1121-1127.
- [15] C. Merzel, N. Van Devanter and M. Irvine, " Adherence to Antiretroviral Therapy among Older Children and Adolescents with HIV: A Qualitative Study of Psychosocial Contexts," *AIDS Patient Care and STDs*, Vol. 22, No. 12, 2008, pp. 977-987. doi:10.1089/apc.2008.0048
- [16] L. M. E. Vaz, E. Eng, S. Maman, T. Tshikandu and F. Behets, " Telling Children They Have HIV: Lessons Learned from Findings of a Qualitative Study in Sub-Saharan Africa," *AIDS Patient Care and STDs*, Vol. 24, No. 4, 2010, pp. 247-256. doi:10.1089/apc.2009.0217
- [17] S. L. Marhefka, L. J. Koenig, S. Allison, P. Bachanas, M. Bulterys, et al., " Family Experiences with Pediatric Anti-retroviral Therapy: Responsibilities, Barriers, and Strategies for Remembering Medications," *AIDS Patient Care and STDs*, Vol. 22, No. 8, 2008, pp. 637-647. doi: 10.1089/apc.2007.0110
- [18] C. A. Mellins, E. Brackis-Cott, C. Dolezal and E. J. Abrams, " The Role of Psychosocial and Family Factors in Adherence to Antiretroviral Treatment in Human Immunodeficiency Virus-Infected Children," *The Pediatric Infectious Disease Journal*, Vol. 23, No. 11, 2004, pp. 1035-1041. doi:10.1097/01.inf.0000143646.15240.ac
- [19] D. A. Murphy, C. M. Wilson, S. J. Durako, L. R. Muenz and M. Belzer, " Antiretroviral Medication Adherence among the REACH HIV-Infected Adolescent Cohort in the USA," *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, Vol. 13, No. 1, 2001, pp. 27-40.
- [20] P. Oberdorfer, T. Puthanakit, O. Louthrenoo, C. Charmsil, V. Sirisanthana, et al., " Disclosure of HIV/AIDS Diagnosis to HIV-Infected Children in Thailand," *Journal of Paediatrics and Child Health*, Vol. 42, No. 5, 2006, pp. 283-288. doi:10.1111/j.1440-1754.2006.00855.x
- [21] P. L. Williams, D. Storm, G. Montepiedra, S. Nichols, B. Kammerer, et al., " Predictors of Adherence to Antiretroviral Medications in Children and Adolescents with HIV Infection," *Pediatrics*, Vol. 118, No.

- [22] S. W. Ledlie, " Diagnosis Disclosure by Family Caregivers to Children Who Have Perinatally Acquired HIV Disease: When the Time Comes," *Nursing Research*, Vol. 48, No. 3, 1999, pp. 141-149. doi:10.1097/00006199-199905000-00004
- [23] C. A. Mellins, E. Brackis-Cott, C. Dolezal, A. Richards, S. W. Nicholas, et al., " Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes," *Clinical Child Psychology and Psychiatry*, Vol. 7, No. 1, 2002, pp. 101-114. doi:10.1177/1359104502007001008
- [24] M. Ferris, K. Burau, A. M. Schweitzer, S. Mihale, N. Murray, et al., " The Influence of Disclosure of HIV Diagnosis on Time to Disease Progression in a Cohort of Romanian Children and Teens," *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, Vol. 19, No. 9, 2007, pp. 1088-1094.
- [25] S. Biadgilign, A. Deribew and A. E. H. K. D. Amberbir, " Factors Associated with HIV/AIDS Diagnostic Disclosure to HIV Infected Children Receiving HAART: A Multi-Center Study in Addis Ababa, Ethiopia," *PLoS One*, Vol. 6, No. 3, 2011, Article ID: e17572. doi:10.1371/journal.pone.0017572
- [26] R. A. Ferrand, E. L. Corbett, R. Wood, J. Hargrove, C. E. Ndhlovu, et al., " AIDS among Older Children and Adolescents in Southern Africa: Projecting the Time Course and Magnitude of the Epidemic," *AIDS*, Vol. 23, No. 15, 2009, pp. 2039-2046.
- [27] O. Shisana, S. Mehtar, T. Mosala, M. Zungu-Dirwayi, T. Rehle, et al., " HIV Risk Exposure in Children: A Study of 2 - 9-Year-Olds Served by Public Health Facilities in the Free State, South Africa," *HSRC Press*, Cape Town, 2005.
- [28] S. A. Walker, V. Mulenga, F. Sinyinza, K. Lishimpi, A. Nunn, et al., " Determinants of Survival without Antiretroviral Therapy after Infancy in HIV-1-Infected Zambian Children in the CHAP Trial," *JAIDS Journal of Acquired Immune Deficiency Syndromes*, Vol. 42, No. 5, 2006, pp. 637-645. doi:10.1097/01.qai.0000226334.34717.dc
- [29] F. G. Kouyoumdjian, T. Meyers and S. Mtshizana, " Barriers to Disclosure to Children with HIV," *Journal of Tropical Pediatrics*, Vol. 51, No. 5, 2005, pp. 285-287. doi:10.1093/tropej/fmi014
- [30] A. Lesch, L. Swartz, A. Kagee, K. Moodley, Z. Kafaar, et al., " Paediatric HIV/AIDS Disclosure: Towards a Developmental and Process-Oriented Approach," *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, Vol. 19, No. 6, 2007, pp. 811-816.
- [31] S. Waugh, " Parental Views on Disclosure of Diagnosis to Their HIV-Positive Children," *AIDS Care: Psychological and Socio-Medical Aspects of AIDS/HIV*, Vol. 15, No. 2, 2003, pp. 169-176.
- [32] L. P. Wiener, C. A. P. Mellins, S. P. Marhefka and H. B. P. Battles, " Disclosure of an HIV Diagnosis to Children: History, Current Research, and Future Directions," *Journal of Developmental & Behavioral Pediatrics*, Vol. 28, No. 2, 2007, pp. 155-166.
- [33] D. Dematteo, C. Harrison, C. Arneson, R. S. Goldie, A. Lefebvre, et al., " Disclosing HIV/AIDS to Children: The Paths Families Take to Truth Telling," *Psychology, Health & Medicine*, Vol. 7, No. 3, 2002, pp. 339-356. doi:10.1080/13548500220139395
- [34] T. P. Nelms and V. L. Zeigler, " A Study to Develop a Disclosure to Children Intervention for HIV-Infected Women," *Journal of the Association of Nurses in AIDS Care*, Vol. 19, No. 6, 2008, pp. 461-469. doi:10.1016/j.jana.2008.05.005
- [35] G. A. Heeren, " Changing Methods of Disclosure. Literature Review of Disclosure to Children with Terminal Illnesses, including HIV," *The European Journal of Social Science Research*, Vol. 24, No. 1-2, 2011, pp. 199-208. doi:10.1080/13511610.2011.553506
- [36] UNGASS, " South Africa UNGASS Country Progress Report," 2010. http://data.unaids.org/pub/report/2010/southafrica_2010_country_progress_report_en.pdf
- [37] A. Strauss and J. Corbin, " Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory," 2nd Edition, Sage, Newbury Park, 1998.
- [38] J. W. Creswell, " Qualitative Inquiry and Research Method: Choosing among Five Approaches," 2nd Edition, Sage, Thousand Oaks, 2007.
- [39] StataCorp, " Stata Statistical Software. Release 10," StataCorp LP, 2007.
- [40] S. Instone, " Perceptions of Children with HIV Infection When Not Told for So Long: Implications for

- [41] L. Chi-Ling and R. Johann-Liang, " Disclosure of the Diagnosis of HIV/AIDS to Children Born of HIV-Infected Mothers," *AIDS Patient Care and STDs*, Vol. 13, No. 1, 1999, pp. 41-45. doi: 10.1089/apc.1999.13.41
- [42] P. Lester, M. Chesney, M. Cooke, P. Whalley, B. Perez, et al., " Diagnostic Disclosure to HIV-Infected Children: How Parents Decide When and What to Tell," *Clinical Child Psychology and Psychiatry*, Vol. 7, No. 1, 2002, pp. 85-99. doi:10.1177/1359104502007001007
- [43] D. Kennedy, B. Cowgill, L. Bogart, R. Corona, G. Ryan et al., " Parents' Disclosure of Their HIV Infection to Their Children in the Context of the Family," *AIDS and Behavior*, Vol. 14, No. 5, 2010, pp. 1095-1105.