Renewed Stigma Against HIV-Positive Children in the Wake of Successes in Treatment and Prevention of Mother-to-Child Transmission: Botswana's Public Health Puzzle

Bianca Dahl, PhD; Brown University

Overview:

In Botswana, significant recent successes in prevention of mother-to-child transmission (PMTCT), coupled with achievements in the nationwide rollout of free antiretroviral therapy (ART), have been widely extolled and publicized in local media, awareness campaigns, and government reports. Along with the obvious epidemiological benefits, scholarship also hails HIV treatment and prevention successes as a necessary precursor to bringing about decreased levels of social stigma related to the virus—and, by extension, increases in quality of life, social integration, and treatment adherence among people living with HIV/AIDS (PLWHA) (see, e.g., Abadia-Barrero and Castro 2006; Brown, MacIntyre, & Trujillo 2003; Cao, Sullivan, Wi et al 2006; Farmer et al. 2001). Thus, scholars and practitioners alike have claimed that eradication of stigma will rely in large degree on successes exactly like Botswana's recent measures [89.9% of people needing ART in the country were receiving treatment as of 2009, and 94.2% of pregnant women were reportedly receiving PMTCT in 2010. Mother-to-child transmission rates are now said to be only 3.8% of children born to HIV-positive mothers (UNAIDS 2010)]. However, contrary to expectations,[1] this paper presents qualitative research from one southeastern village that suggests the presumed negative relationship between ART availability and stigma does not play out in the case of *children*. HIV-positive children appear to be experiencing *renewed* forms of stigma in the wake of epidemiological successes at the population level.

Drawing on qualitative research comprised of participant observation and in-depth interviews with villagers (n=43) and with relatives of HIV-positive children (n=16) in one southeastern Botswana village between 2005 and 2010, this paper seeks to identify and explain cultural reasons why the successes of PMTCT have led many villagers to claim that "natural" HIV transmission from mothers to children "just doesn't happen in Botswana"—and why this has resulted in the perpetuation, reformulation, and endurance of stigmatizing attitudes and behaviors precisely where they were expected to decrease—even against children born before PMTCT was widely available. This paper traces a shift in public opinion regarding the source of HIV infection of a cohort of children who were born before high rates of PMTCT uptake, yet who have benefitted from ART treatment to live significantly longer and more socially engaged lives than they would otherwise have done. This research indicates that PMTCT's successes have been publicized in such a way that villagers now point to positive public health outcomes as indication that the increasingly visible population of HIV-positive children must have been infected by pedophilic rape or witchcraft. Both of these alleged sources of infection result in stigmatizing attitudes about, discomfort with, and gossip against children and their families.

Research Aims:

This research had the following specific aims:

1) To identify and understand what forms stigma takes in the lives of HIV-positive children and their caretakers, and to better document social and cultural factors that perpetuate and even

[1] However, some other recent studies demonstrate emerging exceptions to the expectation that prevention and treatment successes cause decreases in stigma. Maman et al. (2009) identify access to antiretroviral therapy as a crucial but potentially insufficient means of decreasing stigma. Maughan-Brown noted in a longitudinal study of stigma in South Africa that despite increases in ART during the three-year study period, stigmatizing attitudes in the region not only did not drop, but even appeared to grow (2010).

augment stigmatizing attitudes against HIV-positive children.
2) To comprehend how public health successes affect children's experiences of stigma.
3) To assess how governmental, medical, community-based, and NGO infrastructures might be harnessed to better address the psychosocial impact of HIV status on children and to better combat stigmatizing attitudes across Botswana.

In so doing, this paper addresses two notably understudied social elements of the HIV epidemic: a) how stigma affects HIV-positive children as a population with a unique relationship to stigma; and b) how public health successes in both treatment and prevention might affect levels of stigma against PLWHA in ways not predicted by current theory.

Botswana is a particularly appropriate site to explore these questions, as its nationwide free ART and PMTCT programs have been hailed as an important public health experiment, and its epidemiological successes are widely promoted as seminal harbingers that may predict the future outcomes across the developing world. Botswana's per capita rate of HIV infection, 23.9% of adults in 2007, is the second highest in the world, behind only that of nearby Swaziland (UNAIDS 2008: 217), and for that reason also it is a noteworthy site for studying the emergence of new or renewed patterns of stigmatization.

Background and Significance

There is an overall paucity of research focused on the experiences of stigma specifically against HIV-positive children in the developing world. Certainly, some work has addressed stigma against children (e.g., Abadia-Barrero & Castro 2005; Brown, Lourie, and Pao 2000); yet many such studies focus on the US context (Battles & Wiener 2002; Ledlie 2001), while others simply identify the need for further targeted research (Domek 2006). Still other studies assume that children share the same stigma as their mothers, and/or that stigma affects children insofar as it impacts the choices their mothers might make to hide their and their children's illnesses (Bond, Chase & Aggleton 2002). In a creative effort, Campbell and colleagues studied children's drawings and stories about families affected by HIV, finding evidence of both stereotypical stigmatizing depictions of HIV-positive children, and of empathy and respect for HIV-positive children (2010). However, Campbell and colleagues did not observe whether and how those attitudes are manifested in social interactions. An ethnographically nuanced, child-focused study of the relationships between stigma and treatment/prevention offers a needed paradigm shift.

Most studies of HIV and AIDS stigma begin with Erving Goffman's seminal definition, which described stigma as "an attribute that is deeply discrediting" (1963:3). As Parker and Aggleton have argued, Goffman's definition has been interpreted as locating discrimination in individuals rather than within relationships demarcated by other forms of sociological difference, such as class or race (2002). Parker and Aggleton instead call for an understanding of HIV stigma and discrimination as "processes" rather than as "things" (2002: 14). Some scholars (e.g., Stein 2003) have further criticized stigma research for recording only self-reported beliefs, sentiments, and behaviors in the form of surveys or structured/semi-structured interviews, which invites social desirability bias. These efforts furthermore only measure reported attitudes without the capacity to trace whether those attitudes are mobilized into noticeable reactions in everyday life. Methods often do not distinguish between stigmatizing beliefs and behaviors, or experiences of stigma and its causes and outcomes (Holzemer et al. 2007). Even highly nuanced studies that try to identify the range of stigmatizing behaviors and beliefs frequently rely upon self-report in surveys or interviews (e.g., Root 2010), rather than observation.

In effort to better explore the meanings of stigmatizing attitudes and their deployment in social circles, this research sought to observe stigmatizing remarks or behaviors in natural,

everyday interactions, as well as to elicit self-reported beliefs in interviews. This research thus takes stigma as an emergent category, defining what forms of stigma are experienced by Batswana children and their families. This permits a nuanced understanding of patterns of stigmatizing behavior as well as of the source of or inspiration for stigmatizing attitudes.

Methods:

The paper draws on methods and theory from anthropological demography, which employs in-depth qualitative research in order to track stigma not simply through self-report, but also through its manifestation in concrete actions, gossip, and behaviors during everyday interactions. Thus, the starting point methodologically was structured, recurrent participant observation in the homes of 11 children who were widely recognized as HIV-positive in one village, as well as in neighboring homes. Observations made fieldnote records of stigmatizing comments voiced in interviews or through casual conversation. Participant observation was also conducted in other village spaces, including churches, the tribal court, and a primary school in the village. These observations were conducted in the course of repeated field visits in 2005-07, 2008, and 2010. All observations were recorded by the author in ethnographic fieldnotes, which were subsequently coded for relevance to the research questions and specific aims of this project.

Observations were supplemented by in-depth ethnographic interviews with neighboring villagers and key informants who did not cohabit with an HIV-positive child (n=43) and with relatives cohabiting with 11 children who do have HIV (n=16). Interviews were conducted by the author in Setswana or English, and were coded according to relevance to the specific aims.

Findings and Analysis:

Content analysis of fieldnotes and interview data found that, while some villagers expressed only concern and sympathy for HIV-positive concern throughout the course of the study, increasing comments as to the "impossibility" of "natural" mother-to-child transmission appeared over time, and individuals frequently made specific reference to widely-publicized successes in PMTCT. Concerns about the transmission source seemed particularly pronounced around children who had reached school age, suggesting that stigmatizing comments may have been a means of grappling with the growing number of HIV-positive children attending school (something that happened only rarely in this village before the rollout of free ART began in 2001, when HIV-positive children began to live longer).

While this research does not purport to offer a quantitative argument measuring an increase in stigmatizing discourses over time, it does point to the emergence of stigmatizing discourses that specifically respond to more recently publicized successes of ART and PMTCT. Although concerns about rape and witchcraft certainly existed before nationwide rollout of PMTCT, one of the key findings in this study is the proliferation of stigma that drew specifically on successes in PMTCT to support concerns about more discomfiting forms of transmission.

As this research reflects, traditionally in Botswana, terminally ill or disabled children have been seen as victims of their parents' breach of sexual morality or of adult's practices of witchcraft and sorcery (see also Livingston 2005). Illness such as HIV is described as being "sent" through the witchcraft of jealous neighbors or relatives or as transmitted during improper sexual conduct. The illness makes the parents' blood "hot" and contaminated and is passed onto the child. The biomedical explanation for HIV transmission through bodily fluids exasperates these rumors as it uses similar and compatible terminology.

Policy Implications:

Policy implications of this research are multiple. The paper indicates that publicity and awareness campaigns surrounding the importance and success of PMTCT may be partially

responsible for promoting incorrect assumptions and revisionist histories about how transmission takes place. The author recommends greater public discussion and openness about fears of witchcraft (which the government has formally discouraged among the population), as a means of addressing concerns about supernatural transmission. Further, anecdotal evidence of child rape mentioned in the news media has fueled preexisting social concerns about moral depravity in the population during the HIV epidemic (see Dahl 2009). This research suggests that awareness campaigns would do well to temper their promotion of successes in PMTCT, and that public health and pediatric AIDS treatment providers would do well to recognize the concerns felt by many villagers as a necessary target for counseling.

References:

Abadia-Barrero, C., & Castro, A. (2005). Experiences of Stigma and Access to HAART in Children and Adolescents Living with HIV/AIDS in Brazil. *Social Science & Medicine*, 62, 1219-1228.

Battles, H., Wiener, L.S. (2002). From adolescence through young adulthood: psychosocial adjustment associated with long-term survival of HIV. *Journal of Adolescent Health*, 30, 161–68.

Bond, V., Chase, E., & Aggleton, P. 2002. Stigma, HIV/AIDS and Prevention of Mother-to-Child Transmission in Zambia. *Evaluation and Program Planning*, 25(4), 347-356.

Brown, L., Macintyre, K., & Trujillo, L. 2003. Interventions to Reduce HIV/AIDS Stigma: What Have We Learned? *AIDS Education and Prevention,* 15(1), 49-69.

Campbell, C., Skovdal, M., Mupambireyi, Z., & Gregson, S. (2010). Children's Stigmatisation of AIDS-Affected Children in Zimbabwe through Drawings and Stories. *Social Science & Medicine*, 71, 975-985.

Cao, X., Sullivan, S., Wi, Z., & the Chilna CIPRA Project 2 Team. (2006). Understanding HIV-related Stigma and Discrimination in a "Blameless" Population. *AIDS Education and Prevention*, 18(6), 518-528.

Dahl, B. (2009). The "Failures of Culture": Christianity, Kinship, and Moral Discourses about Orphans during Botswana AIDS Crisis. *Africa Today*, 56(1), 23-43.

Domek, G. (2006). Social Consequences of Antiretroviral Therapy: Preparing for the Unexpected Futures of HIV-Positive Children. *Lancet*, 367, 1367-69.

Farmer, P., Leandre, F., Mukherjee, J., Claude, M., Nevil, P., Smith-Fawzi, M., et al. (2001). Community-Based Approaches to HIV Treatment in Resource-Poor Settings. *Lancet*, 348, 404-409.

Goffman, Erving. (1963). *Stigma: Notes on the Management of Spoiled Identity.* New York: Simon & Schuster.

Holzemer, W.L., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Diamini, P.S., et al. (2007). A Conceptual Model of HIV/AIDS Stigma from Five African Countries. *Journal of Advanced Nursing*, 58(6), 541-551.

Ledlie, S.W. (2001). The psychosocial issues of children with perinatally acquired HIV disease becoming adolescents: a growing challenge for providers. *AIDS Patient Care* STDS, 15, 231–36.

Livingston J, (2005.) *Debility and the moral imagination in Botswana: disability, chronic illness, and aging*. Bloomington (Indiana): Indiana University Press.

Maman, S., Abler, L., Parker, L., Lane, T., Chirowodza, A., Ntogwisangu, J., et al. (2009). A Comparison of HIV Stigma and Discrimination in Five International Sites: The Influence of Care and Treatment Resources in High Prevalence Settings. *Social Science & Medicine*, 12, 2271-78.

Maughan-Brown, B. (2010). Stigma Rises Despite Antiretroviral Roll-Out: A Longitudinal Analysis in South Africa. *Social Science & Medicine*, 70, 368-374.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action. *Social Science & Medicine*, 57, 13-24.

Root, R. (2010). Situating Experiences of HIV-Related Stigma in Swaziland. *Global Public Health*, 5(5), 523-538.

Stein, J. (2003). HIV/AIDS Stigma: The Latest Dirty Secret. Centre for Social Science Research, Aids and Society Research Unit, University of Cape Town, Working Paper No. 46.

Weiser SD, Heisler M, Leiter K, et al. 2006. Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. *PLoS Med*. 3:261.

UNAIDS. 2008. 2008 Report on the global AIDS epidemic. Geneva: UNAIDS.

UNAIDS. (2010). Progress Report of the National Response to the 2001 Declaration of Commitment on HIV and AIDS: Botswana Country Report. Accessed online on Sept. 01, 2010, at: http://data.unaids.org/pub/Report/2010/botswana_2010_country_progress_report_en.pdf