



Published in final edited form as:

AIDS. 2015 June ; 29(0 1): S1–S5. doi:10.1097/QAD.0000000000000730.

HIV disclosure to children in low-and middle-income countries: towards effective interventions

Xiaoming Li^a, John de Wit^b, Shan Qiao^a, and Lorraine Sherr^c

^aPediatric Prevention Research Center, Wayne State University School of Medicine, Detroit, Michigan, USA

^bCenter for Social, Research in Health, University of New South Wales, Sydney, New South Wales, Australia

^cResearch Department of Infection, Population Health, University College London, London, UK

Disclosure is a complex behaviour with widespread social ramifications [1]. Disclosure of HIV status is irreversible and has been studied in terms of the onset of complex stigma on the one hand and the gateway to social support on the other hand [2–4]. Disclosure has been linked with other behaviours over the course of HIV infection, ranging from risk behaviour to treatment adherence [5,6]. Much of the literature is focused on adult self-disclosure, yet there is an allied enquiry into understanding paediatric disclosure whereby a child is informed of their own HIV status [7], or the HIV status of their parent or close family member [8–10].

Although the world has recently witnessed a change in the trajectory of the global HIV epidemic (e.g. a nearly 50% reduction in new HIV infections globally in 2013 compared with that in 2005), millions of new HIV infections still occur every year [11]. Low-and middle-income countries (LMIC) continue to bear a disproportionate burden of the epidemic and will continue to do so in the foreseeable future [11]. Worldwide, 2.1 million adolescents (aged 10–19 years) were living with HIV in 2012 and 260 000 new HIV infections occurred among children in LMIC in 2012 [12]. HIV/AIDS not only affects the physical and psychological wellbeing of those who are infected but also impacts their community and family, including their children [13]. Over 18 million children under age 18 have lost one or both parents to HIV/AIDS and millions more are living with HIV-infected parents; most of these children live in LMIC, especially sub-Saharan Africa [12]. The timing and manner in which parents/caregivers disclose either their children's infection (paediatric HIV disclosure) or their own infection (parental HIV disclosure) to their children has an established impact on children's response to their own HIV infection or adjustment to their parent's infection [8,9,14]. Studies have shown that paediatric HIV disclosure is positively associated with adherence to antiretroviral treatment of HIV infection and safer sexual

Correspondence to Xiaoming Li, Pediatric Prevention Research Center, School of Medicine, Wayne State University, 4707 St Antoine St, W534, Detroit, MI 48201, USA. xiaoli@med.wayne.edu.

Conflicts of interest

None of the authors has a conflict of interest of any type.

behaviours in adolescents [7,15] and full, timely and supportive parental HIV disclosure can benefit the psychological wellbeing of children as well as family relationships [10,16,17].

Recognizing the importance of HIV disclosure, WHO developed guidelines in 2011 regarding HIV status disclosure for children up to 12 years of age [18]. These WHO guidelines recommended developmentally appropriate disclosure to children that requires fully considering children's cognitive development, emotional maturity and their ability to understand HIV. The guidelines were based on a series of systematic literature reviews [19–23] and key stakeholder and expert guidance. Reasons for delaying or denying disclosure such as possible psychological harm were explored and scant research evidence supported such concerns. On the contrary, timely, sensitive and well managed disclosure demonstrated a range of positive effects and hence the emerging global guidance. This was endorsed for both paediatric and parental disclosure [18]. For either paediatric or parental disclosure, parents/caregivers need to make decisions regarding when, what and how to disclose [24,25].

Parents/caregivers may be concerned about possible stigma and discrimination and may also experience internalized stigma and negative feelings, including shame, guilt and fear [26]. Many parents/caregivers feel challenged to disclose their own or the child's HIV status because they often are concerned about possible adverse consequences of the disclosure, uncertain about the disclosure process and not confident that they can handle children's reactions to HIV status disclosure [27]. Systematic review evidence suggests that disclosure rates are often low [7,28]. Many parents/caregivers choose to conceal their own or the child's HIV status from their children [7], but involuntary and unplanned disclosure is common and may be distressing [29]. Healthcare and other service providers can play an important role in assisting parents/caregivers in planning, preparing and carrying out the disclosure [30,31]. This may ensure that the benefits of such disclosure are maximized, while minimizing any adverse effects. Effective interventions are needed in LMIC to support parents/caregivers and healthcare providers to undertake culturally and developmentally appropriate HIV status disclosure (either paediatric or parental disclosure) to children.

This special issue comprises novel studies that address various issues related to the design, development and evaluation of HIV status disclosure interventions in LMIC. We hope that these studies, conducted in five different countries, will assist in moving the field forward towards more effective interventions for both paediatric and parental HIV status disclosure. As reported by Kennedy *et al.* [32], only few interventions to date have been robustly tested in LMIC that were intended to support either paediatric or parental HIV status disclosure. Of the 13 disclosure intervention studies they identified, only one was concerned with disclosure to children, focusing in particular on maternal HIV status disclosure to HIV-uninfected children [32]. Cluver *et al.* [33] extended the evidence base regarding the important benefits of HIV status disclosure, and their study in South Africa showed that early and full disclosure of HIV status for perinatally infected adolescents was strongly associated with improved treatment adherence.

Although paediatric and parental HIV status disclosure differ in many ways, qualitative and quantitative empirical studies reported in this special issue draw on similar conceptual approaches to examine factors that may shape disclosure decision-making, some of which may influence paediatric as well as parental HIV status disclosure. Qiao *et al.* [34] reported a quantitative study among people living with HIV in Guangxi, China. Guided by a socio-ecological model, findings from this study suggested that positive coping with HIV infection and a good parent–child relationship in particular facilitated parental disclosure [34]. The qualitative study presented by Vreeman and her interdisciplinary and multinational team [35] demonstrated that paediatric HIV status disclosure in Kenya was shaped by factors at multiple social levels, including influences from the caregiver-child dyad, family members, neighbours, friends, schools, churches and media. These findings underscore that HIV disclosure is an interactive process that occurs in complex social environments. Intervention programmes need to engage the multiple stakeholders and target the multiple factors in a dynamic system in order to assist children to navigate normative development processes and cope with additional challenges associated with living with HIV and/or living with HIV-infected parents/caregivers.

Several studies in this special issue report the design and evaluation of paediatric or parental HIV status disclosure interventions. Each of these innovative interventions is based on an understanding of the complex, dynamic influences on HIV status disclosure and illustrates the importance of identifying not only key intervention components but also culturally appropriate modalities for various settings. Three studies address the design and evaluation of paediatric HIV status disclosure interventions. Beck-Sague *et al.* [36] reported promising results of an ongoing quasi-experimental trial of a culturally adapted paediatric HIV disclosure intervention in Haiti, which included healthcare worker training, education for youth, capacity-strengthening for caregivers, a scheduled disclosure session and postdisclosure support for care-givers and youth. Equally reporting on an ongoing study, Reynolds *et al.* [37] presented the background, process and methods of a collaborative approach to develop and evaluate a paediatric HIV disclosure intervention in Ghana; challenges and implications are also reported. Brandt *et al.* [38] undertook a qualitative study to identify the key components of a child-friendly ‘disclosure book’ to assist caregivers and healthcare workers in Namibia with paediatric HIV status disclosure. This tool was easy to implement and helped overcome barriers to disclosure by reducing caregiver resistance, increasing HIV and disclosure knowledge, and providing a gradual, structured disclosure framework [38].

Two further studies in this special issue report parental HIV status disclosure interventions. Simoni *et al.* [39] undertook a preliminary evaluation of a nurse-delivered intervention in China for HIV-infected outpatients living with at least one child who was not aware of their parent’s HIV status. The intervention consisted of three 1-h long individual sessions that comprised family assessment, discussion of advantages and disadvantages of disclosure, education about children’s cognitive, social and emotional development stages, and disclosure planning and practicing. Effects at 4 and 13 months after the intervention are promising and suggest that appropriately powered trials are warranted [39]. Rochat *et al.* [40] reported preliminary results of an evaluation for a family-centred maternal HIV

disclosure intervention implemented in rural South Africa. The six-session intervention package included printed materials, narrative therapeutic tools as well as child-friendly activities and games and delivered in participants' homes by local lay counsellors and community healthcare workers over a 6 to 8-week period. HIV-infected mothers and their children received the intervention, but fathers and other family members were encouraged to join in. The sessions covered issues related to disclosure, family relationships, life stories of living with HIV, planning and preparing the disclosure event, taking children to clinic visits and custody planning. The pre/posttest suggested reduced psychological stress and parenting stress among mothers and improved parent-child relationship and reduced child emotional and behavioural problems [40].

Most of the interventions reported in this special issue, along with other studies, are funded by the HIV disclosure research programmes of the National Institutes of Health (NIH), described by Allison and Siberry [41]. Although interventions are in early phases of programme development and evaluation studies are mostly ongoing, the reported preliminary findings suggest promising directions and provide some valuable lessons. Future HIV disclosure intervention development would benefit from some general principles, endorsed by researchers and funders, applicable to paediatric disclosure and parental disclosure, and validated with empirical data [41].

Researchers suggest that disclosure interventions need to be guided by theory or conceptual models that are appropriate to the target population and local culture. Consistent with the multilevel factors that influence HIV disclosure, researchers have developed or adapted a variety of theories and models for HIV disclosure research [8], and some of these, individually or in combination, have been applied in the studies reported in this special issue. Theories that are applicable to HIV disclosure include those focusing on decision-making (e.g. Consequence Theory; [42]), the disclosure process (e.g. Disclosure Process Model; [43]), the role of healthcare workers or other parties (e.g. Disclosure Stage Model; [31]) or the role of children's development stages in understanding HIV (e.g. Piaget's Stage of Cognitive Development; [44]). Future research needs to continue examining the relevance and applicability of relevant theories in both guiding the behavioural assessment and designing behavioural intervention and to improve our understanding of the disclosure decision-making and process. Nevertheless, a guiding theory should not be utilized without first determining its relevance to a particular population or cultural context, as the theory provides foundation on which particular cultural elements and environmental factors can be examined in a specific sociocultural context and appropriately integrated into the theoretical framework [45].

The literature suggests that HIV status disclosure needs to be considered as a process, not a discrete event. Although this is widely accepted amongst disclosure researchers, the implications of a process notion for intervention development and evaluation needs to be further explored. In particular, effective interventions may need to address issues along a continuum of HIV status disclosure, from predisclosure to postdisclosure, as there may be different influential factors at different points along the disclosure continuum. HIV status disclosure per se may not be the most appropriate behavioural outcome for evaluating the efficacy of an intervention programme [41]. There can be situations when disclosure is not

appropriate and more work is needed in postdisclosure if parents/caregivers do decide to disclose. All intervention programmes should include a protocol for assessing disclosure readiness and should ensure that parents/caregivers or healthcare workers do not feel pressured to disclose [41].

Intervention programmes need to apply a multilevel and multimode approach to engage multiple actors in the social ecosystem of children's life and address multiple issues related to child development and adjustment. It is unrealistic or unfair to delegate the responsibilities to only parents/caregivers or only healthcare workers. Because of the limited financial or human resources in LMIC, it may be easier for a given intervention programme to target one or two of the actors (such as parents/caregivers and healthcare providers), but an ultimate goal will be to mobilize and empower a broader community including schools, neighbours and media, so these children's diverse physical and developmental needs can be appropriately and timely addressed. Interventions may also need to target a variety of stakeholders, as factors influencing disclosure go well beyond the parent-child dyad.

Finally, it is clear that we need to be methodologically savvy in designing, implementing and evaluating intervention programmes, to ensure evidence-based practice with recourse to experimental or quasi-experimental designs. Clearly good quality, longitudinal studies with sufficient sample size and appropriate comparison groups will allow us to draw valid conclusions on the true effect of interventions. The identification of potential mediators and moderators at individual, family, community or culture levels will help us to better understand the underlying mechanism of the intervention effect. In addition, future intervention programmes need to incorporate clinical outcomes of the parents and/or children as well as biomarkers of physiological response to stress and antiretroviral treatment adherence so that we can assess the intervention effects beyond the selfreported psychological and behavioural outcomes.

This special issue has described a few innovative studies, but undoubtedly there are others. The studies reported here are not comprehensive and conclusions need to be considered in the light of various conceptual and methodological limitations described within the articles. This special issue will hopefully serve as a call for more theory-guided and methodologically sound studies to build a more comprehensive evidence base. We hope that with the innovative and diligent work of many researchers, healthcare workers, community leaders, funding agencies, parents/caregivers and children, the global community will succeed in comprehensively implementing the WHO recommendations and improve both policies and clinical practices to assist parents/caregivers and children in navigating the complexities of HIV disclosure.

Acknowledgments

The study was in part supported by the National Institute of Child and Human Development Grant #R01HD074221. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Child and Human Development.

References

1. Chelune, GJ. Measuring openness in interpersonal communication In: Chelune GJ Origins, patterns and implications of openness in interpersonal relationships. San Francisco, CA: Jossey-Bass; 1979. p. 1-27.
2. Wohl AR, Galvan FH, Myers HF, Garland W, George S, Witt M, et al. Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? *AIDS Behav.* 2011; 15:1098–1110. [PubMed: 20963630]
3. Lyimo RA, Stutterheim SE, Hospers HJ, deGlee T, van der Ven A, de Bruin M. Stigma, disclosure, coping, and medication adherence among people living with HIV/AIDS in Northern Tanzania. *AIDS Patient Care STDS.* 2014; 28:98–105. [PubMed: 24517541]
4. Stutterheim SE, Bos AE, Pryor JB, Brands R, Liebrechts M, Schaalma HP. Psychological and social correlates of HIV status disclosure: the significance of stigma visibility. *AIDS Educ Prev.* 2011; 23:382–392. [PubMed: 21861610]
5. Eustace RW, Ilagan PR. HIV disclosure among HIV positive individuals: a concept analysis. *J Adv Nurs.* 2010; 66:2094–2103. [PubMed: 20626492]
6. Shacham E, Small E, Onen N, Stamm K, Overton ET. Serostatus disclosure among adults with HIV in the era of HIV therapy. *AIDS Patient Care STDS.* 2012; 26:29–35. [PubMed: 22107039]
7. Vreeman RC, Gramelspacher AM, Gisore PO, Scanlon ML, Nyandiko WM. Disclosure of HIV status to children in resource-limited settings: a systematic review. *J Int AIDS Soc.* 2013; 16:18466. [PubMed: 23714198]
8. Qiao S, Li X, Stanton B. Theoretical models of parental HIV disclosure: a critical review. *AIDS Care.* 2013; 25:326–336. [PubMed: 22866903]
9. Krauss BJ, Letteney S, De Baets AJ, Baggaley R, Okero FA. Caregiver's HIV disclosure to children 12 years and under: a review and analysis of the evidence. *AIDS Care.* 2013; 25:415–429. [PubMed: 22880755]
10. Tenzek KE, Herrman AR, May AR, Feinerd B, Allenb M. Examining the impact of parental disclosure of HIV on children: a meta-analysis. *Western J Commun.* 2013; 77:323–339.
11. UNAIDS. The gap report. Geneva: UNAIDS; 2014.
12. UNICEF Towards an AIDS-free generation – children and AIDS: sixth stocktaking report. New York: UNICEF; 2013.
13. UNICEF. Protection, care, and support for an AIDS-free generation: a call to action for all children. New York: UNICEF; 2014.
14. Letteney S, Krauss B, Kaplan R. Examining HIV-positive parents' disclosure to their children: a biopsychosocial approach. *Soc Work Public Health.* 2012; 27:345–360. [PubMed: 22657148]
15. Santamaria EK, Dolezal C, Marhefka SL, Hoffman S, Ahmed Y, Elkington K, et al. Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care STDS.* 2011; 25:257–264. [PubMed: 21323530]
16. Palin FL, Armistead L, Clayton A, Ketchen B, Lindner G, Kokot Louw P, et al. Disclosure of maternal HIV-infection in South Africa: description and relationship to child functioning. *AIDS Behav.* 2009; 13:1241–1252. [PubMed: 18770026]
17. Murphy DA, Armistead L, Marelich WD, Payne DL, Herbeck DM. Pilot trial of a disclosure intervention for HIV+ mothers: the TRACK program. *J Consult Clin Psychol.* 2011; 79:203–214. [PubMed: 21355637]
18. WHO. Guideline on HIV disclosure counselling for children up to 12 years of age. Geneva: WHO; 2011.
19. Mellins CA, Brackis-Cott E, Dolezal C, Leu CS, Valentin C, Meyer-Bahlburg HF. Mental health of early adolescents from high-risk neighborhoods: the role of maternal HIV and other contextual, self-regulation, and family factors. *J Pediatr Psychol.* 2008; 33:1065–1075. [PubMed: 18250092]
20. Wiener L, Mellins CA, Marhefka S, Battles HB. Disclosure of an HIV diagnosis to children: history, current research, and future directions. *J Develop Behav Pediatr.* 2007; 28:155–166.
21. Letteney S, LaPorte HH. Deconstructing stigma: perceptions of HIV-seropositive mothers and their disclosure to children. *Soc Work Healthcare.* 2004; 38:105–123.

22. Armistead L, Tannenbaum L, Forehand R, Morse E, Morse P. Disclosing HIV status: are mothers telling their children? *J Pediatr Psychol*. 2001; 26:11–20. [PubMed: 11145728]
23. Murphy DA, Marelich WD, Amaro H. Maternal HIV/AIDS and adolescent depression: A covariance structure analysis of the ‘Parents and Adolescents Coping Together’ (PACT) model. *Vulnerable Child Youth Stud*. 2009; 4:67–82. [PubMed: 20209025]
24. Kiwanuka J, Mulogo E, Haberer JE. Caregiver perceptions and motivation for disclosing or concealing the diagnosis of HIV infection to children receiving HIV care in Mbarara, Uganda: a qualitative study. *PLoS One*. 2014; 9:e93276. [PubMed: 24667407]
25. Gachanja G, Burkholder GJ, Ferraro A. HIV-positive parents, HIV-positive children, and HIV-negative children’s perspectives on disclosure of a parent’s and child’s illness in Kenya. *Peer J*. 2014; 2:e486. [PubMed: 25071999]
26. Kennedy DP, Cowgill BO, Bogart LM, Corona R, Ryan GW, Murphy DA, et al. Parents’ disclosure of their HIV infection to their children in the context of the family. *AIDS Behav*. 2010; 14:1095–1105. [PubMed: 20509046]
27. Edwards LL, Donovan-Kicken E, Reis JS. Communicating in complex situations: a normative approach to HIV-related talk among parents who are HIV+ *Health Commun*. 2014; 29:364–374. [PubMed: 23799804]
28. Krauss BJ, Letteney S, De Baets AJ, Baggaley R, Amolo Okero F. Disclosure of HIV status to HIV-positive children 12 and under: a systematic cross-national review of implications for health and well being. *Vulner Child Youth Stud*. 2013; 8:99–119.
29. Walsh ME, Bibace R. Children’s conceptions of AIDS: a developmental analysis. *J Pediatr Psychol*. 1991; 16:273–285. [PubMed: 1890554]
30. Hardon A, Desclaux A, Lugalla J. Disclosure in times of ART: a relational analysis of social practices. *SAHARA J*. 2013; 10(Suppl 1):S1–S4. [PubMed: 23844798]
31. Gerson AC, Joyner M, Fosarelli P, Butz A, Wissow L, Lee S, et al. Disclosure of HIV diagnosis to children: when, where, why, and how. *J Pediatr Healthcare*. 2001; 15:161–167.
32. Kennedy CE, Fonner VA, Armstrong KA, O’Reilly KR, Sweat MD. Increasing HIV serostatus disclosure in low- and middle-income countries: a systematic review of intervention evaluations. *AIDS*. 2015; 29(Suppl 1):S7–S24. [PubMed: 26049541]
33. Cluver LD, Hodes RJ, Toska E, Kidia KK, Orkin FM, Sherr L, Meinck F. ‘HIV is like a *tsotsi* ARVs are your guns’: associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *AIDS*. 2015; 29(Suppl 1):S57–S65. [PubMed: 26049539]
34. Qiao S, Li X, Zhou Y, Shen Z, Tang Z, Stanton B. Factors influencing the decision-making of parental HIV disclosure: a socio-ecological approach. *AIDS*. 2015; 29(Suppl 1):S25–S34. [PubMed: 26049536]
35. Vreeman RC, Scanlon ML, Inui TS, McAteer CI, Fischer LJ, McHenry MS, et al. ‘Why did you not tell me?’: perspectives of caregivers and children on the social environment surrounding child HIV disclosure in Kenya. *AIDS*. 2015; 29(Suppl 1):S47–S55. [PubMed: 26049538]
36. Beck-Sagué CM, Dévieux J, Pinzón-Iregui MC, Lerebours-Nadal L, Abreu-Pérez R, Bertrand R, et al. Disclosure of their HIV status to perinatally infected youth using the adapted Blasini disclosure model in Haiti and the Dominican Republic: preliminary results. *AIDS*. 2015; 29(Suppl 1):S91–S98. [PubMed: 26049543]
37. Reynolds NR, Ofori-Atta A, Lartey M, Renner L, Antwi S, Enimil A, et al. SANKOFA: a multisite collaboration on paediatric HIV disclosure in Ghana. *AIDS*. 2015; 29(Suppl 1):S35–S45. [PubMed: 26049537]
38. Brandt L, Beima-Sofie K, Hamunime N, Shepard M, Ferris L, Ingo P, et al. Growing-up just like everyone else: key components of a successful pediatric HIV disclosure intervention in Namibia. *AIDS*. 2015; 29(Suppl 1):S81–S89. [PubMed: 26049542]
39. Simoni JM, Yang JP, Shiu C-S, Chen W-t, Udell W, Bao M, et al. Nurse-delivered counselling intervention for parental HIV disclosure: Results from a pilot randomized controlled trial in China. *AIDS*. 2015; 29(Suppl 1):S99–S107. [PubMed: 26049544]

40. RoCHAT TJ, ArTeche AX, SteIn A, MitcheLL J, BlaND RM. Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: the Amagugu intervention. *AIDS*. 2015; 29(Suppl 1):S67–S79. [PubMed: 26049540]
41. Allison SM, Siberry GK. National Institutes of Health investment in studies of HIV disclosure to children. *AIDS*. 2015; 29(Suppl 1):S109–S118. [PubMed: 26049535]
42. Derlega VJ, Winstead BA, Greene K, Serovich JM, Elwood WN. Reasons for HIV disclosure/nondisclosure in close relationships: testing a model of HIV-disclosure decision making. *J Soc Clin Psychol*. 2004; 23:747–767.
43. Chaudoir SR, Fisher JD, Simoni JM. Understanding HIV disclosure: a review and application of the disclosure processes model. *Soc Sci Med*. 2011; 72:1618–1629. [PubMed: 21514708]
44. Piaget, J. *The child's conception of physical causality*. London: Routledge and Kegan Paul; 1951.
45. Wingwood, GM.; DiClemente, RJ. The use of psychosocial models for guiding the design and implementation of HIV prevention interventions: translating theory into practice. In: Gibney, L.; DiClemente, RJ.; Vermund, SH., editors. *Preventing HIV in developing countries: biomedical and behavioral approaches*. New York: Plenum Publishers; 1999.