

WHO, then what? The need for interventions to help young people with perinatally acquired HIV disclose their HIV status to others

Short title: onward HIV disclosure interventions

Michael EVANGELI¹ and Caroline FOSTER²

Word count: 1499

1 Department of Psychology, Royal Holloway University of London, TW20 0EX, UK.

2 Imperial College Healthcare NHS Trust, St. Mary's Hospital, London, W2 1NY, UK

Corresponding Author: Dr. Michael Evangelini. Department of Psychology, Royal Holloway University of London, Egham Hill, Egham, Surrey, TW20 0EX, UK. Tel: 00441784443851. Fax: 00441784472746. Email: michael.evangelini@rhul.ac.uk

Conflict of Interests and Sources of Funding: The authors declare no conflicts of interest or sources of funding for this work.

Key words: HIV, disclosure, perinatally acquired HIV, adolescence, youth, young people, onward disclosure, self-disclosure

There are 3.4 million HIV positive children globally, with 2 million aged between 10 and 19 years of age [1]. The majority have perinatally acquired HIV (PAH). One of the key challenges for any HIV positive person is disclosing the condition to others (for example, to a partner, family member or friend). This on-going process has been variously termed *self-disclosure* [2] or *onward disclosure*.

There has been considerable interest in *paediatric HIV disclosure*. This is the process leading to full disclosure (when the condition is named for the HIV positive child, usually by a caregiver or healthcare worker). World Health Organization (WHO) guidelines state that children should be aware of the name of their condition by the age of 12, with younger children told their status incrementally to accommodate their cognitive skills and emotional maturity in preparation for full disclosure [3]. There is evidence, however, of variation in the age of full disclosure with this taking place later in resource limited contexts than in other parts of the world [4]. Being aware of one's status (*full disclosure*) is a pre-requisite for *onward disclosure* and there is evidence of more onward disclosure if children are aware of their status earlier [5]. *How* one was disclosed to, for example, if there was an opportunity to ask questions about HIV and to feel listened to, may also impact on onward disclosure decision-making.

Rates of onward disclosure and barriers to disclosure

Rates of onward HIV disclosure in young people with PAH are low. Lee and Oberdorfer [6] reported that only 48% of their sample of perinatally infected adolescents (median age 14.6 years) in Thailand had disclosed their status to anyone. Tassiopoulos et al [7] reported

that only a third of their US sample of sexually active youth (aged ≤ 18) with PAH had disclosed their HIV status to their first sexual partner. A similar rate of HIV disclosure to sexual partners was reported by Birungi et al [8] in their Ugandan sample of 15 to 19 year-olds. Lower rates of HIV disclosure to the friends of young people with PAH than to the friends of those with behaviourally infected HIV, have been reported. Abramowitz et al [9] studied 13 to 21 year olds in the US, with either perinatally acquired or behaviourally infected HIV. They reported that a mean of 1.7 friends knew the serostatus of youth with PAH, whereas a mean of 4.5 friends knew the serostatus of behaviourally infected youth.

Qualitative studies have revealed the subjective difficulty of disclosing one's HIV positive status to others in young people with PAH, particularly to partners [5, 10-12]. Themes from in-depth interviews include a fear of negative responses from others, a lack of disclosure self-efficacy, a fear that the recipient of disclosure will tell others, and the importance of parental attitudes towards onward disclosure [11, 13].

Characteristics of young people with PAH

Some of the characteristics of having PAH may affect onward disclosure. The onset of sexual relationships in the knowledge of having a stigmatised sexually transmittable condition may be challenging. In this context both sexual communication and sexual behavioural skills need to be developed concurrently with consideration of partner disclosure issues.

Young people with PAH often have long histories of medication use with suboptimal regimens and treatment failure [14]. This, alongside other stressors associated with living with a chronic condition (e.g., hospitalisations, missed school and social opportunities, and exposure to pain[15]) may affect adjustment to HIV and consequently reduce readiness to disclose.

One of the central features of living with PAH is growing up in a family affected by HIV. Many HIV positive youth live with single carers and have experienced multiple caretaking transitions due to parental illness or death [15]. Onward disclosure may be associated with young peoples' concerns about revealing their mother's HIV positive status [11]. Negative parental attitudes to disclosure, including directives to not disclose [16], may be internalised [11, 17]. Greater dependence on adult caregivers, overprotective parenting, and the effect of parental HIV on parenting competence [9, 15, 18], may all affect preparedness to disclose.

Some young people with PAH have subcortical white matter and frontostriatal abnormalities that affects emotion and behaviour regulation [19]. They may be more likely to have cognitive functioning difficulties than controls, particularly executive functioning problems (e.g., limitations in working memory, processing speed and cognitive flexibility) and compromised verbal abilities [20]. These difficulties may affect HIV disclosure problem-solving and planning. Finally, some young people with PAH have metabolic complications including lipodystrophy [14], that may lead to concerns about unintentional HIV disclosure [21].

Onward disclosure consequences

There are many potentially positive consequences of onward HIV disclosure in young people with PAH.

Onward disclosure may facilitate greater condom negotiation and use, reduced levels of unprotected sexual intercourse and secondary HIV transmission. There is evidence of a relationship between higher levels of onward disclosure and condom use in some populations of young HIV positive people (e.g., in samples of young MSM [22]). Studies that have contained participants with PAH have failed to find an association between onward disclosure and unprotected sex [8, 23]. A relationship has, however, been reported between lower rates of onward disclosure and having multiple sexual partners in one study [23].

Onward disclosure may also facilitate improved antiretroviral (ART) adherence, perhaps through the availability of disclosure-specific support or the reduced need to hide medication from others. Less medication hiding and higher CD4 counts have been associated with higher onward disclosure rates in youth with PAH [24]. In addition, fear of disclosure is commonly cited as a barrier to ART adherence in this population [25].

Onward disclosure may enhance well-being, potentially through helpful cognitive appraisal of HIV-related stressors [18]. The relationship between onward disclosure and well-being has been seen in other HIV positive populations [26, 27]. Higher rates of onward disclosure have been associated with higher self-esteem in some studies of youth with PAH [5] but not

in others that have included perinatally infected youth [18]. Onward disclosure may also increase social support in those with PAH [28] and a relationship between higher rates of onward disclosure and greater social support has been found in other HIV populations [29]. Associations between social support and better mental health have been shown in youth with PAH [15, 30]. There is also some evidence that higher rates of and increases in onward disclosure are related to improvements in immune functioning in young people with HIV [18, 24].

Disclosure interventions in other populations

Given the relevance of HIV disclosure to sexual risk behaviour, ART adherence and well-being, recent psychosocial HIV disclosure interventions aiming to increase HIV disclosure rates have been developed. These have focused on HIV positive mothers disclosing their HIV positive status to their children [31-33], HIV positive women disclosing to others [34] and MSM disclosing to their family [35] or to sexual partners [36]. Promising outcomes have been shown with increased disclosure rates and well-being in some studies [31, 35].

There are no onward disclosure interventions for young people with PAH, or young people with HIV more generally [2]. This contrasts with the effort made to ensure that paediatric disclosure is handled well [3]. HIV positive populations, including young people with HIV, have stressed the need for assistance in developing the skills to disclose their HIV positive status to others effectively [2, 32, 37]. Health workers have also expressed a desire for more guidance and support regarding HIV disclosure [38].

The need for HIV disclosure interventions for young people with PAH

We argue that there is a crucial need for culturally sensitive, tailored, implementable, onward HIV disclosure interventions for young people with PAH, particularly as the average age of this globally large population increases. The absence of current guidance on *how* to facilitate disclosure to friends, family or sexual partners leaves young people, their families and health care workers, without disclosure-specific support.

Adolescence is a stage where mutually disclosing friendships and intimate relationships in the context of increased autonomy are important [18]. This presents interpersonal challenges around HIV disclosure with diagnosis concealment becoming increasingly difficult as time and intimacy increases [39]. Developing a disclosure intervention specifically for adolescents and young people with PAH may enhance functional disclosure decision-making, provide a framework for thinking about disclosure, and increase perceived comfort, self-confidence, competence and satisfaction with disclosure decision-making. Intervening with young people before disclosure difficulties have become entrenched may enable a pattern of functional disclosure behaviour to develop.

We argue that professionals have a particular responsibility to facilitate young people's onward HIV disclosure to *sexual* partners, particularly given the legal context in many countries [38]. Providing opportunities for young people to start their sexual relationship history better prepared for HIV disclosure is of real importance. Despite the specific features of perinatally acquired HIV, many characteristics are shared with other populations. If disclosure interventions for young people with PAH are shown to be

effective, there may be the potential for modified interventions to be developed for disclosure of other chronic transmittable health conditions associated with stigma (for example, Hepatitis B and C).

Acknowledgements

The authors would like to thank the following, who contributed to discussions on the issues presented in this article: Mary-Jane Rotheram Borus, Sung-Jae Lee, Debra Murphy, Bill Miller, Theresa Moyers, Julianne Serovich, Judy Kimberly, Sandra Reed, and Stephanie Marhefka. We would also like to thank Amber Wilson for collecting relevant articles.

References

1. WHO U, UNICEF. Global HIV/AIDS response: epidemic update and health sector progress towards universal access, 2011 progress report. In. Geneva: World Health Organization; 2011.
2. Thoth CA, Tucker C, Leahy M, Stewart SM. Self-disclosure of serostatus by youth who are HIV-positive: a review. *J Behav Med* 2013.
3. WHO. Guideline on HIV disclosure counselling for children up to 12 years of age. In; 2011.
4. Pinzon-Iregui MC, Beck-Sague CM, Malow RM. Disclosure of their HIV status to infected children: a review of the literature. *J Trop Pediatr* 2013,**59**:84-89.
5. Wiener LS, Battles HB. Untangling the web: a close look at diagnosis disclosure among HIV-infected adolescents. *J Adolesc Health* 2006,**38**:307-309.
6. Lee B, Oberdorfer P. Risk-taking behaviors among vertically HIV-infected adolescents in northern Thailand. *J Int Assoc Physicians AIDS Care (Chic)* 2009,**8**:221-228.
7. Tassiopoulos K, Moscicki AB, Mellins C, Kacanek D, Malee K, Allison S, *et al*. Sexual risk behavior among youth with perinatal HIV infection in the United States: predictors and implications for intervention development. *Clin Infect Dis* 2013,**56**:283-290.
8. Birungi H, Obare F, Mugisha JF, Evelia H, Nyombi J. Preventive service needs of young people perinatally infected with HIV in Uganda. *AIDS Care* 2009,**21**:725-731.
9. Abramowitz S, Koenig LJ, Chandwani S, Orban L, Stein R, Lagrange R, *et al*. Characterizing social support: global and specific social support experiences of HIV-infected youth. *AIDS Patient Care STDS* 2009,**23**:323-330.
10. Greenhalgh C, Evangelini M, Frize G, Foster C, Fidler S. Intimate relationships in young adults with perinatally acquired HIV: partner considerations. *AIDS Care* 2013,**25**:447-450.
11. Hogwood J, Campbell T, Butler S. I wish I could tell you but I can't: adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. *Clin Child Psychol Psychiatry* 2013,**18**:44-60.
12. Fernet M, Wong K, Richard ME, Otis J, Levy JJ, Lapointe N, *et al*. Romantic relationships and sexual activities of the first generation of youth living with HIV since birth. *AIDS Care* 2011,**23**:393-400.
13. Marhefka SL, Valentin CR, Pinto RM, Demetriou N, Wiznia A, Mellins CA. "I feel like I'm carrying a weapon." Information and motivations related to sexual risk among girls with perinatally acquired HIV. *AIDS Care* 2011,**23**:1321-1328.
14. Sohn AH, Hazra R. The changing epidemiology of the global paediatric HIV epidemic: keeping track of perinatally HIV-infected adolescents. *J Int AIDS Soc* 2013,**16**:18555.

15. Mellins CA, Malee KM. Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. *J Int AIDS Soc* 2013,**16**:18593.
16. Murphy DA, Roberts, K., & Hoffman, D. . Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus. *Journal of Child and Family Studies* 2002,**11**:191-202.
17. Michaud PA, Suris JC, Thomas LR, Kahlert C, Rudin C, Cheseaux JJ. To say or not to say: a qualitative study on the disclosure of their condition by human immunodeficiency virus-positive adolescents. *J Adolesc Health* 2009,**44**:356-362.
18. Sherman BF, Bonanno GA, Wiener LS, Battles HB. When children tell their friends they have AIDS: possible consequences for psychological well-being and disease progression. *Psychosom Med* 2000,**62**:238-247.
19. Sharer LR. Neuropathological aspects of HIV-1 infection in children. In: *The neurolog of AIDS*. Edited by Gendelman HE, Grant, I., Everall, I.P., Lipton, S.A., Swindells, S. Oxford: Oxford University Press; 2005. pp. 875-906.
20. Laughton B, Cornell M, Boivin M, Van Rie A. Neurodevelopment in perinatally HIV-infected children: a concern for adolescence. *J Int AIDS Soc* 2013,**16**:18603.
21. Reynolds NR, Neidig JL, Wu AW, Gifford AL, Holmes WC. Balancing disfigurement and fear of disease progression: Patient perceptions of HIV body fat redistribution. *AIDS Care* 2006,**18**:663-673.
22. Hightow-Weidman LB, Phillips G, 2nd, Outlaw AY, Wohl AR, Fields S, Hildalgo J, *et al*. Patterns of HIV disclosure and condom use among HIV-infected young racial/ethnic minority men who have sex with men. *AIDS Behav* 2013,**17**:360-368.
23. Dempsey AG, MacDonell KE, Naar-King S, Lau CY, Adolescent Medicine Trials Network for HIVAI. Patterns of disclosure among youth who are HIV-positive: a multisite study. *J Adolesc Health* 2012,**50**:315-317.
24. Calabrese SK, Martin S, Wolters PL, Toledo-Tamula MA, Brennan TL, Wood LV. Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS Care* 2012,**24**:1092-1096.
25. Buchanan AL, Montepiedra G, Sirois PA, Kammerer B, Garvie PA, Storm DS, *et al*. Barriers to medication adherence in HIV-infected children and youth based on self- and caregiver report. *Pediatrics* 2012,**129**:e1244-1251.
26. Vyavaharkar M, Moneyham L, Corwin S, Tavakoli A, Saunders R, Annang L. HIV-disclosure, social support, and depression among HIV-infected African American women living in the rural southeastern United States. *AIDS Educ Prev* 2011,**23**:78-90.
27. Quinn DM, Chaudoir SR. Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *J Pers Soc Psychol* 2009,**97**:634-651.
28. Fair C, Albright J. "Don't tell him you have HIV unless he's 'the one'": romantic relationships among adolescents and young adults with perinatal HIV infection. *AIDS Patient Care STDS* 2012,**26**:746-754.
29. Smith R, Rossetto K, Peterson BL. A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care* 2008,**20**:1266-1275.

30. Lee SJ, Detels R, Rotheram-Borus MJ, Duan N. The effect of social support on mental and behavioral outcomes among adolescents with parents with HIV/AIDS. *Am J Public Health* 2007,**97**:1820-1826.
31. 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.
32. Rochat TJ, Mkwanzazi N, Bland R. Maternal HIV disclosure to HIV-uninfected children in rural South Africa: a pilot study of a family-based intervention. *BMC Public Health* 2013,**13**:147.
33. Nicastro E, Continisio GI, Storace C, Bruzzese E, Mango C, Liguoro I, *et al.* Family group psychotherapy to support the disclosure of HIV status to children and adolescents. *AIDS Patient Care STDS* 2013,**27**:363-369.
34. Kaaya SF, Blander J, Antelman G, Cyprian F, Emmons KM, Matsumoto K, *et al.* Randomized controlled trial evaluating the effect of an interactive group counseling intervention for HIV-positive women on prenatal depression and disclosure of HIV status. *AIDS Care* 2013,**25**:854-862.
35. Serovich JM, Reed SJ, Grafsky EL, Hartwell EE, Andrist DW. An intervention to assist men who have sex with men disclose their serostatus to family members: results from a pilot study. *AIDS Behav* 2011,**15**:1647-1653.
36. Chiasson MA, Shaw FS, Humberstone M, Hirshfield S, Hartel D. Increased HIV disclosure three months after an online video intervention for men who have sex with men (MSM). *AIDS Care* 2009,**21**:1081-1089.
37. Murphy DA, Roberts, K., & Hoffman, D. Regrets and advice from mothers who have disclosed their HIV+ status to their young children. *Journal of Child and Family Studies* 2003,**12**:307-318.
38. Bott S, Obermeyer CM. The social and gender context of HIV disclosure in sub-Saharan Africa: a review of policies and practices. *SAHARA J* 2013,**10 Suppl 1**:S5-16.
39. Kang E, Mellins CA, Ng WYK, Robinson LG, Abrams EJ. Standing between two worlds in Harlem: A developmental psychopathology perspective of perinatally acquired human immunodeficiency virus and adolescence. *Journal of Applied Developmental Psychology* 2008,**29**:227-237.