

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

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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).

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