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Growing up positive: adolescent HIV disclosure to sexual partners and others

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ABSTRACT

Over three million youth live with HIV worldwide. Very little is known about whether youth disclose their HIV status to family, friends or sexual partners, and what risks and benefits may accrue from doing so. This study characterizes HIV disclosure among 250 youth with perinatally-acquired HIV (PHIV; age 13–24 years) living in Soweto, South Africa. A third had self-disclosed their HIV status to at least one person; similarly, only a third of sexually-active PHIV had disclosed their HIV status to their most recent partner. It is not clear whether HIV disclosure alone leads to positive impact: we found perceived social support from the family was negatively associated with disclosure (aOR 0.81, 95% 0.70–0.94). PHIV who spoke to a provider about disclosure were more likely to share their HIV status with a sexual partner (aOR 2.48; 95% CI 1.28–4.81). However, those PHIV who disclosed their status were no more likely to use a condom. The World Health Organization recommends that health providers advise adolescent patients on safe disclosure, but we still lack evidence on the consequences for young people and effective tools to help them weigh benefits and risks.

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HIV; perinatal infection; South Africa; disclosure; youth

Introduction

In 2018, there were 3.5 million youth aged 15–24 years living with HIV worldwide (UNAIDS, 2019), an increasing proportion of whom acquired HIV perinatally (UNAIDS & UNICEF, 2015). When met with acceptance, studies have shown that HIV disclosure can increase social support (Madiba & Mokgatle, 2016; Smith et al., 2007) and improve adherence and immunologic outcomes (Calabrese et al., 2012). Currently, the World Health Organization (WHO) recommends HIV disclosure among adolescents for the purpose of increasing social support and associated treatment outcomes; it does not recommend such for the prevention of onward transmission (World Health Organization, 2013). Very little is known about whether young people share their HIV status with family, friends or sexual partners, and what risks and benefits may accrue from doing so.

Disclosure may be particularly challenging for young people who have grown up with HIV. Many are not told of their own HIV status until they are adolescents (Vreeman et al., 2013). For example, a study in South Africa found only 67% of adolescents age 10–19 with perinatally-acquired HIV (PHIV) knew their status (Cluver et al., 2015). As they navigate their first romantic relationships and sexual experiences, PHIV may be acutely aware of the potential stigma attached to their HIV status. Stigma (Greenhalgh et al., 2013; Siu et al., 2012), and the related fear of rejection from partners or friends (Fernet et al., 2011; Hogwood et al., 2013; Madiba & Mokgatle, 2016; Mburu et al., 2014; Michaud et al., 2009; Siu et al., 2012), create substantial barriers to disclosure. For PHIV, the process is further complicated by the fact that HIV was acquired from vertical transmission. Disclosing their status often means exposing their mother's, and potentially father's, HIV status. Thus, PHIV may be reluctant to disclose, and may even be actively discouraged by their parents (Madiba & Mokgatle, 2016; Michaud et al., 2009). Finally, researchers have noted that HIV infection from an early age can affect cognitive functioning, which in turn could impede disclosure (Evangeli & Foster, 2014). Regardless of the mechanism, perinatally-infected adolescents disclose to less than half as many friends than behaviorally-infected adolescents in the USA (Abramowitz et al., 2009).

We could find only two studies that captured HIV disclosure among PHIV in low or middle-income countries, both which indicate that onward disclosure is low. In Thailand, Lee and Oberdorfer (2009) found almost half (48%) of PHIV (aged 13+ years) had not told anyone; 22% had disclosed to a close friend and 28% to a teacher. In Uganda, Birungi, Obare et al. (2009) found 38% of PHIV (aged 15–19 years) in a relationship disclosed

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their HIV status to their partners. This level of disclosure to sexual partners is similar to what has been reported among PHIV in the US (Dempsey et al., 2012; Koenig et al., 2010; Tassiopoulos et al., 2013).

Several other studies do not distinguish between adolescents with behaviorally and perinatally- acquired HIV. In Kenya, 48% of adolescents living with HIV (aged 15–19 years) had told at least one person, most commonly a friend (37%). Among those who were sexually active, only 43% had told their partner (Wolf et al., 2016). Similarly, in a study of HIV self-disclosure to peers in Uganda and Kenya, Nostlinger et al. (2015) found that 56% of adolescents (aged 13–17 years) had told at least one person; only 18% had told a friend. Among those with a romantic partner, about a third had disclosed their HIV status (Nostlinger et al., 2015). Similar disclosure rates (36%) were found among sexually active adolescents in South Africa (Toska et al., 2015).

This is an exploratory study focused on youth with perinatally-acquired HIV who have grown up in Soweto, South Africa. The aims are (1) to determine the prevalence of disclosure to the adolescent's social network (family, peers, romantic partners) and to sexual partners specifically; (2) to examine psychosocial and HIV-related factors associated with disclosure in order to identify potential benefits and harms.

Methods

Procedures and participants

This study characterizes HIV disclosure among 250 perinatally-infected respondents. A convenience sample was primarily recruited from patients routinely attending the Paediatric Wellness Clinic, part of the Perinatal HIV Research Unit in Soweto, South Africa. To reach our target of 250 participants, patients were also recruited from other clinics within the Soweto community after obtaining approval from local health authorities. The inclusion criteria was the same for all: being aged 13–24 years; being aware of their HIV diagnosis; having documented HIV infection before age 10; and being literate in English. Less than 10% of those who fulfilled age criteria were not invited to participate because they were not fully aware of their HIV status. Eleven adolescents could not read the English consent/assent forms and were excluded. Exclusion criteria were acute psychiatric illness and cognitive impairment in the opinion of the study staff.

Potential participants and their guardians were approached by a research coordinator to briefly explain the study purpose and schedule a clinic visit. This was done either at a routine visit, or by calling to briefly explain the study purpose. At the clinic visit, the research coordinator explained the procedures and the informed consent. Before proceeding, all minors provided assent with guardian consent; participants aged 18–24 years provided consent. The cohort description has been published previously (Kidman et al., 2018).

After an individualized tutorial, respondents completed a survey themselves using the touch pad of a tablet computer in a private space. Before leaving, respondents were debriefed and given the opportunity to meet with a staff psychologist. Additional HIV data were abstracted directly from medical records. The protocol was granted approval by both Stony Brook University and the University of the Witwatersrand's Human Research Ethics Committee.

Measures

General HIV disclosure (whether they have actively told someone of their status) was measured by asking "Since you learned of your HIV status, have you told anyone that you are HIV-positive?" If yes, they were asked about disclosure to specific people (friends, teachers, family, romantic partner, and their most recent sexual partner) (Nyblade & MacQuarrie, 2006). Those who indicated they had not disclosed to a sexual partner were asked to report on barriers by selecting options from a predetermined list (adapted from (Deribe et al., 2008)). Disclosure self-efficacy was measured continuously (4 = low to 20 = high) with the Brief HIV Disclosure Scale (Kalichman et al., 2001). All respondents were asked about disclosure discussion with health providers: "Did anyone at this clinic ever mention or talk to you about telling a sex partner that you are HIV-positive?"

We also collected data on current psychosocial states that can influence disclosure. Respondents completed the Beck Depression Inventory (analyzed using a pre-established cut-off of 20 for moderate to severe depression) (Beck et al., 1988); the adolescent self-administered version of the CRAFFT Screening Questionnaire for alcohol and substance abuse (Knight et al., 1999); the Multidimensional Scale of Perceived Social Support (MSPSS; a total score and family, friends, and significant other subscales were all coded 1 = low to 5 = high) (Zimet et al., 1988), and the WHO Violence Against Women Instrument to capture a combined measure of physical and/or sexual intimate partner violence (IPV), coded separately for lifetime and past-year experiences (World Health Organization, 2005).

HIV-related variables were also measured. We captured the years since the respondent learned of his or her HIV diagnosis; HIV knowledge (using an inventory of 8 questions designed for seropositive adolescents (Barnes et al., 2013)); and the Internalized AIDS-Related Stigma Scale (measured continuously 0 = low to 6 =

high) (Kalichman et al., 2009). Viral load was abstracted from their most recent laboratory report; unsuppressed viral load was defined as greater than 400 copies/ml.

Participants were asked whether they had ever had sex. If so, they were asked additional questions about past-year experiences including partner type (boyfriend/girlfriend, casual or transactional); partner HIV status; and whether they used a condom every time they had sex with their most recent partner. Finally, we captured three demographic variables: age, gender and orphanhood (death of either parent).

Analysis

Descriptive analyses focused on the calculation of frequencies for disclosure outcomes. We built binomial logistic regression models to capture correlates for two outcomes: (1) any disclosure and (2) disclosure to the most recent sexual partner specifically. Each potential correlate (e.g., depression) was examined separately. In each case, we created two models: the first examined the unadjusted, bivariate correlation with disclosure; the second adjusted for age and gender. All analyses were done in Stata v13.0.

Results

Briefly, the average age of the sample was 16.3 years, a slight majority (54%) were female, and most (88%) identified as Black African. Two of five reported food insecurity. Three of five had been orphaned by at least one parent.

Prevalence of onward HIV disclosure among youth with perinatally-acquired HIV

In our sample of PHIV aged 13–24 years, 36% reported disclosing their HIV status to at least one other person (see Figure 1). Disclosure rose steadily with age: it was 27% among those 13–16 years; 38% among those 17–19; and 63% among those 20–24 years old. PHIV most commonly reported sharing their status with a family member (31% overall), followed by friends (15%), teachers/religious leaders (13%), and finally romantic partners (12%).

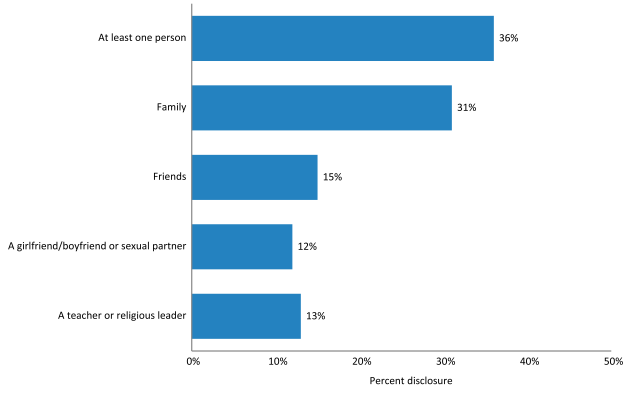


Figure 1. General diclosure of HIV-positive serostatus to any one person and to specific people, among South African youth aged 13–24 years with perinatally-acquired infection ($N = 250$).

Among the youth reporting past-year sexual activity ($n = 69$), most (78%) reported that their most recent sexual partner was a boyfriend or girlfriend. About one third (34%) reported no or inconsistent condom use with this partner. Disclosure to this sexual partner was 35% overall (23% among males and 46% among females). Among those who did not disclose their HIV status, 30% had detectible viral loads and were thus at risk of passing the virus on to their partner. Reasons for non-disclosure are presented in Table 1. The most commonly endorsed reasons were not wanting the partner to worry (93%) and fearing the partner may leave (83%).

Predictors of onward HIV disclosure among youth with perinatally-acquired HIV

In the adjusted models (see Table 2), both older age (aOR 1.16; 95% CI 1.10–1.22) and being female (aOR 1.45; 95% CI 1.03–2.13) were significantly associated with onward disclosure to at least one person. Just under a fifth (18.6%) of girls reported past year IPV, and this was associated with greater odds of disclosure at any time (aOR 1.50; 95% CI 1.02–2.21). Perceived social support was negatively associated with disclosure (aOR 0.80; 95% CI 0.66–0.98). When examining the social support subscales, only family support mirrors this association (aOR 0.81, 95% 0.70–0.94). Neither depression nor substance abuse was related to disclosure. Similarly, no HIV-related variables (i.e., years since diagnosis; HIV knowledge; internalized stigma, viral load, time since diagnosis) showed an association with disclosure after adjusting for covariates.

Among the smaller subsample ($n = 69$) reporting a sexual partner in the last year, females were also more likely to report that they had disclosed to their most

Table 1. Reasons cited for non-disclosure to a sexual partner ($n = 44$).

Reason	*N* (%)*
He/she might leave me	33 (83%)
He/she might physically hurt me	16 (39%)
HIV is a private and personal matter	33 (75%)
He/she might get angry with me	33 (77%)
I don't want him/her to worry	41 (93%)
He/she might be afraid of catching HIV from me	43 (79%)
He/she might think I'm a bad person	32 (74%)

*total *N* may vary due to item non-response.

Table 2. Factors associated with disclosure of HIV-positive serostatus among South African youth aged 13–24 years with perinatally-acquired infection.

		Association with HIV Disclosure to at Least One Other Person ($N = 250$)		Association with HIV Disclosure to the Most Recent Sexual Partner ($N = 69$)	
	N (%) or mean	Crude RR (95% CI)	Adjusted RR (95% CI)	Crude RR (95% CI)	Adjusted RR (95% CI)
Demographic variables					
Age	16.3	**1.16 (1.10–1.22)*****	**1.16 (1.10–1.22)*****	0.93 (0.81–1.07)	0.92 (0.82–1.05)
Gender: female	136 (54.4%)	**1.50 (1.03–2.19)***	**1.48 (1.03–2.13)***	2.03 (0.96–4.29)	2.06 (0.99–4.28)
Orphanhood (at least one parent deceased)	159 –(63.6%)	1.36 (0.91–2.02)	1.21 (081–1.79)	1.70 (0.733.96)	1.59 (0.68–3.69)
Psychosocial variables					
Depressive symptoms, moderate to severe	78 (33.8%)	0.91 (0.62–1.34)	0.86 (0.60–1.22)	1.41 (0.75–2.66)	1.21(0.64–2.29)
Alcohol and substance use problem	45 (18.0%)	1.40 (0.94–2.07)	1.25 (0.83–1.88)	0.99 (0.48–2.02)	1.10 (0.53–2.24)
Perceived social support (1 = low–5 = high)					
Overall	3.8	0.80 (0.64–1.00)	**0.80 (0.66–0.98)***	**0.67 (0.46–0.98)***	0.69 (0.47–1.01)
Significant other sub-scale	4.0	0.99 (0.80–1.23)	0.96 (0.80–1.14)	0.88 (0.64–1.23)	0.86 (0.65–1.15)
Friends sub-scale	3.4	0.94 (0.78–1.13)	0.93 (0.78–1.12)	0.78 (0.59–1.03)	0.82 (0.63–1.05)
Family sub-scale	3.8	**0.79 (0.67–0.93)****	**0.81 (0.70–0.94)****	0.81 (0.60–1.10)	0.84 (0.63–1.13)
Lifetime IPV‡	45 (32.6%)	1.29 (0.94–1.98)	1.20 (0.81–1.77)	1.43 (0.69–2.94)	1.33 (0.44–3.97)
Past year IPV‡	24 (18.6%)	**1.71 (1.12–2.60)***	**1.50 (1.02–2.21)***	1.24 (0.62–2.48)	1.22 (0.60–2.47)
HIV-related variables					
Years since learned of HIV diagnosis					
More than 2 years ago	154 (68.1%)	ref	ref	ref	ref
1–2 years ago	31 (13.7%)	1.26 (0.81–1.93)	1.48 (0.97–2.26)	**2.36 (1.15–4.82)***	**2.38 (1.16–4.88)***
Less than a year ago	41 (18.1%)	**0.44 (0.22–0.90)***	0.57 (0.28–1.15)	1.77 (0.71–4.41)	1.79 (0.65–4.90)
HIV knowledge (0–8 correct)	5.7	**1.17 (1.02–1.34)***	1.09 (0.96–1.25)	0.93 (0.74–1.16)	0.89 (0.71–1.11)
Disclosure self-efficacy (4 = low – 20 = high)	11.4	1.00 (0.94–1.08)	0.98 (0.92–1.04)	1.09 (0.96–1.24)	1.08 (0.95–1.22)
Internalized stigma (0 = low – 6 = high)	3.4	0.91 (0.82–1.01)	0.93 (0.84–1.03)	1.06 (0.85–1.33)	1.00 (0.79–1.23)
Unsuppressed viral load (>400)	77 (30.8%)	1.02 (0.69–1.49)	0.82 (0.56–1.18)	1.12 (0.57–2.21)	1.01 (0.46–2.23)
Sexual relationship variables†					
Partner type					
Boyfriend/girlfriend	52 (77.6%)	na	na	Ref	ref
Casual or transactional partner	15 (22.4%)	na	na	0.35 (0.09–1.32)	0.45 (0.11–1.79)
Partner's HIV status					
Unknown	32 (64.4%)	na	na	Ref	ref
HIV-positive	10 (14.5)	na	na	**6.20 (1.87–20.54)****	**5.97 (1.89–18.84)****
HIV-negative	(39.1%)	na	na	**5.96 (1.92–18.51)****	**5.26 (1.63–16.90)****
Consistent condom use	45 (66.2%)	na	na	0.70 (0.36–1.34)	0.72 (0.38–1.35)
Health service variables					
Discussion of disclosure to sexual partner	92 (38.3%)	na	na	**2.06 (1.02–4.17)***	**2.48 (1.28–4.81)****

Notes: denominators vary slightly due to missing data; †refers to the most recent partner among those sexually active in the past year; ‡among females only (n = 129); adjusted models control for age and gender.
*$p < 0.05$, **$p < 0.01$; ***$p < 0.001$.

recent partner (aOR 2.06; 95% CI 0.99–4.28), but this association did not reach significance. PHIV who recently learned about their diagnosis were more likely to share this information with their sexual partner; this reached significance for the group that learned of their diagnosis 1–2 years prior to the survey (aOR 2.38; 95% CI 1.16–4.88) and showed a similar but non-significant trend for those who learned of their diagnosis less than a year before (aOR 1.79; 95% CI 0.65–4.90). Knowledge of their sexual partner's HIV status (seropositive or seronegative) substantially increased the odds that they had disclosed. We note, however, this may be a marker for whether the couple had communicated about HIV, rather than a predictor of disclosure. Unlike general disclosure, past-year IPV was not related to disclosure to a sexual partner. Critically, those PHIV who reported having a discussion with someone at the health clinic about disclosure to a sexual partner were more likely to report actually having disclosed (aOR 2.48; 95% CI 1.28–4.81).

Discussion

Consistent with prior studies (e.g., Birungi, Obare, et al., 2009), we find low rates of youth's HIV disclosure to others: only a third of PHIV had self-disclosed their HIV status to at least one person. As they grapple with a highly stigmatized health condition, our results suggest youth may have few people in whom they can confide their worries or ask for advice related to growing up with HIV.

The WHO encourages counseling on HIV disclosure to parents and friends, as disclosure can be a means to garner greater social support (World Health Organization, 2013). In our study, however, we found no evidence that disclosure was positively related to social support or viral suppression in PHIV. In fact, we found a negative correlation between disclosure and family support. There are two competing interpretations. First, young people who disclose to family members may experience rejection and a loss of support, as has been

reported elsewhere (Lee & Oberdorfer, 2009; Madiba & Mokgatle, 2016). We note that for PHIV growing up with HIV, the immediate family will likely already be aware of their status. Thus, questions on family disclosure may have been largely interpreted to refer to extended members. Second, it is possible that youth in supportive families are choosing not to disclose to others outside the family, a possibility we cannot eliminate with cross-sectional data. If their parents disclosed to them in a sensitive and supportive manner, they may not feel the need to access additional social support from friends, teachers or religious leaders. In the USA, PHIV report high levels of instrumental support from family, including having family who reminds them to go to the clinic and who care for them when sick (Abramowitz et al., 2009). Moreover, youth in supportive families may also be more willing to keep their parent's, and thus their own, HIV status a secret.

Disclosure is also often cited as a key strategy for HIV prevention. For example, Evangeli and Foster (2014) "argue that professionals have a particular responsibility to facilitate young people's onward HIV disclosure to sexual partners". In our study, only a third of sexually-active PHIV had disclosed their HIV status to their most recent partner, and this was not related to condom use. Similarly low rates of disclosure to sexual partners have been reported among youth living with HIV in South Africa (Simbayi et al., 2017), in Uganda (Birungi, Mugisha, et al., 2009), in Zambia (Okawa et al., 2018) and in the U.S. (Dempsey et al., 2012; Tassiopoulos et al., 2013; Weintraub et al., 2017).

Moreover, in our study many PHIV were having unprotected sex without disclosing their HIV status to partners. Other studies have also documented behaviors that increase onward HIV transmission risk (Dempsey et al., 2012; Koenig et al., 2010; Obare & Birungi, 2010; Okawa et al., 2018; Tassiopoulos et al., 2013). Clearly, the accumulating evidence suggests a need for strategies to encourage safer sex (Birungi, Obare, et al., 2009; Gray, 2010). However, it does not necessarily follow that disclosure would be an effective prevention strategy for this age group. In our study, there was no association between disclosure to a sexual partner and condom use. This is consistent with prior literature: HIV disclosure has not been associated with safer sexual practices among youth (Birungi, Obare, et al., 2009; Dempsey et al., 2012; Rongkavilit et al., 2010; Toska et al., 2015); while evidence among adults has been mixed (Simoni & Pantalone, 2004). More research is needed to understand why disclosure does not lead to safer sexual practices; such insights could generate promising strategies for effective intervention (Thoth et al., 2013). In the absence of disclosure and condom use, achieving and maintaining an undetectable viral load emerges as an important strategy for preventing onward transmission from youth living with HIV (Eisinger et al., 2019).

We also examined potential harms that may arise from disclosure. Strong existing evidence links disclosure to rejection by friends or romantic partners (Fair & Albright, 2012); unauthorized disclosure to others; isolation and loss of social support (Madiba & Mokgatle, 2016); and violence (Thoth et al., 2013). In fact, the WHO explicitly does not recommend that adolescents disclose their HIV status to sexual partners, citing concerns that this might result in isolation or violence (World Health Organization, 2013). In our study, we examined IPV and found no association with disclosure to a current sexual partner. Given the cross-sectional nature of the data and potential for a bidirectional relationship, however, we cannot eliminate the possibility that disclosure leads to IPV or other harm. Longitudinal data is needed to tease apart whether IPV is a product of and/or discourages disclosure. We note that youth reporting past-year IPV were more likely to have disclosed to someone else in their social sphere, though not their partner. One possible scenario is that HIV disclosure occurs in the context of seeking help or support after experiencing IPV.

Finally, it is notable that our results showed a strong correlation between disclosure to sexual partners and having discussed disclosure with HIV clinic staff. It may be that young people raise this topic on their own, and seek out information or support when they are considering disclosure. It may also be that providers are urging disclosure, unaware that recommendations for adults and adolescents diverge in this area. Specifically, the current WHO guidelines underscore the complexity and the need for better evidence, particularly in low-resource contexts: "Adolescents with HIV should be counseled about the potential benefits and risks of disclosure of their HIV status and empowered and supported to determine if, when, how and to whom to disclose" (World Health Organization, 2013, pg xi). Our results suggest that health professionals are discussing disclosure with at least some clients, despite a dearth of tools to help young people weigh individual benefits and risks. Theoretically-informed interventions, developed in partnership with PHIV, are needed to guide young people through the process of disclosing to their family and friends. While there is a burdening literature on interventions to facilitate disclosure to PHIV (Li et al., 2015), we are not aware of similar efforts around onward disclosure.

Study limitations include the cross-sectional nature of the data, which limits inference about the causal direction of the reported associations. It may also obscure important relationships, such as the example of IPV above.

Similarly, if depression both lowers disclosure, and is alleviated by such, the opposing forces may cancel one another out. The authors are not aware of longitudinal studies among adolescents that report on factors that inhibit or encourage disclosure. In the future, such studies could not only better document what factors influence disclosure, they could also quantify both the positive and negative impacts of disclosure. Such information would help health professionals better guide discussions around disclosure with PHIV. In addition, this study did not collect data on how PHIV first learned of their HIV status. It is likely that some close family members already knew of their HIV status, without PHIV self-disclosure, and offered important social support. We examined fourteen potential predictors across two outcomes; running several models increases the likelihood of Type 1 error. Finally, participants were recruited from a leading research clinic in Soweto; both the exposure to high quality services and the urban setting may influence disclosure decisions and thus the generalizability of these findings.

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