

# Vulnerable Children and Youth Studies

An International Interdisciplinary Journal for Research, Policy and Care

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/rvch20>

## How does learning one's HIV status relate to viral suppression? an analysis among perinatally infected adolescents and young adults in Ndola, Zambia

Christiana Frimpong, Virginia Burke, Sam Miti, Bareng Aletta Sanny Nonyane, Katherine Merrill, Jonathan Mwansa & Julie Denison

To cite this article: Christiana Frimpong, Virginia Burke, Sam Miti, Bareng Aletta Sanny Nonyane, Katherine Merrill, Jonathan Mwansa & Julie Denison (2021): How does learning one's HIV status relate to viral suppression? an analysis among perinatally infected adolescents and young adults in Ndola, Zambia, *Vulnerable Children and Youth Studies*, DOI: [10.1080/17450128.2021.1944710](https://doi.org/10.1080/17450128.2021.1944710)

To link to this article: <https://doi.org/10.1080/17450128.2021.1944710>



© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 05 Jul 2021.



Submit your article to this journal [↗](#)



Article views: 193




View related articles [↗](#)



View Crossmark data [↗](#)

## How does learning one's HIV status relate to viral suppression? an analysis among perinatally infected adolescents and young adults in Ndola, Zambia

Christiana Frimpong<sup>a</sup>, Virginia Burke<sup>b</sup>, Sam Miti<sup>a</sup>, Bareng Aletta Sanny Nonyane<sup>b</sup>, Katherine Merrill<sup>b,c</sup>, Jonathan Mwansa<sup>a</sup> and Julie Denison <sup>b</sup>

<sup>a</sup>Arthur Davison Children's Hospital, Ndola, Zambia; <sup>b</sup>Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, USA; <sup>c</sup>Department of Medicine, University of Illinois at Chicago, Chicago, USA

### ABSTRACT

Little data exist on how 15-to-24-year-old perinatally infected youth living with HIV (p-YLHIV) learn their HIV status, and how those disclosure experiences may relate to current viral suppression (VS). Cross-sectional analyses were conducted using baseline data from a randomized controlled trial testing a peer mentoring program in Ndola, Zambia. Analyses were restricted to self-reported p-YLHIV to assess associations between disclosure experiences and VS using logistic regression models, adjusted for sex, age, time on treatment and enrolment site. Of 198 p-YLHIV, 55% knew their HIV status by age 12. The odds of VS was 3.43 greater among p-YLHIV who learned their HIV status through a healthcare provider (HCP) and caregiver together compared to learning from either a HCP or caregiver alone [95% CI:1.02,11.54]. P-YLHIV who had people to talk with about living with HIV after disclosure were twice as likely to have VS compared to peers who did not [OR: 1.87, 95% CI: 1.0, 3.45]. These findings highlight the importance of disclosure support and having a HCP-caregiver team handle disclosure with perinatally infected children and youth, indicating strong service delivery opportunities that may support future VS in youth. Future studies should examine youth peer mentors living with HIV's support during disclosure processes.

### ARTICLE HISTORY

Received 18 September 2020  
Accepted 9 June 2021

### KEYWORDS

Disclosure; HIV; Perinatally infected Adolescents and young adults; Viral suppression; Zambia

## Introduction

Increased global access to antiretroviral treatment (ART) for children has led to a decrease in HIV-related child mortality, and an increasing number of adolescents living with HIV (Kidia et al., 2014; Lowenthal et al., 2014). Despite this success, the World Health Organization (WHO) reports that HIV/AIDS is one of the world's leading causes of death among adolescents (WHO, 2018a). The death burden is greatest in countries with high HIV prevalence and large numbers of youth, such as Zambia where 12% of the general population aged 15–59 years has HIV (MOH, 2019; UNAIDS, 2019). An estimated 30% of adolescents living with HIV in Zambia have

**CONTACT** Christiana Frimpong  [christy.frimpong@gmail.com](mailto:christy.frimpong@gmail.com)  Arthur Davison Children's Hospital, Ndola, Zambia

This article has been republished with minor changes. These changes do not impact the academic content of the article.

© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

achieved viral suppression (VS) and youth tend to have poorer adherence and immunological outcomes compared to adults, resulting in their comparatively higher mortality (MOH, 2019).

A number of factors contribute to HIV outcomes among youth living with HIV (YLHIV), including how the youth initially learns their HIV status (Cluver et al., 2015; Denison, Banda et al., 2015; Denison et al., 2018; Kim et al., 2017; WHO, 2011). Disclosing to a child or YLHIV is a process that involves explaining to them that they have HIV and is an essential component of the HIV care continuum (WHO, 2011). This knowledge fulfils children's right to know about their own health, and may improve their adherence to therapy and ultimately save their lives (Cluver et al., 2015; Mburu et al., 2014). WHO recommends beginning the HIV disclosure process with perinatally infected children by the time the child is school-age (6–12 years), and having adults disclose to younger children incrementally to match their evolving developmental capacity (WHO, 2011).

Despite this guidance from WHO, little is known about status disclosure among youth living with HIV (p-YLHIV) in sub-Saharan Africa (SSA) (Brown et al., 2011; Hodgson et al., 2012; Mburu et al., 2014; Moodley et al., 2006; Lara M; Vaz et al., 2010; Lara M, 2011). What data exist reveals regional differences among countries in disclosure practices, and that these practices are often not consistent with WHO recommendations (Hodgson et al., 2012; Kidia et al., 2014; Mburu et al., 2014). For example, some caregivers delay disclosing to their children for fear of rejection or confrontation by the children, psychosocial effects on both the child and the rest of the family and stigma from the community (Finnegan et al., 2019; Kidia et al., 2014; Mandalazi et al., 2014; Mburu et al., 2014; Vreeman et al., 2010; WHO, 2011). Many caregivers prefer to disclose to their children when they are deemed mature enough to marry (Das et al., 2016).

A program in a New York hospital found that gradually disclosing to perinatally infected children with constant support from a multidisciplinary team comprised of healthcare providers (HCPs) along with others such as parents/caregivers and social workers helped to attain complete disclosure among a greater number of the children (Lee & Johann-Liang, 1999). In a qualitative study involving 31 adolescents in Zimbabwe, most participants shared that they preferred learning their HIV status at a health facility with a HCP in order for them to appreciate the reality of their condition and to obtain more information about HIV (Kidia et al., 2014). While these data provide insight into the experiences of perinatally infected youth, little data exists from SSA that examines when and how p-YLHIV learned their own HIV status and how those experiences may relate to VS as they have aged into adolescence and young adulthood (L. L. Vaz et al., 2008).

The aim of this analysis was to examine the disclosure experiences of p-YLHIV in Ndola, Zambia, and determine whether these experiences were associated with current VS.

## Materials and methods

We analyzed baseline data from a randomized controlled trial (RCT) among youth living with HIV called Project YES! Youth Engaging for Success. The purpose of the RCT was to evaluate the impact of a peer mentoring program on increasing VS and reducing self-

stigma among YLHIV. Details of the methods used in the parent study, which occurred in four HIV clinics in Ndola, Zambia, are described elsewhere (Denison et al., 2020). Study eligibility criteria for the RCT included being aged 15–24 years, diagnosed HIV-positive and aware of one's HIV status, on ART for at least six months, Bemba- or English-speaking and planning to be available to attend study activities over the next 18 months as needed. All assenting and consenting participants completed a baseline survey and underwent viral load (VL) testing. The data on 'age at diagnosis' were collected from participants' medical charts (Denison et al., 2020).

### **Analysis sample**

This analysis was restricted to participants who self-reported during the baseline data collection that they were perinatally infected with HIV, as mode of HIV acquisition was not routinely collected and recorded in medical charts at the ART clinics.

### **Variables**

#### **Outcome measure**

Youth with a VL of <1000 copies of HIV-RNA/mL were categorized as having viral suppression (VS) in line with WHO guidelines and the consolidated guidelines on HIV Treatment and Prevention from the Zambian Ministry of Health (MOH, 2020; WHO, 2016). A sensitivity analysis using a cut-off of <200 copies/mL for VS was also conducted as this is a critical cut-off found in the undetectable is equal to untransmissible (U = U) literature (WHO, 2018b).

#### **Exposures**

**Disclosure.** Several questions in the baseline questionnaire assessed HIV disclosure experiences, including how youth learnt their HIV status (directly informed or found out on their own); age at disclosure (a continuous variable categorized as  $\leq 12$  or  $> 12$  years of age); location where disclosure took place (health facility or other location); youth had people they could talk with about living with HIV after they found out their HIV status (yes/no); and was someone with the youth when they first learnt their HIV status? (yes/no). We also asked who directly disclosed to the youth, with responses categorized as parent/caregiver-HCP team together, parent/caregiver alone, HCP alone, or any other person.

**ART adherence.** ART adherence was assessed using a 48-consecutive hour treatment gap measure. This variable was constructed from two questions: 'In the past three months, did you have a day when you did not take any ART drugs?' and 'What were the most days in a row that you missed swallowing your drugs in the past three months?' Youths who did not have a 48 consecutive hour treatment gap were categorized as adherent (Denison et al., 2020; Denison, Koole et al., 2015; Denison et al., 2018).

#### **Socio-demographic and background variables**

Baseline socio-demographic characteristics included p-YLHIV's age (15–19 vs 20–24), sex (male/female), completion of primary school (yes/no), marital status (single/

married), orphan status (both biological parents living/one biological parent deceased/both biological parents deceased), number of households lived in (one/two/three or more), enrolment clinic (pediatric/adult setting), baseline viral suppression (yes/no), age at diagnosis at the study clinic (less than 12 years/greater than 12 years) and time on ART (less than 3 years/3-6 years/more than 6 years).

### **Sample size**

The parent study enrolled 276 participants, of whom 198 self-reported being perinatally infected with HIV (Denison et al., 2020). These 198 were included in the analysis presented here.

### **Data analysis**

Data were analyzed using STATA 15 (StataCorp, Texas USA). Means and standard deviations were used to summarize continuous variables, and counts and percentages were used to summarize categorical variables. Bivariate logistic regressions were used to evaluate the associations between VS and each of the main exposures of interest. Multivariable regression models, adjusted for age, sex, length of time on treatment and enrolment site were fitted for the main exposures that had p-value of <0.2 in the bivariate regressions. The primary analysis was based on VS of <1000 copies/mL and multivariable models were repeated for VS of <200 copies/mL as a sensitivity analysis.

We also evaluated a potential mediation effect of ART adherence (treatment gap) in the relationship between disclosure experience (main exposures of interest) and the outcome of VS. We extended the multivariable regression models into generalized structural equation models (GSEMs) with ART adherence (treatment gap) as a mediator, and from this analysis we report direct, indirect, and total effects of the disclosure experiences on VS.

### **Ethical considerations**

The Project YES study was approved by the ERES Converge Institutional Review Board in Zambia, the Ministry of Health through the National Health Research Authority, Zambia and the Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health in the United States. Participants 18 years and above provided written informed consent and participants 15 to 17 years provided written assent, with parental permission obtained from their parents/caregivers. Other details of the ethical considerations are published elsewhere (Denison et al., 2020).

## **Results**

### **Socio-demographic characteristics**

Of the 198 p-YLHIV participants included in this analysis, more than half were female (57%), between 15 and 19 years of age (68%) and attending HIV care at the pediatric clinic (58%) (Table 1). More than three-quarters were orphaned (42% single and 36%

double orphans). Most (93%) had completed primary school, few were married (2%), and the majority (70%) had lived-in two or more-family households.

### **How perinatally Infected youth learned their HIV status**

Out of the 198 p-YLHIV participants, 157 had accessible medical record data on their age of HIV diagnosis, with 65% diagnosed by age 12. More than half of the p-YLHIV also self-reported they learned their HIV status by the age of 12 (54%) (Table 2). Sixteen percent of p-YLHIV learned their status by themselves or by accident. The majority were told their status by either a HCP (38%) or a parent/caregiver (43%) alone. Only 11% had both a HCP and parent/caregiver together tell them they were living with HIV. Slightly more than half of p-YLHIV (58%) also learned their HIV status at a health facility, and the majority had someone with them when they first learned they were living with HIV (95%). Just over half reported having someone they could talk with about living with HIV after they found out their status (51%) and 58% wished they had

**Table 1.** Socio-demographic characteristics of study participants (N = 198)

Characteristics	n (%)
Sex	
Male	86 (43.43)
Female	112 (56.57)
Age	
15–19 years	134 (67.68)
20–24 years	64 (32.32)
Marital Status	
Single, never married	195 (98.48)
Married	3 (1.52)
Completed Primary school	
Yes	184 (92.93)
No	14 (7.07)
Orphan status	
Both biological parents living	43 (21.72)
One biological parent deceased	84 (42.42)
Both biological parents deceased	71 (35.86)
How many families/households youth have lived in	
One	59 (29.80)
Two	71 (35.86)
Three or more	67 (33.84)
Missing	1 (0.51)
Enrolment Site	
Pediatric setting	114 (57.78)
Adult setting	84 (42.42)
HIV Suppressed	
Yes	123 (62.12)
No	74 (37.37)
Missing	1 (0.51)
ART Adherent	
Yes	119 (60.10)
No	79 (39.90)
Time on ART	
<3 yrs	29 (14.65)
3–6 yrs	30 (15.15)
>6 yrs	136 (68.69)
Missing	3 (1.52)

n is the number of participants in each category

**Table 2.** Perinatally infected Youth's disclosure experiences (N = 198)

Characteristic/experience	n (%)		
	TOTAL (n = 198)	MALE (n = 86)	FEMALE (n = 112)
Age at diagnosis (from medical chart)			
12 years and below	102 (51.52)	52 (60.47)	50 (44.64)
Above 12 years	55 (27.78)	19 (22.09)	36 (32.14)
Missing	41 (20.71)	15 (17.44)	26 (23.21)
Age youth learned their HIV status			
12 years and below	108 (54.55)	42 (48.84)	66 (58.93)
Above 12 years	87 (43.94)	42 (48.84)	45 (40.18)
*Don't know & refused to answer	3 (1.52)	2 (2.33)	1 (0.89)
How youth first learned their HIV status			
Directly informed	166 (83.84)	67 (77.91)	99 (88.39)
Figured it out on their own	32 (16.16)	19 (22.09)	13 (11.61)
Was someone with youth when youth first learned they were living with HIV?			
Yes	188 (94.95)	81 (94.19)	107 (95.54)
No	10 (5.05)	5 (5.81)	5 (4.46)
Who directly told youth their HIV status the first time they learned of it?			
Both HCP and Caregiver together	21 (10.61)	9 (10.47)	12 (10.71)
HCP only	76 (38.38)	25 (29.07)	51 (45.54)
Caregiver only	85 (42.93)	47(54.65)	38 (33.93)
Other (figured it out themselves, other adult family member, etc)	16 (8.08)	5 (5.81)	11 (9.82)
Location where youth learned HIV status			
Health facility	115 (58.08)	45 (52.33)	70 (62.50)
Other (Home, School, Community)	83 (41.92)	41(47.67)	42 (37.50)
Youth had people they could talk with about living with HIV after they found out their HIV status?			
Yes	101 (51.01)	38 (44.19)	63 (56.25)
No	97 (48.99)	48 (55.81)	49 (43.75)
Youth wish their parent/caregiver had told them their HIV status earlier?			
Yes	53 (26.77)	25 (29.07)	28 (25.00)
No	138 (69.70)	58 (67.44)	80 (71.43)
Missing	7 (3.54)	3 (3.49)	4 (3.57)
Age youth wish their parent/caregiver had told them their HIV status (Out of those who wish their parent/caregiver had told them their HIV status earlier;n = 53)			
12 years and below	44 (22.22)	20 (23.26)	24 (21.43)
Above 12 years	7 (3.54)	5 (5.81)	2 (1.79)
Missing	2 (1.01)	0 (0.00)	2 (1.79)
Youth wish they had more time with counsellor at facility when learnt their HIV			
Yes	114 (57.58)	47 (54.65)	67 (59.82)
No	69 (34.85)	29 (33.72)	40 (35.71)
Not applicable (learned status themselves or outside of facility)	15 (7.58)	10 (11.63)	5 (4.46)
Did youth wish they belonged to peer support group immediately after learning HIV status?			
Yes	159 (80.30)	67 (77.91)	92 (82.14)
No	32 (16.16)	16 (18.60)	16 (14.29)
Already belonged to one	7 (3.54)	3 (3.49)	4 (3.57)

n is the number of participants in each category

\*\* Average age youth learnt their HIV status is 11.9 years (standard deviation =3.11, age range 4 to 21 years).

more time with a counsellor at the facility at the time they learned their HIV status. Out of the 53 youths who wished their parent/caregiver had told them their HIV status earlier, 83% wished they had learned by the age of 12. Only about 4% of youth participants reported belonging to a peer support group immediately after learning their HIV status.

### Bivariate analyses

Two exposures of interest met the pre-determined cut-off point of p-value  $\leq 0.2$  for the bivariate analyses. First, those who were directly told their HIV status by HCP and parent/caregiver together had almost three times the odds of VS compared to p-YLHIV who learned their HIV status from HCP only [81% versus 57%. Odds ratio (OR) 2.83, 95% Confidence interval (CI):0.91, 8.81, p = 0.06] (Table 3). Second, p-YLHIV who had people they could talk with about living with HIV after learning their status had a higher odds of VS than those who did not [70% versus 54%, respectively; OR = 2.11, 95% [(CI):1.18, 3.82, p = 0.01].

**Table 3.** Percentage of perinatally infected Youth with viral suppression and bivariate odds ratios (95% confidence intervals) N = 198

Characteristic/experience	n with VS/ n in sub-category	%	Bivariate OR (95% CI)	P value
Age				
15–19 years	86/134	64.18	1	
20–24 years	37/64	57.81	0.79 (0.43,1.46)	0.46
Sex				
Male	52/86	60.47	1	
Female	71/112	63.39	1.10 (0.61,1.97)	0.75
Time on ART				
<3 yrs	20/29	68.97	1.44 (0.61,3.39)	0.41
3–6 yrs	21/30	70.00	1.51 (0.64,3.54)	0.35
>6 yrs	82/136	60.29	1	
Missing	0/3	0.00		
How youth first learned their HIV status				
Directly informed	101/166	60.84	1	
Figured it out on their own	22/32	68.75	1.39 (0.62,3.14)	0.42
Age at diagnosis				
12 years and below	60/102	58.82	0.65 (0.33,1.31)	0.23
Above 12 years	38/55	69.09	1	
Missing	25/41	60.98	1.07 (0.51,2.24)	0.41
Youth learnt HIV status by age 12?				
Yes	69/108	63.89	1.05 (0.58,1.78)	0.88
No	54/87	62.07	1	
Who directly told youth their HIV status the first time they learned of it?				
Both HCP and Caregiver together	17/21	80.95	3.16 (0.97,10.3)	0.06
HCP only	43/76	56.58	1	
Caregiver only	53/85	62.35	1.23 (0.65,2.32)	0.52
Other (figured it out themselves, other adult family member, etc)	10/16	62.50	1.24 (0.41,3.77)	0.70
Location where youth learned HIV status				
Health facility	70/115	60.87	1	
Other (Home, School, Community)	53/83	63.86	1.11 (0.62,2.00)	0.73
Youth had people they could talk with about living with HIV after they found out their HIV status?				
Yes	71/101	70.30	2.11 (1.18,3.82)	0.01
No	52/97	53.61	1	
Enrolment Site				
Pediatric setting	67/114	58.77	1	
Adult setting	56/84	66.67	1.45 (0.81,2.63)	0.21

**Note:** Controlled for current age, sex, time on ART and enrolment site

n is the number of participants in each category

VS is Viral Suppression

OR is Odds Ratio



**Table 4.** Percentage of Perinatally Infected Youth with Viral Suppression (<1000 copies/mL) and Multivariable Odds Ratios (95% confidence intervals) N = 198

Characteristic/experience	n with VS/ n in sub Category	%	Adjusted OR (95% CI)	P value
Who directly told youth their HIV status the first time they learned of it?				
Both HCP and Caregiver together	17/21	80.95	3.43 (1.02,11.54)	0.05
HCP only	43/76	56.58	1	1
Caregiver only	53/85	62.35	1.50 (0.73,3.08)	0.27
Other (figured it out themselves, other adult family member, etc)	10/16	62.50	1.46 (0.46,4.63)	0.52
Youth had people they could talk with about living with HIV after they found out their HIV status?				
Yes	71/101	70.30	1.87 (1.0,3.45)	0.05
No	52/97	53.61	1	

**Note:** Controlled for current age, sex, time on ART and enrolment site  
n is the number of participants in each category  
VS is Viral Suppression  
OR is Odds Ratio

### Multivariable analysis

Multivariable regression models, adjusted for current age, sex, time on ART and enrolment site, were fitted for the two exposures separately: Who directly told youth their HIV status the first time they learned of it? and Youth had people they could talk with about living with HIV the time they found out their HIV status? P-YLHIV who were directly told their HIV status by a HCP and caregiver together were almost three and a half times more likely to have VS than p-YLHIV who learned by either a HCP alone or caregiver alone [OR: 3.43, 95% CI:1.02,11.54,  $p = 0.05$ ] (table 4). P-YLHIV who had people they could talk with about living with HIV after disclosure were almost two times more likely to have VS compared to peers who did not [OR:1.87, 95% CI:1.0, 3.45, $p = 0.05$ ]. There was no significant association between VS and our disclosure variables using the cut-off of <200 copies/mL for VS.

### Mediation analysis

In bivariate analyses, p-YLHIV who did not have a treatment gap of 48 consecutive hours or more (adherent,  $n = 119$ ) were almost twice as likely to have VS [OR 1.83, 95% CI 1.01–3.29,  $p = 0.05$ ]. In a chi-square test, we did not find a statistically significant

**Table 5.** Direct, indirect and total effects from the GSEMs evaluating the potential mediation effect of ART adherence on the relationship between VS and disclosure experiences

Disclosure experience	Direct effect	Indirect effect	Total effect
How youth first learned their HIV status	0.44 (−0.34,1.21)	−0.21 (−0.72,0.30)	0.23 (−0.74,1.19)
Who directly told youth their HIV status the first time they learned of it?	1.59 (−0.51,3.69)	0.29 (−0.90,1.49)	1.88 (−0.534,4.30)
Age youth learnt HIV status	−0.06 (−0.67,0.54)	0.17 (−0.21,0.54)	0.10 (−0.59,0.80)
Location where youth learned HIV status	0.04 (−0.56,0.64)	0.21 (−0.19,0.62)	0.25 (−0.46,0.96)
Youth had people they could talk with about living with HIV after they found out their HIV status	0.74 (0.15,1.34)*	0.07 (−0.28,0.41)	0.81 (0.12,1.50)

a value is significant at 0.05

association between adherence and who directly told the youth their HIV status (joint healthcare professional and parent/caregiver vs just one of these) the first time they learned it (Pearson  $\chi^2 = 0.26$ ). Table 5 shows direct, indirect and total effects from the GSEM after adjusting for current age, sex, and enrolment site. There was no evidence of a mediation effect of ART adherence on any of the five exposure variables.

## Discussion

This study found that how p-YLHIV learned their HIV status was associated with their VS at <1000 copies/mL at enrolment into the Project YES! study. Our analysis contributes important evidence that having a HCP and parent/caregiver together as a team handling a youth's disclosure, and having someone the p-YLHIV could talk with about living with HIV at the time they learned their status, were both associated with an increased odds of achieving VS as older p-YLHIV.

These findings have several programmatic implications. First, there is a benefit of caregivers and HCPs being a team and telling a youth their HIV status together. Only 11% of youth in this study experienced this type of disclosure. Studies in similar settings have shown heterogeneous findings with respect to preference for disclosure process. In a health facility-based study in Tanzania, only 3.8% of 211 parents/caregivers preferred both parent/caregiver and HCP together to disclose a child's HIV status compared to the majority of parent/caregiver (65%) wanting to disclose by themselves and fewer (28%) preferring HCPs to disclose to their child alone (Mumburi et al., 2014). In a study in West Bengal, some parents/caregivers acknowledged the difficulty with disclosure but preferred to do it themselves or have another family member/friend do it. They explained that they know their children better, and that makes them best to disclose, adding that it is no one else's business (Das et al., 2016). However, most parents/caregivers in Das' study felt that HCPs were best to disclose to children since HCPs have more authority over the subject and will explain it better. They also believed that the child will pay attention to the HCP and that it would hurt less when the child hears it from the HCP (Das et al., 2016).

HCP views on disclosure also vary in existing literature. Some HCPs in studies in Zimbabwe, Tanzania and South Africa argue that parents/caregivers should be primarily responsible to disclose a child's HIV status, but with the support of HCPs (Kidia et al., 2014; Mumburi et al., 2014; Myer et al., 2006; Watermeyer, 2015). The HCPs described parents/caregivers as being the most suitable people to lead disclosure (Myer et al., 2006), that HCPs do not have enough time to spend with each child to disclose, and that the children had HIV concepts explained to them when they were younger during post HIV testing. HCPs in this study further shared how HCPs should come in only to correct misinformation by parents/caregivers (Kidia et al., 2014). Other HCPs in Watermeyer's study expressed confusion and uncertainty regarding whether they are to disclose to the child and what exactly a HCP's role is in child HIV disclosure (Watermeyer, 2015). In the WHO guidelines on HIV disclosure counselling for children up to 12 years, it is stated:

HCWs challenged by the complicated issues facing HIV-affected families are often without the support of definitive, evidence-based policies and guidelines on when, how, and under

what conditions children should be informed about their own or their caregivers' HIV status (WHO, 2011).

While challenging, the data from this exploratory analysis begins to address WHO's question 'who can best disclose a child's HIV status to him/her' (WHO, 2011). Unlike the aim of most disclosure studies to unveil the importance of disclosure versus non-disclosure, our study examined how disclosure experiences relate to viral status, and support the testing of strategies to increase HCP/caregiver team disclosure and the development of guidance on how to foster this team approach.

Second, our findings indicate a need for support systems. In addition to the significant association established between p-YLHIV who had someone they could talk with about HIV and VS, 80% of p-YLHIV participants in this current study reported wishing they belonged to a peer support group immediately after learning their HIV status. Often, youth may experience feelings of anger, confusion, shock, sadness, and worry as part of a normal process of learning they are living with a chronic and highly stigmatized illness (Beck-Sagué et al., 2015; WHO, 2011). Having someone with whom to work through those feelings may help youth adjust and cope. The parent study had young adults living with HIV mentor YLHIV who were on ART for at least six months and found a statistically significant relative reduction in internalized stigma (feelings of worthlessness, blame and shame) and, among a sub-set of participants attending the pediatric clinic site, a relative increase in VS (Denison et al., 2020). Offering such a program earlier when a young person first learns their HIV status may further bolster the health and wellbeing of youth living with HIV. These data, combined with the WHO guidelines and prior data on short-term benefits of HIV disclosure, highlight the need to incorporate support systems into HIV care and treatment service delivery for youth.

We conducted mediation analysis to investigate potential mediation of adherence between the disclosure experiences and VS at  $<1,000$  copies/mL, and in this study, we did not find evidence of mediation. Further work is needed to understand the mechanism of disclosure that support long-term VS among p-YLHIV. A limitation of this study is that both self-reported measures of acquisition of HIV perinatally and ART adherence behaviors are subject to social desirability bias. The ART treatment gap measure also assessed certain patterns of adherence, and while it has been shown to be related to viral failure in past research, the definition of a treatment gap may miss cases of incomplete adherence. Another limitation is the time lapse between actual disclosure experiences and when our outcome of interest, VS, was measured, potentially introducing recall bias. The mediation analysis was also a post-hoc explorative analysis and our reliance on a conservative rule of thumb of 10–20 data points per parameter estimate (Wolf et al., 2013) may have resulted in unreliable estimate of power. Finally, the significant associations among disclosure and viral suppression were not found in the sensitivity analysis with a cut-off of  $<200$  copies/mL, a critical cut-off found in the undetectable = untransmissible literature. Further research exploring learning one's status and obtaining undetectable viral load is warranted.

## Conclusion

This study provides great insights into disclosure experiences of p-YLHIV. Findings highlight the importance of having a HCP-caregiver team handle disclosure with

p-YLHIV and of having someone with whom the p-YLHIV can talk to about living with HIV after learning their status. These two findings support very clear service delivery opportunities to support achieving VS in older p-YLHIV. Future studies should examine how to engage HCP/caregiver teams, and the potential role of youth peer mentors who are living with HIV, to support the disclosure process.

## Acknowledgments

The authors of this paper are grateful to youth participants for taking part in the study, thus making it possible for us to add on to scientific knowledge and take one more step forward in the fight against HIV/AIDS. We are also grateful to the hospitals and clinics where the study took place and the healthcare providers in charge of the ART clinics in these facilities, for embracing the study and supporting it in every way possible.

## Author contributions

Conceptualization: Christiana Frimpong and Julie A. Denison

Data Curation: Christiana Frimpong and Virginia M. Burke

Formal Data Analysis: Christiana Frimpong and Bareng A.S Nonyane

Funding Acquisition: Julie A. Denison

Writing – Original Draft: Christiana Frimpong

Writing – Review and Editing: Christiana Frimpong, Julie A. Denison, Virginia M. Burke, Bareng A.S Nonyane, Sam Miti, Katherine G. Merrill, Jonathan K. Mwansa

## Data Availability Statement

Data will be made available under Project SOAR's subsection of the Harvard Dataverse: <https://dataverse.harvard.edu/dataverse/projectsoar>.

## Disclosure Statement

The authors have declared that there are no competing interests.

## Funding

This work was supported by Project SOAR (Cooperative agreement AID-OAA-A-14-00060), made possible by the generous support of the American people through the United States President's Emergency Plan for AIDS Relief (PEPFAR) and United States Agency for International Development (USAID). The content of this paper is the sole responsibility of the authors and do not necessarily reflect the views of PEPFAR, USAID, or the United States Government. This research has also been facilitated by the infrastructure and resources provided by the Johns Hopkins University Center for AIDS Research, an NIH funded program (P30AI094189), which is supported by the following NIH Co-Funding and Participating Institutes and Centers: NIAID, NCI, NICHD, NHLBI, NIDA, NIMH, NIA, FIC, NIGMS, NIDDK, and OAR. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

**ORCID**Julie Denison  <http://orcid.org/0000-0002-4670-093X>**References**

- Beck-Sagué, C. M., Dévieux, J., Pinzón-Iregui, M. C., Lerebours-Nadal, L., Abreu-Pérez, R., Bertrand, R., Rouzier, V., Gaston, S., Ibanez, G., & Halpern, M. (2015). Disclosure of their HIV status to perinatally infected youth using the adapted blasini disclosure model in Haiti and the Dominican Republic: Preliminary results. *AIDS (London, England)*, 29(Suppl. 1), S91. <https://doi.org/10.1097/QAD.0000000000000665>
- Brown, B. J., Oladokun, R. E., Osinusi, K., Ochigbo, S., Adewole, I. F., & Kanki, P. (2011). Disclosure of HIV status to infected children in a Nigerian HIV care programme. *AIDS Care*, 23(9), 1053–1058. <https://doi.org/10.1080/09540121.2011.554523>
- Cluver, L. D., Hodes, R. J., Toska, E., Kidia, K. K., Orkin, F. M., Sherr, L., & Meinck, F. (2015). ‘HIV is like a tsotsi. ARVs are your guns’: Associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa. *LWW*.
- Das, A., Detels, R., Javanbakht, M., & Panda, S. (2016). Issues around childhood disclosure of HIV status—findings from a qualitative study in West Bengal, India. *Child: Care, Health and Development*, 42(4), 553–564. <https://doi.org/10.1111/cch.12338>
- Denison, J. A., Banda, H., Dennis, A. C., Packer, C., Nyambe, N., Stalter, R. M., Mwansa, J. K., Katayamoyo, P., & McCarraher, D. R. (2015). “The sky is the limit”: Adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society*, 18(1), 19358. <https://doi.org/10.7448/IAS.18.1.19358>
- Denison, J. A., Burke, V. M., Miti, S., Nonyane, B. A., Frimpong, C., Merrill, K. G., Abrams, E. A., & Mwansa, J. K. (2020). Project YES! youth engaging for success: A randomized controlled trial assessing the impact of a clinic-based peer mentoring program on viral suppression, adherence and internalized stigma among HIV-positive youth (15–24 years) in Ndola, Zambia. *PloS One*, 15(4), e0230703. <https://doi.org/10.1371/journal.pone.0230703>
- Denison, J. A., Koole, O., Tsui, S., Menten, J., Torpey, K., Van Praag, E., Mukadi, Y. D., Colebunders, R., Auld, A. F., & Agolory, S. (2015). Incomplete adherence among treatment-experienced adults on antiretroviral therapy in Tanzania, Uganda and Zambia. *AIDS (London, England)*, 29(3), 361. <https://doi.org/10.1097/QAD.0000000000000543>
- Denison, J. A., Packer, C., Stalter, R. M., Banda, H., Mercer, S., Nyambe, N., Katayamoyo, P., Mwansa, J. K., & McCarraher, D. R. (2018). Factors related to incomplete adherence to antiretroviral therapy among adolescents attending three HIV clinics in the copperbelt, Zambia. *AIDS and Behavior*, 22(3), 996–1005. <https://doi.org/10.1007/s10461-017-1944-x>
- Finnegan, A., Langhaug, L., Schenk, K., Puffer, E. S., Rusakaniko, S., Choi, Y., Mahaso, S., & Green, E. P. (2019). The prevalence and process of pediatric HIV disclosure: A population-based prospective cohort study in Zimbabwe. *PloS One*, 14(5), e0215659. <https://doi.org/10.1371/journal.pone.0215659>
- Hodgson, I., Ross, J., Haamujompa, C., & Gitau-Mburu, D. (2012). Living as an adolescent with HIV in Zambia—lived experiences, sexual health and reproductive needs. *AIDS Care*, 24(10), 1204–1210. <https://doi.org/10.1080/09540121.2012.658755>
- Kidia, K. K., Mupambireyi, Z., Cluver, L., Ndhlovu, C. E., Borok, M., & Ferrand, R. A. (2014). HIV status disclosure to perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and healthcare worker perspectives. *PloS One*, 9(1), e87322. <https://doi.org/10.1371/journal.pone.0087322>
- Kim, M. H., Mazenga, A. C., Yu, X., Ahmed, S., Paul, M. E., Kazembe, P. N., & Abrams, E. J. (2017). High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: Barriers and associated factors. *Journal of the International AIDS Society*, 20(1), 21437. <https://doi.org/10.7448/IAS.20.1.21437>

- Lee, C.-L., & Johann-Liang, R. (1999). Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. *AIDS Patient Care and STDs*, 13(1), 41–45. <https://doi.org/10.1089/apc.1999.13.41>
- Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., & Ferrand, R. A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. *The Lancet Infectious Diseases*, 14(7), 627–639. [https://doi.org/10.1016/S1473-3099\(13\)70363-3](https://doi.org/10.1016/S1473-3099(13)70363-3)
- Mandalazi, P., Bandawe, C., & Umar, E. (2014). HIV disclosure: Parental dilemma in informing HIV infected children about their HIV status in Malawi. *Malawi Medical Journal*, 26(4), 101–104.
- Mburu, G., Hodgson, I., Kalibala, S., Haamujompa, C., Cataldo, F., Lowenthal, E. D., & Ross, D. (2014). Adolescent HIV disclosure in Zambia: Barriers, facilitators and outcomes. *Journal of the International AIDS Society*, 17(1), 18866. <https://doi.org/10.7448/IAS.17.1.18866>
- MOH. (2019). *Zambia Population-based HIV Impact Assessment (ZAMPHIA) 2016: Final Report*. Ministry of Health Zambia. Retrieved from August 24. [https://phia.icap.columbia.edu/wp-content/uploads/2019/02/ZAMPHIA-Final-Report\\_2.22.19.pdf](https://phia.icap.columbia.edu/wp-content/uploads/2019/02/ZAMPHIA-Final-Report_2.22.19.pdf)
- MOH. (2020). Zambia consolidated guidelines for treatment and prevention of HIV infection 2020. MOH. Retrieved from August 25, 2020. <https://www.moh.gov.zm/wp-content/uploads/filebase/Zambia-Consolidated-Guidelines-for-Treatment-and-Prevention-of-HIV-Infection-2020.pdf>
- Moodley, K., Myer, L., Michaels, D., & Cotton, M. (2006). Paediatric HIV disclosure in South Africa-caregivers' perspectives on discussing HIV with infected children. *South African Medical Journal*, 96(3), 201–204.
- Mumburi, L. P., Hamel, B. C., Philemon, R. N., Kapanda, G. N., & Msuya, L. J. (2014). Factors associated with HIV-status disclosure to HIV-infected children receiving care at kilimanjaro christian medical centre in Moshi, Tanzania. *The Pan African Medical Journal*, 18.
- Myer, L., Moodley, K., Hendricks, F., & Cotton, M. (2006). Healthcare providers' perspectives on discussing HIV status with infected children. *Journal of Tropical Pediatrics*, 52(4), 293–295. <https://doi.org/10.1093/tropej/fml004>
- UNAIDS. (2019). UNAIDS Zambia Country fact sheet. Retrieved from August 24. <https://www.unaids.org/en/regionscountries/countries/zambia>
- Vaz, L., Corneli, A., Dulyx, J., Rennie, S., Omba, S., Kitetele, F., Group, A. R., & Behets, F. (2008). The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care*, 20(7), 842–852. <https://doi.org/10.1080/09540120701742276>
- Vaz, L. M., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care and STDs*, 24(4), 247–256. <https://doi.org/10.1089/apc.2009.0217>
- Vaz, L. M., Maman, S., Eng, E., Barbarin, O. A., Tshikandu, T., & Behets, F. (2011). Patterns of disclosure of HIV-status to infected children in a sub-Saharan African setting. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 32(4), 307. <https://doi.org/10.1097/DBP.0b013e31820f7a47>
- Vreeman, R. C., Nyandiko, W. M., Ayaya, S. O., Walumbe, E. G., Marrero, D. G., & Inui, T. S. (2010). The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care and STDs*, 24(10), 639–649. <https://doi.org/10.1089/apc.2010.0079>
- Watermeyer, J. (2015). 'Are we allowed to disclose?': A healthcare team's experiences of talking with children and adolescents about their HIV status. *Health Expectations*, 18(4), 590–600. <https://doi.org/10.1111/hex.12141>
- WHO. (2011). *Guideline on HIV disclosure counselling for children up to 12 years of age*. World Health Organization. Retrieved from August 25. [https://apps.who.int/iris/bitstream/handle/10665/44777/9789241502863\\_eng.pdf;jsessionid=9CE11067E698EEA0E0A44A7DF2B35588?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/44777/9789241502863_eng.pdf;jsessionid=9CE11067E698EEA0E0A44A7DF2B35588?sequence=1)

- WHO. (2016). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach*. Retrieved from August 25, 2020. [https://apps.who.int/iris/bitstream/handle/10665/208825/9789241549684\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/208825/9789241549684_eng.pdf?sequence=1)
- WHO. (2018a). *Adolescents: Health risks and solutions*. World Health Organization. Retrieved from September 9, 2020. <https://www.who.int/news-room/fact-sheets/detail/adolescents-health-risks-and-solutions>
- WHO. (2018b). *Viral suppression for HIV treatment success and prevention of sexual transmission of HIV*. Retrieved from April 15 2021. <https://www.who.int/hiv/mediacentre/news/viral-suppression-hiv-transmission/en/>
- Wolf, E. J., Harrington, K. M., Clark, S. L., & Miller, M. W. (2013). Sample size requirements for structural equation models: an evaluation of power, bias, and solution propriety. *Educational and Psychological Measurement*, 73(6), 913–934. <https://doi.org/10.1177/0013164413495237>