ORIGINAL PAPER

HIV-Related Stigma and Psychological Adjustment Among Perinatally HIV-Infected Youth in Cape Town, South Africa

Alexander Perez[1,2] · Kirsty Brittain[1,2] · Nicole Phillips[3,4] · Dan J. Stein[3,4] · Heather J. Zar[5,6] · Landon Myer[1,2] · Jacqueline Hoare[3,4]

Abstract

The effect of chronic HIV-infection on psychological adjustment, including the impact of HIV-related stigma in perinatally HIV-infected (PHIV+) youth across Africa is largely unknown. This study examined psychological adjustment and HIV-related stigma using the Strengths and Difficulties Questionnaire (SDQ) and a 10-item stigma questionnaire in a cohort of PHIV+ youth in Cape Town, South Africa. The relationships between SDQ scores, elevated viral load, and suboptimal antiretroviral therapy (ART) adherence were also explored. Among 473 PHIV+ youth (aged 9–14 years, on ART > 6 months at enrollment), higher perceived HIV-related stigma was associated with higher scores across all adolescent and caregiver-reported SDQ difficulty subscales. Higher socioeconomic status (SES) was associated with lower scores on adolescent self- and caregiver-reported hyperactivity subscales. Higher adolescent-reported prosocial scores were associated with lower odds of self-reported suboptimal ART adherence, and higher caregiver-reported conduct scores were associated with higher odds of elevated viral load. No associations were observed between perceived HIV-related stigma and treatment outcomes. These findings highlight the potentially detrimental impact of perceived stigma on psychological adjustment in PHIV+ youth. The use of psychosocial metrics and interventions aimed at reducing illness related stigma in PHIV+ youth is also considered.

Keywords Perinatal HIV-infection · Adolescents · Youth · Mental health · South Africa

Introduction

In 2019, the United Nations estimated that approximately 1.7 million children around the world were living with HIV, of which 88% reside in the region of Sub-Saharan Africa, SSA [1]. Enormous progress towards reducing morbidity and mortality among youth living with HIV has shifted the focus of treatment to chronic complications and comorbidities, including mental health problems [2, 3]. Despite this, existing studies in SSA are few and have produced mixed results regarding the prevalence of psychological impairment amongst HIV-infected (HIV+) youth, with estimates ranging between 17 and 80% across the SSA region [4, 5]. Further, most of the globally published data focus predominantly on behaviorally-infected youth, with the mental health of perinatally HIV-infected (PHIV+) youth being poorly characterized [4, 6]. PHIV+ youth may face more significant challenges relative to behaviorally-infected youth due to early exposure to risk factors throughout crucial stages in development [7, 8].

✉ Jacqueline Hoare
   Hoare.Jax@gmail.com

1   Division of Epidemiology and Biostatistics, School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa

2   Centre for Infectious Disease Epidemiology & Research, School of Public Health & Family Medicine, University of Cape Town, Cape Town, South Africa

3   Department of Psychiatry and Mental Health in the Neuroscience Institute, University of Cape Town, Cape Town, South Africa

4   South African Medical Research Council Research Unit on Risk & Resilience in Mental Disorders, Cape Town, South Africa

5   Department of Paediatrics & Child Health, University of Cape Town, Cape Town, South Africa

6   Medical Research Council Unit on Child & Adolescent Health, Cape Town, South Africa

Perceived HIV-related stigma has been identified as a key challenge amongst behaviorally-infected youth [9], with negative effects on psychosocial and treatment outcomes [10–12]. However, the effects of HIV-related stigma among PHIV+ youth have not been well studied in SSA, with existing studies providing contrasting results [4, 10, 13–15]. Associations between demographic or clinical characteristics and psychological outcomes similarly differ across studies. Studies from the United States (US) and South Africa have found that younger age and female sex are associated with worse psychological outcomes in PHIV+ youth, whereas no associations were observed between these factors and psychological outcomes in other studies [5, 16–18]. Similarly, low CD4 cell count has been found to be associated with depressive and conduct-related symptoms in high- and low-income settings, with other studies from the same contexts providing contradictory findings [3, 19–22]. Given this, identifying the context-specific socio-demographic and clinical predictors of poor psychological adjustment in high-burden settings is crucial to be able to identify high-risk adolescents and ensure that the most vulnerable youth receive appropriate support [5, 6].

In addition to HIV-related stigma, there is some evidence to suggest that poor mental health itself may lead to adverse treatment outcomes in HIV+ youth, with rates of suboptimal antiretroviral therapy (ART) adherence ranging anywhere from 18 to 50% in those with documented mental health symptoms [10, 18, 23]. Adolescents demonstrating suboptimal adherence in the US, for example, have been observed to have higher depression scores relative to their adherent counterparts [18, 24, 25]. However, other literature from the US has suggested that poor treatment outcomes may be more dependent on structural socio-environmental barriers (for example, problems with medical insurance, or increased school or family responsibility) than on psychological health in PHIV+ youth [26]. With an estimated 50% of lifelong mental illness beginning in adolescence and a dearth of existing literature in South Africa, there is a crucial need to further explore the relationship between psychological health and treatment outcomes in PHIV+ youth as a way of ensuring positive health outcomes throughout the lifespan [24, 25, 27]. We thus examined factors associated with psychological adjustment, including the role of HIV-related stigma, and explored the relationship between psychological adjustment and treatment outcomes in PHIV+ youth in Cape Town, South Africa.

Methods

Study Design

This analysis draws on data from a larger cohort of 515 PHIV+ youth aged 9–14 years at enrollment and followed

as part of the Cape Town Adolescent Antiretroviral Cohort (CTAAC). Youth were recruited from 7 ART services throughout Cape Town and were eligible for enrollment if they had been on ART for at least 6 months and knew their HIV-status. Follow-up visits were conducted every 6 months after enrollment, through 48 months. All study measurement visits were conducted separately from routine HIV care. Measures for this analysis were gathered from the 3rd (12-month after enrollment), 4th (18-month after enrollment), and 5th (24-month after enrollment) follow-up visits as described in the sections that follow. Informed consent and assent were obtained from caregivers and adolescents prior to enrollment. Approval for the CTAAC study was obtained from the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town (HREC Ref. 215/2013).

Measures

All adolescent- and caregiver-reported measures were administered by trained interviewers in the participant's preferred language. Demographic data, including age, gender and educational attainment, were collected at enrollment in the CTAAC study. Socioeconomic status (SES) was assessed based on housing type, household assets, and caregiver employment status using a composite poverty score that was developed following the approach used in the South African Stress and Health Study [28]. SES was categorized into Most, Moderately, and Least Disadvantaged groups using distribution-based cut-offs to facilitate comparisons within the study sample. Clinical information was collected via medical record abstraction from routine ART sites at enrollment and included age at ART initiation and ART regimen history.

Psychosocial Measures

Psychosocial measures were assessed at the 4th follow-up visit (18 months after enrollment).

HIV-related stigma among adolescents was assessed using a 10-item scale from a family-based intervention developed and piloted in South Africa [29]. The scale quantifies perceived HIV-related stigma by exploring themes centered around self-esteem and the perceived consequences of disclosure. Each item was assessed on a scale ranging from 1 to 3 based on the corresponding response options of "Not at all", "Sometimes", and "All the Time". The mean response was calculated across items, where higher scores indicated higher levels of perceived HIV-related stigma [Cronbach's alpha (α) = 0.87].

The Strengths and Difficulties Questionnaire (SDQ) was administered separately to adolescents and caregivers as a measure of psychological adjustment. The SDQ is a 25-item

instrument that is divided into five subscales measuring emotional symptoms (Cronbach α for adolescent/caregiver report, respectively [α] = 0.65/0.69), conduct problems (α = 0.46/0.57), hyperactivity inattention (α = 0.49/0.56), peer problems (α = 0.36/0.56), and prosocial behavior (α = 0.55/0.56); difficulty subscales can be summed into a total difficulties score (α = 0.77/0.81). The inventory is widely used in child mental health research and has been validated in several cross-cultural settings, including in the Sotho-speaking population in South Africa, thus serving as a suitable measure for gauging the emotional and behavioral well-being of PHIV+ youth [30, 31]. Response options for each item are "Not True", "Somewhat True", and "Certainly True", with each item scored between 0 and 2 [32]. Items on each subscale can be summed, with higher scores indicating greater difficulties on the emotional symptoms, conduct problems, hyperactivity-inattention, peer problems, and total difficulties subscales, and higher scores indicating greater strengths on the prosocial behavior subscale [32].

Information on the relationship between adolescents and their healthcare providers was collected using a 17-item patient–provider relationship scale which gauged the adolescent's experience in the clinical setting and their consistency of contact with the same health personnel. This self-reported questionnaire was developed and validated in the South West Tshwane sub-district of Pretoria, South Africa using similar tools from the US as a model [33]. The scale correlates with global measures that indicate an association between patient characteristics, increased adherence to ART, and having an undetectable viral load [33]. Response items were selected based on the relevance of each item to CTAAC study objectives and were scored from 1 to 4, ranging from "Always" to "Never" [33]. A mean score was then calculated across items, where higher scores indicated a better patient–provider relationship.

Adherence and HIV Viral Load

At enrollment and then annually, adolescent-reported adherence was assessed using structured questionnaires, and HIV viral load testing (Abbott RealTime HIV-1) was conducted by the South African National Health Laboratory Services. For the purposes of this analysis, viral load and adolescent-reported adherence measures were collapsed into a single variable from data collected at the 3rd (12 months after enrollment) and 5th (24 months after enrollment) study measurement visit, as these measures were not assessed at the 4th study measurement visit. Given the dynamic nature of adherence behaviors over time, we compared participants who reported suboptimal adherence or had an elevated viral load at either visit with those who reported optimal adherence or were virally suppressed at both visits. This was used

to give a general sense of adherence and viral suppression at the 4th study measurement visit.

Data Analysis

Data were analyzed using STATA Version 14 (Stata Corporation, College Station, Texas, USA). Summary statistics in the form of medians and proportions were used to describe socio-demographic and clinical characteristics. For the purposes of this analysis, each subscale of the SDQ scale, including the total difficulties subscale, was assessed separately. Multivariable linear regression was used to examine associations between HIV-related stigma and SDQ scores, adjusting for socio-demographic and clinical characteristics. Multivariable logistic regression models were used to examine the impact of SDQ scores and HIV-related stigma on elevated viral load and adolescent-reported suboptimal adherence to ART. Elevated viral load was defined as viral load ≥ 50 copies/mL at either the 3rd or 5th study measurement visit, and suboptimal adherence as reporting missing ART dose(s) on ≥ 1 day(s) during the last 30 days at either of these visits. Sensitivity analyses were conducted to assess the consistency of results when elevated viral load was defined as ≥ 1000 copies/mL and suboptimal adherence as reporting missing ART dose(s) on ≥ 2 days during the last 30 days.

Results

Socio-demographic and Clinical Characteristics

A total of 515 PHIV+ youth were enrolled in the overarching CTAAC study between July 2013 and March 2015. Of this sample, 92% (n = 473) attended the 18-month follow-up visit and completed the adolescent-reported SDQ; 97% (n = 461) of caregivers completed the SDQ. No appreciable differences in socio-demographic or clinical characteristics were observed between youth who did and did not attend the 18-month follow-up visit. The median age at 18-month follow-up was 13.6 years, and 50% of adolescents were male (Table 1). At the time of the 18-month follow-up visit, the median duration on ART was 7.8 years.

HIV-Related Stigma

Of youth with completed adolescent-reported SDQ's, 99.8% (n = 472) also completed the HIV-related stigma questionnaire. Overall, participants did not frequently report experiencing HIV-related stigma. In most cases, participants did not report perceived discrimination, fear from others, or a perceived doubt of their integrity. However, 10% did report having been teased ["Sometimes" n = 33 (7%), "All

Table 1 Demographic and clinical characteristics for perinatally HIV-infected (PHIV+) youth

Characteristics	Total sample n (%)
n	473 [100%]
Median age [IQR]	13.56 [12.28;14.9]
Sex	235 [50.32%]
Female	238 [49.68%]
Male	
Ethnicity	444 [93.87%]
Black/African	27 [5.71%]
Mixed Race	2 [<1%]
Other	
Socioeconomic status	120 [25.37%]
Most disadvantaged	169 [35.73%]
Moderately disadvantaged	184 [38.90%]
Least disadvantaged	
Current education	355 [75.05%]
Primary	102 [21.56%]
Secondary	6 [3.38%]
School without grades	
Primary caregiver	295 [62.37%]
Biological parent	128 [27.06%]
Other family member	50 [10.57%]
Non-family member	
Repeated a grade at school	218 [46.09%]
No	255 [53.91%]
Yes	
Median patient–provider relationship score (IQR)	3.5 [3.5–3.58]
Median HIV-stigma score [IQR]	1 [1−1]
Age at ART initiation	177 [38.06%]
0–2 years	128 [27.53%]
3–5 years	160 [34.41%]
6–14 years	
Median ART duration [IQR]	7.78 [4.72–9.3]
ART regimen	284 [60.04%]
2xNRTI+NNRTI	171 [36.15%]
2xNRTI+PI	10 [2.11%]
Other	8 [1.69%]
Unknown	

Table 2 Adolescent report of HIV-related stigma

Item: "Because I or someone in my family is sick with HIV…"	n (%) n = 472
I've been teased	427 (90%)
Not at all	33 (7%)
Sometimes	12 (3%)
All the time	
I've been treated badly	451 (96%)
Not at all	18 (4%)
Sometimes	3 (0.6%)
All the time	
People have gossiped behind my back	433 (92%)
Not at all	33 (7%)
Sometimes	6 (1%)
All the time	
I worry about being rejected	440 (93%)
Not at all	25 (5%)
Sometimes	7 (1%)
All the time	
Parents who know don't want me around their kids	458 (97%)
Not at all	10 (2%)
Sometimes	4 (0.9%)
All the time	
I avoid making new friends	431 (91%)
Not at all	21 (4%)
Sometimes	20 (4%)
All the time	
I feel different and alone	429 (91%)
Not at all	30 (6%)
Sometimes	13 (3%)
All the time	
If people know, they avoid touching me	449 (95%)
Not at all	14 (3%)
Sometimes	8 (2%)
All the time	
If people know, they are afraid of me	455 (96%)
Not at all	10 (2%)
Sometimes	7 (1%)
All the time	
If people know, they think that I am a bad person	454 (96%)
Not at all	12 (3%)
Sometimes	6 (1%)
All the time	
Mean (SD) HIV-related stigma score	0.1 (0.2)

the Time" n = 12 (3%)], 9% experienced feeling different and alone ["Sometimes" n = 30 (6%); "All the Time" n = 13 (3%)], and 8% stated that they avoided making new friends ["Sometimes" n = 21 (4%); "All the Time" n = 20 (4%)] or that people have gossiped behind their backs ["Sometimes" n = 33 (7%); "All the Time" n = 6 (1%)]. The mean score for HIV-related stigma responses was 0.1 [Standard Deviation (SD) = 0.2] based on the 1–3 scoring scale described earlier (Table 2).

Patient–Provider Relationship

Adolescents generally indicated positive experiences when interacting with their healthcare providers for regular ART follow-up visits. Participants reported a median score of 3.5

[Interquartile Range (IQR): 3.5–3.58] on the patient–provider relationship scale, indicating an overall satisfaction with their relationships to their regular healthcare providers (Table 1). The vast majority of participants reported feeling listened to (90%) or cared about (95%) by their healthcare providers, even though a similar proportion felt some fear when speaking to their providers about their problems (95%).

Stigma and SDQ Scores

All adolescent and caregiver reported inventories were significantly correlated ($p < 0.001$) with a moderate linear trend for each subscale (Spearman's ρ 0.28–0.56). No significant differences were found between median reported total difficulties for PHIV+ youth amongst adolescent (5.86; IQR 2–9) and caregiver (6.06; IQR 2–9) reported scores. Unadjusted linear regression revealed significant associations between adolescent reports of perceived HIV-related stigma and each of the adolescent and caregiver-reported difficulty subscales. After adjustment for socio-demographic factors, the associations between perceived HIV-related stigma persisted for all adolescent (Table 3) and caregiver (Table 4) reported difficulty subscales.

On average, higher perceived HIV-related stigma was significantly associated with an 8-point increase on the adolescent-reported total difficulties subscale [Adjusted β Coefficient (Adj.) 8.81, 95% confidence interval (CI) 7; 10.63, $p < 0.001$] and a 7-point increase on the caregiver-reported total difficulties subscale (Adj. 7.85, 95% CI 5.83; 9.87, $p < 0.001$). Similarly, adjusted models for the prosocial strengths subscale revealed that higher perceived HIV-related stigma was significantly associated with lower scores on the adolescent-reported subscale (Adj. −0.72, 95% CI −1.26; −0.17, $p < 0.05$). These associations persisted when stratified by age and sex.

Findings also revealed some associations between SDQ scores and demographic characteristics. Older age at follow-up was associated with lower adolescent-reported hyperactivity scores (Adj. −0.11, 95% CI −0.19; −0.03, $p < 0.05$) and higher adolescent-reported prosocial scores (Adj. 0.11, 95% CI 0.04; 0.19, $p < 0.05$). Higher SES was associated with lower scores on the adolescent (Adj. −0.5, 95% CI −0.84; −0.16, $p < 0.05$) and caregiver (Adj. −0.64, 95% CI −1.07; −0.21, $p < 0.05$) reported hyperactivity scales and the caregiver reported conduct (Adj. −0.54, 95% CI −0.92; −0.17, $p < 0.05$] and total difficulties subscales (Adj. −1.61, 95% CI −2.77; −0.46, $p < 0.05$). Male sex was also associated with lower scores on the caregiver reported conduct (Adj. −0.36, 95% CI −0.63; −0.04, $p < 0.05$) and hyperactivity (Adj. −0.49, 95% CI −0.84; −0.15, $p < 0.05$) subscales.

SDQ Scores, Stigma and Treatment Outcomes

The relationship between SDQ scores and treatment outcomes was examined in a sub-analysis of 428 youth with complete viral load and adherence data (Supplementary Tables V, VI, VII, VIII), with no significant differences in socio-demographic or clinical characteristics observed relative to youth who did not have full adherence and viral load data. After adjustment for age at follow-up, sex, SES, and patient–provider relationship, it was found that a one-point increase in the caregiver reported conduct subscale was associated with a 20% increased likelihood [Adjusted Odds Ratio (Adj. OR) 1.2, 95% CI 1.06; 1.4, $p < 0.05$] of elevated viral load defined as ≥ 50 copies/mL (Table V). Analysis

Table 3 Linear regression models comparing the relationship of perceived HIV-related stigma with adolescent-reported strengths and difficulties scores among perinatally HIV-infected (PHIV+)

Variable[a] coefficient [95% CI]	Emotion	Conduct	Hyper-activity	Peer relations	Prosocial behavior	Total difficulties
HIV-stigma	2.63** [1.87; 3.39]	1.72** [1.16; 2.28]	2.52** [1.93; 3.12]	1.94** [1.34; 2.54]	−0.72* [−1,26; −0.17]	8.81** [7; 10.63]
Age at follow up	−0.05 [−0.16; 0.05]	−0.02 [−0.09; 0.06]	−0.11* [−0.19; −0.03]	−0.05 [−0.14; 0.03]	0.11* [0.04; 0.19]	−0.23 [−0.48; 0.02]
Sex						
Female	Reference	Reference	Reference	Reference	Reference	Reference
Male	0.08 [−0.26; 0.42]	−0.18 [−0.43; 0.07]	−0.23 [−0.5; 0.04]	0.04 [−0.23; 0.3]	0.16 [−0.08; 0.4]	−0.3 [−1.11; 0.51]
Socioeconomic status						
Most disadvantaged	Reference	Reference	Reference	Reference	Reference	Reference
Moderately disadvantaged	0.19 [−0.25; 0.64]	0.01 [−0.3; 0.35]	0.07 [−0.27; 0.42]	0.16 [−0.19; 0.5]	0.004 [−0.31; 0.32]	0.45 [−0.6; 1.5]
Least disadvantaged	−0.2 [−0.63; 0.24]	−0.19 [−0.5; 0.13]	−0.5* [−0.84; −0.16]	0.03 [−0.31; 0.37]	0.1 [−0.21; 0.41]	−0.85 [−1.88; 0.17]
Median scores [IQR]	1.85 [0–3]	1.16 [0–2]	1.4 [0–2]	1.46 [0–2]	9.1 [8–10]	5.86 [2–9]

*p-value < 0.05; **p-value < 0.001

[a]Adjusted models are controlled for age at follow-up, sex, and socio-economic status

Table 4 Linear regression models comparing the relationship of perceived HIV-related stigma with caregiver-reported strengths and difficulties scores among perinatally HIV-infected (PHIV+)

Variable[a] coefficient [95% CI]	Emotion	Conduct	Hyper-activity	Peer relations	Prosocial behavior	Total difficulties
HIV-stigma	2.35** [1.57; 3.14]	2.14** [1.49; 2.79]	2.34** [1.59; 3.1]	1.01** [0.64; 1.81]	0.002 [−0.58; −0.58]	7.85** [5.83; 9.87]
Age at follow up	−0.06 [−0.17; 0.05]	−0.07 [−0.16; 0.02]	−0.1 [−0.21; 0.003]	−0.03 [−0.1; 0.05]	0.02 [−0.62; 0.1]	−0.25 [−0.54; 0.03]
Sex						
Female	Reference	Reference	Reference	Reference	Reference	Reference
Male	0.24 [−0.11; 0.6]	−0.36* [−0.63; −0.04]	−0.49* [−0.84; −0.15]	−0.03 [−0.33; 0.28]	0.2 [−0.06; 0.46]	−0.53 [−1.45; 0.38]
Socioeconomic status						
Most disadvantaged	Reference	Reference	Reference	Reference	Reference	Reference
Moderately disadvantaged	0.33 [−0.12; 0.79]	−0.26 [−0.65; 0.12]	0.02 [−0.44; 0.45]	−0.03 [−0.33; 0.28]	0.6 [−0.28; 0.39]	0.05 [−1.13; 1.23]
Least disadvantaged	−0.24 [−0.69; 0.2]	−0.54* [−0.92; −0.17]	−0.64* [−1.07; −0.21]	−0.18 [−0.48; 0.16]	0.26 [−0.07; 0.59]	−1.61* [−2.77; −0.46]
Median scores [IQR]	1.88 [0–3]	1.35 [0–2]	1.79 [0–3]	1.06 [0–2]	9.06 [8–10]	6.06 [2–9]

*p-value < 0.05; **p-value < 0.001

[a]Adjusted models are controlled for age at follow-up, sex, and socio-economic status

of adolescent-reported adherence in models adjusted for age, sex, and SES revealed that a one-point increase in adolescent-reported prosocial strengths was associated with a 15% decreased likelihood (Adj. OR 0.85; 95% CI 0.74; 0.99, p < 0.05) of reporting a missing ART dose(s) for ≥ 1 day(s) in the last 30 days (Table VI). No other associations between SDQ and viral load or SDQ and suboptimal adherence were found among adjusted models for either adolescent- or caregiver-reported inventories, even after stratification for age and sex. Similarly, an analysis of the relationship between perceived HIV-related stigma and treatment outcomes found no associations. Sensitivity analyses were conducted to assess the consistency of results when elevated viral load was defined as ≥ 1000 copies/mL and sub-optimal adherence as reporting missing ART dose(s) on ≥ 2 days during the last 30 days. Findings remained consistent between adolescent-reported prosocial strengths and adolescent-reported adherence (Table VIII), yet did not persist between elevated viral load and caregiver-reported conduct scores (Table VII).

Discussion

These data are among the first to use the SDQ to assess psychological adjustment in PHIV+ youth in SSA. Findings from this study revealed that HIV-related stigma was significantly associated with all adolescent- and caregiver-reported SDQ difficulty subscales and with adolescent-reported prosocial strengths. Exploration of other possible associations with SDQ scores found significant associations between socio-demographic factors and the adolescent-reported hyperactivity and prosocial scales, as well as the caregiver-reported hyperactivity, conduct, and total difficulties scales. Amongst clinical characteristics, sub-analysis of adolescent- and caregiver-reported SDQ scores and treatment outcomes identified associations between worse scores on the caregiver-reported conduct subscale and elevated viral load (which did not remain consistent after sensitivity analysis), as well as the adolescent-reported prosocial subscale and adolescent report of suboptimal ART adherence (which remained consistent after sensitivity analysis).

The finding that HIV-related stigma is associated with symptoms of psychological distress is consistent with outcomes from other studies conducted among PHIV+ youth in the SSA region [4, 13, 34]. Healthy cognitive and behavioral functioning has been identified to be closely related to a well-regulated self-concept, which can be significantly affected by a high degree of perceived illness-related stigma [4]. Perceived HIV-related stigma prompts internalized fear of gossip, of physical assault, or of discrimination in family and community circles, which can manifest in internalized and externalized symptoms of mental disorders [35]. This is particularly troubling when considering that 1 in 10 adolescents who completed the HIV-stigma questionnaire in this study reported having been teased. Both internal and external awareness of an individual's HIV-status

is also constantly reinforced through daily consumption of medication, frequent medical visits, and witnessing other HIV-related incidences, such as deaths in the household, which are triggers for mental health difficulties [34]. This relationship is exemplified by the consistent and significant effect of HIV-related stigma on SDQ scores across adolescent- and caregiver-reported subscales, despite the relatively infrequent reporting of stigma-related experiences by youth in this study.

We observed few associations between socio-demographic or clinical variables and SDQ scores, consistent with findings from several studies in the US [18, 21, 22, 36]. However, it is important to highlight some of the exceptions identified in this study. For example, the finding that male sex and higher SES were significantly associated with lower scores on the caregiver-reported hyperactivity and conduct subscales contradicts findings by Mellins et al., but is consistent with other literature on adolescent conduct disorders [37]. It is possible that families with more material resources (i.e., better SES) may be more involved in their children's lives in a supervisory or disciplinary role, such that they have fewer perceived symptoms of hyperactivity or conduct problems [38]. Similarly, the finding that older age was associated with lower adolescent-reported hyperactivity and higher prosocial behavior scores, whereas better SES was associated with lower caregiver-reported total difficulty scores may suggest that older youth may have improved inhibition and that youth with better SES may have fewer perceived total difficulties due to reduced neighborhood-related stressors (i.e., violence, crime, etc.) [17]. Certainly, low-SES individuals may face compounded stressors through contextual and socially regulated factors, such as increased exposure to poverty, orphanhood, or inconsistent guardianship, all of which are frequently found in the South African context [39]. These findings reinforce the argument that psychological health in this population is tied to socio-environmental influences [4].

Although we observed few associations between SDQ scores and treatment outcomes, we observed associations between caregiver reports of conduct difficulties and elevated viral load, as well as poorer adolescent-reported prosocial strengths and suboptimal ART adherence. The finding that increased conduct problems are associated with a greater likelihood of elevated viral load is consistent with evidence from studies in the US and Rwanda, where HIV+ children with noted conduct problems were significantly more likely to report suboptimal adherence to treatment [40, 41]. Similarly, studies in the US and SSA have found aspects of better caregiver–child relationships to be linked with better adherence and prosocial strengths in PHIV+ youth, which may explain the associations found here [4, 42, 43]. Given the inherently low level of self-reliance experienced by many youth and adolescents, it is possible that adherence behaviors may be more heavily effected by youth–caregiver relationships than by the youth's mental health. It is also possible that the high prevalence of self-reported positive relationships between patients and their providers could play a role in treatment outcomes. Previous studies have found that patients who feel understood and cared for by their providers had higher rates of medication adherence and undetectable viral loads, which may also influence the associations discussed here [44].

Several limitations deserve emphasis. First, the cross-sectional nature of this study limits causal conclusions in the relationships between SDQ scores and socio-demographic factors or treatment outcomes. Second, the internal consistency observed in some of the SDQ subscales used in this population are slightly lower than those found in some western cohorts, although they were similar to those found in other South African cohorts of a similar age range [30, 45, 46]. This may lower the reliability of the SDQ for measuring psychological adjustment in this cohort and skew overall scores, influencing the relationships observed in this study. Moreover, the sample size for the viral load and ART adherence sub-analysis was smaller than that used for the main analysis, bringing into question the power of statistical analysis to make meaningful comparisons between the groups. The adolescent-reported nature of the SDQ and adherence measures may result in errors inherent to self-reported measures, such as the under/over reporting of behaviors or social desirability bias. Finally, this study did not assess caregiver-related factors that have shown to be related to psychological impairment in PHIV+ youth, such as caregiver mental health status, which may play an important role in assessing the relationships between SDQ scores, stigma, and treatment outcomes [5, 16].

Conclusion

Perceived HIV-related stigma may serve as an important trigger for psychological adjustment issues amongst PHIV+ youth in the South African context. These issues may promote behaviors that are not conducive to positive health outcomes for people living with HIV, such as difficulties with attention or difficulties establishing connections with peers. Poor prosocial strengths and conduct problems may serve as potential indicators for suboptimal adherence, highlighting the importance of understanding psychological adjustment as a way of promoting treatment outcomes. These findings outline the need for further investigation of the socio-environmental factors that may impact HIV-affected South African youth, drawing specific attention to the need for interventions designed around reducing illness-related stigma. Ultimately, these findings highlight

the importance of psychosocial health in achieving positive health outcomes amongst HIV-affected youth overall, and they add to the argument for more integrated use of psycho-social metrics and interventions aimed at reducing illness-related stigma across HIV care in South Africa.

Declarations

Conflict of interest The authors declare that they have no financial or non-financial conflict of interest to disclose.

Ethical approval This study was conducted in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments, and was approved by and conducted in accordance with the standards of the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town (HREC Ref. 215/2013).

Informed Consent Written informed consent was obtained from the primary caregiver of each individual adolescent included in the study, and child assent was obtained.

References

1. HIV and AIDS in adolescents. UNICEF data (cited 15 Nov 2020). https://data.unicef.org/topic/adolescents/hiv-aids/. Accessed 15 Nov 2020.
2. Mellins CA, Brackis-Cott E, Dolezal C, Abrams EJ. Psychiatric disorders in youth with perinatally acquired human immunodeficiency virus infection. Pediatr Infect Dis J. 2006;25(5):432–7.
3. Vreeman RC, Scanlon ML, McHenry MS, Nyandiko WM. The physical and psychological effects of HIV infection and its treatment on perinatally HIV-infected children. J Int AIDS Soc. 2015;18(Suppl 6):20258.
4. Bhana A, Mellins CA, Small L, et al. Resilience in perinatal HIV+ adolescents in South Africa. AIDS Care. 2016;28(Suppl 2):49–59.
5. Louw K-A, Ipser J, Phillips N, Hoare J. Correlates of emotional and behavioural problems in children with perinatally acquired HIV in Cape Town, South Africa. AIDS Care. 2016;28(7):842–50.
6. Chandwani S, Koenig LJ, Sill AM, Abramowitz S, Conner LC, D'Angelo L. Predictors of antiretroviral medication adherence among a diverse cohort of adolescents with HIV. J Adolesc Health Off Publ Soc Adolesc Med. 2012;51(3):242–51.
7. Betancourt TS, Meyers-Ohki SE, Charrow A, Hansen N. Annual research review: mental health and resilience in HIV/AIDS-affected children—a review of the literature and recommendations for future research. J Child Psychol Psychiatry. 2013;54(4):423–44.
8. Bukatko D, Daehler MW. Child development: a thematic approach. Boston: Houghton Mifflin; 2004.
9. Petersen I, Bhana A, Myeza N, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa. A qualitative investigation. AIDS Care. 2010;22(8):970–8.
10. Pantelic M, Boyes M, Cluver L, Meinck F. HIV, violence, blame and shame: pathways of risk to internalized HIV stigma among South African adolescents living with HIV. J Int AIDS Soc. 2017;20:1–9.
11. Dow DE, Turner EL, Shayo AM, Mmbaga B, Cunningham CK, O'Donnell K. Evaluating mental health difficulties and associated outcomes among HIV-positive adolescents in Tanzania. AIDS Care. 2016;28(7):825–33.
12. Midtbø V, Shirima V, Skovdal M, Daniel M. How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. Afr J AIDS Res. 2012;11(3):261–71.
13. Mutumba M, Bauermeister JA, Musiime V, et al. Psychosocial challenges and strategies for coping with HIV among adolescents in Uganda: a qualitative study. AIDS Patient Care STDs. 2015;29(2):86–94.
14. Gentz SG, Calonge Romano I, Martínez-Arias R, Ruiz-Casares M. Predictors of mental health problems in adolescents living with HIV in Namibia. Child Adolesc Ment Health. 2017;22(4):179–85.
15. Boyes M, Cluver L. Relationships between familial HIV/AIDS and symptoms of anxiety and depression: the mediating effect of bullying victimization in a prospective sample of South African children and adolescents. J Youth Adolesc. 2015;44(4):847–59.
16. Gadow KD, Angelidou K, Chernoff M, et al. Longitudinal study of emerging mental health concerns in youth perinatally infected with HIV and peer comparisons. J Dev Behav Pediatr. 2012;33(6):456–68.
17. Kang E, Mellins CA, Dolezal C, Elkington KS, Abrams EJ. Disadvantaged neighborhood influences on depression and anxiety in youth with perinatally acquired human immunodeficiency virus: how life stressors matter. J Community Psychol. 2011;39(8):956–71.
18. Mellins CA, Brackis-Cott E, Leu C-S, et al. Rates and types of psychiatric disorders in perinatally human immunodeficiency virus-infected youth and seroreverters. J Child Psychol Psychiatry. 2009;50(9):1131–8.
19. Nachman S, Chernoff M, Williams P, Hodge J, Heston J, Gadow KD. Human immunodeficiency virus disease severity, psychiatric symptoms, and functional outcomes in perinatally infected youth. Arch Pediatr Adolesc Med. 2012;166(6):528–35.
20. Das-Munshi J, Lund C, Mathews C, Clark C, Rothon C, Stansfeld S. Mental health inequalities in adolescents growing up in post-apartheid South Africa: cross-sectional survey, SHaW Study. PLoS ONE. 2016;11(5):e0154478.
21. Mellins CA, Tassiopoulos K, Malee K, et al. Behavioral health risks in perinatally HIV-exposed youth: co-occurrence of sexual and drug use behavior, mental health problems, and nonadherence to antiretroviral treatment. AIDS Patient Care STDs. 2011;25(7):413–22.
22. Kapetanovic S, Wiegand RE, Dominguez K, et al. Associations of medically documented psychiatric diagnoses and risky health behaviors in highly active antiretroviral therapy-experienced

perinatally HIV-infected youth. AIDS Patient Care STDs. 2011;25(8):493–501.

23. McKernan McKay M, Alicea S, Elwyn L, et al. The development and implementation of theory-driven programs capable of addressing poverty-impacted children's health, mental health, and prevention needs: CHAMP and CHAMP+, evidence-informed, family-based interventions to address HIV risk and care. J Clin Child Adolesc Psychol Off J Soc Clin Child Adolesc Psychol Am Psychol Assoc Div 53. 2014;43(3):428–41.

24. Van Dyke RB, Patel K, Kagan RM, et al. Antiretroviral drug resistance among children and youth in the United States with perinatal HIV. Clin Infect Dis Off Publ Infect Dis Soc Am. 2016;63(1):133–7.

25. Marais DL, Petersen I. Health system governance to support integrated mental health care in South Africa: challenges and opportunities. Int J Ment Health Syst. 2015;9:14.

26. Rudy BJ, Murphy DA, Harris DR, Muenz L, Ellen J. Prevalence and interactions of patient-related risks for nonadherence to antiretroviral therapy among perinatally infected youth in the United States. AIDS Patient Care STDs. 2010;24(2):97–104.

27. McBain R, Salhi C, Morris JE, Salomon JA, Betancourt TS. Disease burden and mental health system capacity: WHO Atlas study of 117 low- and middle-income countries. Br J Psychiatry. 2012;201(6):444–50.

28. Herman AA, Stein DJ, Seedat S, Heeringa SG, Moomal H, Williams DR. The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. South Afr Med J Suid-Afr Tydskr Vir Geneeskd. 2009;99(5 Pt 2):339–44.

29. Bhana A, Mellins CA, Petersen I, et al. The VUKA family program: piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. AIDS Care. 2014;26(1):1–11.

30. Van Roy B, Veenstra M, Clench-Aas J. Construct validity of the five-factor Strengths and Difficulties Questionnaire (SDQ) in pre-, early, and late adolescence. J Child Psychol Psychiatry. 2008;49(12):1304–12.

31. Skinner D, Sharp C, Marais L, Serekoane M, Lenka M. Assessing the value of and contextual and cultural acceptability of the Strength and Difficulties Questionnaire (SDQ) in evaluating mental health problems in HIV/AIDS affected children. Int J Ment Health. 2014;43(4):76–89.

32. Goodman R. The Strengths and Difficulties Questionnaire: a research note. J Child Psychol Psychiatry. 1997;38(5):581–6.

33. Barry OM, Bergh A-M, Makin JD, Etsane E, Kershaw TS, Forsyth BWC. Development of a measure of the patient–provider relationship in antenatal care and its importance in PMTCT. AIDS Care. 2012;24(6):680–6.

34. Woollett N, Black V, Cluver L, Brahmbhatt H. Reticence in disclosure of HIV infection and reasons for bereavement: impact on perinatally infected adolescents' mental health and understanding of HIV treatment and prevention in Johannesburg, South Africa. Afr J AIDS Res. 2017;16(2):175–84.

35. Yi S, Chhoun P, Suong S, Thin K, Brody C, Tuot S. AIDS-related stigma and mental disorders among people living with HIV: a cross-sectional study in Cambodia. PLoS ONE. 2015;10(3):e0121461.

36. Malee KM, Tassiopoulos K, Huo Y, et al. Mental health functioning among children and adolescents with perinatal HIV infection and perinatal HIV exposure. AIDS Care. 2011;23(12):1533–44.

37. Mellins CA, Elkington KS, Leu C-S, et al. Prevalence and change in psychiatric disorders among perinatally HIV-infected and HIV-exposed youth. AIDS Care. 2012;24(8):953–62.

38. Ewart CK. Social action theory for a public health psychology. Am Psychol. 1991;46(9):931–46.

39. Lowenthal ED, Bakeera-Kitaka S, Marukutira T, Chapman J, Goldrath K, Ferrand RA. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. Lancet Infect Dis. 2014;14(7):627–39.

40. Smith Fawzi MC, Ng L, Kanyanganzi F, et al. Mental health and antiretroviral adherence among youth living with HIV in Rwanda. Pediatrics. 2016;138(4). http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5051202/. Accessed 20 Aug 2019.

41. Malee K, Williams P, Montepiedra G, et al. Medication adherence in children and adolescents with HIV infection: associations with behavioral impairment. AIDS Patient Care STDs. 2011;25(3):191–200.

42. Gross R, Bandason T, Langhaug L, Mujuru H, Lowenthal E, Ferrand R. Factors associated with self-reported adherence among adolescents on antiretroviral therapy in Zimbabwe. AIDS Care. 2015;27(3):322–6.

43. Naar-King S, Montepiedra G, Garvie P, et al. Social ecological predictors of longitudinal HIV treatment adherence in youth with perinatally acquired HIV. J Pediatr Psychol. 2013;38(6):664–74.

44. Beach MC, Keruly J, Moore RD. Is the quality of the patient–provider relationship associated with better adherence and health outcomes for patients with HIV? J Gen Intern Med. 2006;21(6):661–5.

45. Williamson A, McElduff P, Dadds M, et al. The construct validity of the Strengths and Difficulties Questionnaire for aboriginal children living in urban New South Wales, Australia. Aust Psychol. 2014;49(3):163–70.

46. de Vries PJ, Davids EL, Mathews C, Aarø LE. Measuring adolescent mental health around the globe: psychometric properties of the self-report Strengths and Difficulties Questionnaire in South Africa, and comparison with UK, Australian and Chinese data. Epidemiol Psychiatr Sci. 2017;27(4):1–12.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.