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BRIEF REPORT

Stigma, Depression, and Substance Use Problems Among Perinatally HIV-Infected Youth in South Africa

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Abstract
A growing population of youth who acquired HIV from their mothers are surviving into adulthood. This group is unique in that they experience both internalized stigma (due to their HIV status) and associative stigma (due to their mothers' HIV status). Results of a cross-sectional survey of 250 perinatally HIV-infected South African youth suggests that internalized stigma is associated with greater risk of depression, and associative stigma is associated with greater risk of depression and substance use problems. Interventions currently focus on internalized stigma; this study highlights the importance of also addressing associative stigma to improve outcomes among perinatally HIV-infected youth.

Keywords HIV · Perinatal infection · South Africa · Stigma · Youth

Resumen
Una población creciente de jóvenes que adquirió el VIH de sus madres está sobreviviendo a la edad adulta. Este grupo es único porque experimenta tanto el estigma internalizado (debido a su estado de VIH) como el estigma asociativo (debido al estado de VIH de su madre). Los resultados de una encuesta transversal de 250 jóvenes sudafricanos infectados por el VIH sugieren que el estigma internalizado se asocia con un mayor riesgo de depresión, y el estigma asociativo se asocia con un mayor riesgo de depresión y problemas de uso de sustancias. Las intervenciones actualmente se enfocan en el estigma internalizado; este estudio destaca la importancia de abordar también el estigma asociativo para mejorar los resultados entre los jóvenes infectados por el VIH en el período perinatal.

Introduction

Advances in HIV treatment and care have led to a growing population of youth who acquired HIV from their mothers and are now surviving into adolescence and early adulthood [1]. The largest population of youth living with HIV (YLWH) is in South Africa, where an estimated 409,000 youth aged 10–24 were living with HIV in 2015 [1, 2]. As of 2015, HIV prevalence was estimated to range from 2.4% among younger adolescents (aged 10–14) to 10.6% among young adults (aged 20–24 years) [1]. Among youth (i.e., adolescents and young adults) in general, these developmental periods are characterized by spikes in depression and experimentation with substances [2]. Among youth living with HIV (YLWH), depression and substance use problems are particularly problematic. Depression is associated with HIV medication nonadherence among YLWH [3], with consequences for both health outcomes and onward HIV transmission. Similarly, substance use is associated with sexual risk behaviors that can lead to onward HIV transmission [4]. In order to effectively intervene, we need a greater understanding of what drives depression and substance use problems among YLWH. HIV stigma (i.e., social devaluation and discrediting associated with HIV [5]) plays an important role in depression and substance use problems among adults living with HIV [5], and

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may likewise be an important driver of these psychosocial and behavioral health outcomes among YLWH.

Evidence suggests that internalized stigma has a particularly deleterious effect on psychosocial and behavioral health among people living with HIV (PLWH). Internalized stigma includes endorsing negative beliefs and feelings about PLWH and applying them to the self [5]. Among adults, internalized stigma is associated with greater risk of depression and substance use [5]. Although there are likely similarities in how YLWH experience internalized stigma as compared to adults, there may also be unique aspects related to being born with and having grown up with HIV. The only known study of internalized stigma among YLWH in South Africa to date found it to be fairly common (26.5%) and associated with depression [6]. Given the documented harmful role of internalized stigma among adult PLWH as well as YLWH, it is critical to further examine internalized stigma among YLWH.

YLWH's experiences of stigma are further shaped by having family members who are also living with HIV. YLWH who acquired HIV from their mothers have at least one family member with HIV, and they often have more than one. YLWH may therefore experience associative stigma, which includes experiences of internalized, experienced, and anticipated stigma due to having a family member living with HIV [7]. Longitudinal research demonstrates that associative stigma is related to greater depressive symptoms among South African youth [8]. Although this study included YLWH (as well as HIV-negative youth), it did not measure internalized stigma nor did it conduct subgroup analyses with YLWH. It is possible that YLWH who internalize greater stigma also experience greater associative stigma, which could result in inflated estimates of impact of associative stigma when not considered simultaneously with internalized stigma. It is therefore important to examine both internalized and associative stigma within the same study to determine their independent effects on outcomes, including depression and substance use problems.

Greater understanding of whether and which stigma mechanisms are associated with depression and substance use problems among South African YLWH can inform targeted efforts to promote HIV treatment and secondary prevention among this growing population. To date, we know of studies that have examined internalized stigma and associative stigma separately among this population [6, 8], but none that have examined them simultaneously. Examining both associative and internalized stigma simultaneously can provide insight into which experiences of stigma are most strongly associated with depression and substance use problems among YLWH, and whether they interact to compound adverse outcomes. The current study therefore explores associations between internalized and associative HIV stigma, depression, and substance use problems among South African YLWH who were born with HIV.

Methods

Procedures and Participants

Study participants (n = 250) included current and former patients of the Paediatric Wellness Clinic, part of the Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital in Soweto, South Africa. Patients were recruited between November 2015 and July 2016, and were eligible to participate if they were between ages 13 and 24 years, aware of their HIV diagnosis, had documented HIV infection before age 10 years, and were literate in English. A documented HIV infection before age 10 years was used as a proxy for perinatal infection. Patients were excluded if they had an acute psychiatric illness or cognitive impairment (excluding depression and/or substance use problems). Participants over age 18 years provided consent to participate and participants under age 18 years provided assent with guardian consent. Participants ranged in age from 13 to 24 years [$M(SD) = 16.34(2.67)$]. More than half (54.4%) of participants identified as female, 41.2% reported food insecurity, and 64.3% were orphans.

Surveys were administered in the clinic via tablets using Qualtrics. Participants received a tutorial on how to use the tablet, and then completed the survey independently in English in a private room. The survey was offered in English due to previous experience at the research site wherein YLWH expressed a preference to complete surveys in English. A study nurse or coordinator was available for the duration of the survey to explain or translate any words or sentences as required. Participants had the opportunity to meet with a staff psychologist if they experienced distress as a result of completing the survey. All procedures received ethics approval from both the Stony Brook University and University of the Witwatersrand's Human Research Ethics Committees.

Measures

Feedback on survey measures from an Adolescent Community Advisory Board was incorporated into the survey prior to its implementation. The survey broadly examined adversity, sexual behavior, psychosocial health, and clinical and sociodemographic variables. This analysis focuses on stigma, depression, and substance use problems.

Stigma

Stigma scales were chosen that had been previously validated in South Africa. Internalized stigma was measured using the Internalized AIDS-Related Stigma Scale [9]. Participants indicated whether they "disagreed" (0) or "agreed" (1) with each item. A preliminary exploratory factor analysis indicated two factors within the measure, with four items measuring internalized stigma (e.g., "I am ashamed that I am HIV positive") and two items measuring disclosure. A sum was created including only the internalized stigma items, ranging 0–4, with higher scores indicating greater internalized stigma (Cronbach's alpha = 0.77). Associative stigma was measured with a stigma-by-association scale [7]. The scale included 10 items (e.g., "feel different or alone"). Participants indicated how often each experience happened to them on a three-point scale, including "not at all" (0), "sometimes" (1), or "all the time" (2). A sum was created, ranging 0-20, with higher scores indicating greater associative stigma (Cronbach's alpha = 0.82). This was further transformed onto a scale of 0–4, by dividing scores by 5, in order to facilitate comparison of the relative influence of internalized and associative stigma.

Outcomes

Depression was measured with the Beck Depression Inventory [10]. The scale includes 21 sets of 4 statements each; participants choose the one that best describes their feelings (e.g., "I do not feel sad" to "I am so sad or unhappy that I can't stand it"). A sum was created (Cronbach's alpha = 0.90). Scores of 20 and above were categorized as moderate to severe depression. Substance use problems were measured with the CRAFFT Screening Questionnaire [11]. The questionnaire includes six items (e.g., "Do you ever use alcohol or drugs to relax, feel better about yourself, or fit in?") used to identify potential substance problems. Participants respond "no" (0) or "yes" (1) to each item. A sum was created, and scores above two were categorized as indicating a substance use problem.

Socio-demographic Characteristics

Information about age, gender, food insecurity, and orphanhood were collected. Food insecurity was assessed with the question: "Would you say people in your home often, sometimes, rarely or never go without food?" Participants reporting that people in their home often went without food were coded as food insecure. Orphanhood was included because previous work suggests that it is associated with both associative HIV stigma and depressive symptoms among youth in South Africa [8].

Analysis

Bivariate and multivariate associations between internalized stigma, associated stigma, and socio-demographic characteristics with depression and substance use problems were examined with Poisson regressions with robust error variances. The interaction between internalized and associative stigma was explored to determine whether these experiences of stigma have a compound or synergistic effect on depression and/or substance use problems. A preliminary diagnostic analysis suggested a lack of collinearity between internalized stigma and associative stigma (variance inflation factor = 1.19), enabling the inclusion of both variables in multivariate regressions.

Results

The average internalized stigma score was 1.68 ($SD = 1.51$), indicating that participants agreed with almost two out of four of the internalized stigma items. The average associative stigma score was slightly lower at 0.93 ($SD = 0.85$). There was a medium-sized positive correlation between internalized and associative stigma ($r = 0.40$). Internalized stigma was not associated with age, food insecurity, or orphanhood. Female participants reported slightly higher internalized stigma [$M(SD) = 1.86(1.52)$] than male participants [$M(SD) = 1.45(1.47)$; $t(df) = 2.10(233)$, $p = 0.02$]. Associative stigma was not associated with age, gender, or orphanhood in this sample. Participants with food insecurity reported greater associative stigma [$M(SD) = 1.14(0.91)$] than participants without food insecurity [$M(SD) = 0.76(0.75)$; $t(df) = 3.44(221)$, $p < 0.001$].

Approximately one-third (33.8%) of participants in this study were classified as moderately to severely depressed and approximately one-fifth (18.0%) reported substance use problems. Results of bivariate and multivariate regression analyses predicting depression and substance use problems are included in Table 1. In the bivariate analyses, internalized [$RR(CI) = 1.27(1.19, 1.34)$] and associative [$RR(CI) = 1.55(1.43, 1.68)$] stigma were both associated with greater risk of depression. In the multivariate analyses, internalized [$RR(CI) = 1.23(1.13, 1.34)$] and associative [$RR(CI) = 1.59(1.37, 1.84)$] stigma remained associated with greater risk of depression after controlling for socio-demographic characteristics. Socio-demographic characteristics were not associated with depression. In the bivariate analyses, associative stigma [$RR(CI) = 1.37(1.16, 1.61)$ was associated with greater risk of substance use problems but internalized stigma was not. In the multivariate analyses,

Table 1 Bivariate and multivariate poisson regression analyses, risk ratio (95% confidence interval)

	Depression		Substance use problems	
	Bivariate models RR (95% CI)	Multivariate model RR (95% CI)	Bivariate models RR (95% CI)	Multivariate model RR (95% CI)
Internalized stigma	1.27 (1.19, 1.34)*	1.23 (1.13, 1.34)*	1.04 (0.93, 1.15)	1.01 (0.86, 1.18)
Associative stigma	1.55 (1.43, 1.68)*	1.59 (1.37, 1.84)*	1.37 (1.16, 1.61)*	1.45 (1.11, 1.90)*
Internalized × associative	1.12 (1.09, 1.14)*	0.96 (0.91, 1.01)	1.05 (0.99, 1.11)	0.99 (0.89, 1.10)
Age	1.02 (0.98, 1.06)	1.03 (0.99, 1.07)	1.11 (1.05, 1.17)*	1.09 (1.03, 1.15)*
Female gender	1.21 (0.98, 1.49)	1.12 (0.93, 1.34)	0.61 (0.44, 0.84)*	0.54 (0.39, 0.74)*
Food insecure	1.17 (0.95, 1.43)	0.94 (0.79, 1.12)	1.00 (0.72, 1.41)	0.95 (0.70, 1.30)
Orphan	0.99 (0.81, 1.21)	0.96 (0.81, 1.15)	1.24 (0.90, 1.71)	1.27 (0.94, 1.73)

*Significant association ($p \leq 0.05$). Internalized stigma, associative stigma, and age were included as continuous variables; female gender, food insecure, and orphan were included as dichotomous variables

associative stigma [$RR(CI) = 1.45(1.11, 1.90)$], but not internalized stigma, was also associated with greater risk of substance use problems after controlling for socio-demographic characteristics. Participants who were older and male were also more likely to have substance use problems. The interaction between internalized and associative stigma was not significant in either of the multivariate models. Additional multivariate linear regression analyses, with depressive symptoms and substance use problems included as continuous outcomes, replicated these findings. That is, these analyses also suggest that internalized [$B(SE) = 1.81(0.72)$, $p = 0.01$] and associative [$B(SE) = 6.08(1.38)$, $p < 0.01$] stigma are associated with greater depressive symptoms, and that associative [$B(SE) = 0.48(0.19)$, $p = 0.01$], but not internalized [$B(SE) = -0.01(0.10)$, $p = 0.97$], stigma is associated with greater substance use problems after controlling for socio-demographic characteristics.

Discussion

Findings from the current study suggest that both internalized and associative stigma undermine the wellbeing of South African YLWH who were born with HIV. YLWH who experienced more internalized stigma were at greater risk of depression, and YLWH who experienced more associative stigma were at greater risk of depression and substance use problems. Previous research among both youth and adults living with HIV has mostly focused on experiences of stigma due to one's own HIV status, including internalized stigma, and has highlighted the deleterious effects of internalized stigma on psychosocial and behavioral health [5, 6]. A smaller body of research has examined the effects of stigma due to one's family member's HIV status, and suggests that associative stigma also undermines health [7, 8]. This is the first known study to examine both internalized and associative stigma simultaneously in order to determine which experiences of stigma are associated with psychosocial and behavioral health outcomes. Results suggest that internalized and associative stigma may both be associated with greater risk of depression among South African YLWH who were born with HIV, and associative stigma may be uniquely associated with substance use problems. Moreover, these results suggest that internalized and associative stigma may not interact to compound adverse outcomes.

The ways in which associative and internalized stigma were operationalized may have contributed to the study's findings. Associative stigma was operationalized as a combination of internalized, experienced, and anticipated stigma due to having a family member living with HIV. It is possible that YLWH engage in substance use to cope with experienced and anticipated associative stigma from others, which may include gossip and verbal taunts about their parents living with HIV, rather than internalized stigma [8]. Future research should examine both internalized, experienced, and anticipated stigma due to one's own HIV diagnosis as well as internalized, experienced, and anticipated stigma due to having a family member living with HIV simultaneously to continue to understand which of these unique experiences of stigma contribute to wellbeing among South African YLWH.

Strengths of the current study include a focus on an understudied but rapidly expanding population of YLWH who were born with HIV in South Africa. Strengths also include examining internalized and associative stigma simultaneously to determine which experiences are associated with psychosocial and behavioral health outcomes. Limitations include the cross-sectional study design, which prevents us from forming firm hypotheses regarding causal associations. Yet, longitudinal research suggests that early experiences of stigma are associated with subsequent negative health outcomes among youth with other stigmatized characteristics [12]. Research that follows YLWH over time can better establish causal pathways,

inform understanding of how HIV stigma changes with age, and test whether there are sensitive periods when HIV stigma has a particularly strong impact on wellbeing [12]. The study included a convenience sample of YLWH with long-term access to high quality medical care, and may therefore not generalize to all South African YLWH. HIV stigma is a global phenomenon, and youth affected by HIV (including YLWH and other youth with parents living with HIV) experience associative stigma and are at increased risk of psychological distress in contexts other than South Africa (e.g., China and the United States) [8]. Moreover, stigma undermines the wellbeing of youth with other stigmatized characteristics such as minority races and ethnicities [12]. Future research should examine whether the findings of the current study generalize to YLWH who do not have access to high quality medical care, YLWH in other socio-cultural contexts and geographic locations, and youth living with other stigmatized health conditions.

This study suggests that both internalized and associative HIV stigma undermine the wellbeing of YLWH and are therefore critical targets for intervention. Pantelic and colleagues note that no known interventions currently exist to address internalized HIV stigma among African YLWH [6], and there is a similar dearth of interventions to address associative HIV stigma among this population. Research is needed to develop, test, and implement strategies to reduce and build resilience to both internalized and associative stigma among YLWH. Interventions that foster empowerment and strengthen self-worth may reduce internalized stigma among YLWH [5]. Interventions that enhance social support and adaptive coping skills may strengthen resilience to stigma among YLWH, and evidence suggests that parents and other caregivers can play an important role in both providing social support and teaching adaptive coping strategies to their children [5]. It may be particularly important to teach YLWH adaptive coping strategies so that they do not engage in maladaptive forms of coping, such a substance use, in response to experiences of stigma. Healthcare providers should screen YLWH for depression and substance use problems, and consider interventions that address internalized and associative stigma for YLWH indicating these issues. Greater attention to the experiences of both internalized and associative stigma experienced by YLWH who were born with HIV is needed from researchers, healthcare professionals, policymakers, and others to support the wellbeing of this growing population.

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Compliance with Ethical Standards

Conflict of interest The authors declare no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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