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Local Service Category:	<b>Mental Health Services</b>
Amount Available:	<b>To be determined</b>
Unit Cost	
Budget Requirements or Restrictions ( <b>TRG Only</b> ):	Maximum of 10% of budget for Administrative Cost.
DSHS Service Category Definition	<p>Mental Health Services include psychological and psychiatric treatment and counseling services offered to individuals with a diagnosed mental illness, conducted in a family/couples, group or individual setting, based on a detailed treatment plan, and provided by a mental health professional licensed or authorized within the State to provide such services, typically including psychiatrists, psychologists, and licensed clinical social workers.</p> <p>Mental health counseling services includes outpatient mental health therapy and counseling (individual and family/couple) provided solely by Mental Health Practitioners licensed in the State of Texas.</p> <p>Mental health services include:</p> <ul style="list-style-type: none"> <li>• Mental Health Assessment</li> <li>• Treatment Planning</li> <li>• Treatment Provision</li> <li>• Individual psychotherapy</li> <li>• Family psychotherapy</li> <li>• Conjoint psychotherapy</li> <li>• Group psychotherapy</li> <li>• Psychiatric medication assessment, prescription and monitoring</li> <li>• Psychotropic medication management</li> <li>• Drop-In Psychotherapy Groups</li> <li>• Emergency/Crisis Intervention</li> </ul> <p>General mental health therapy, counseling and short-term (based on the mental health professional's judgment) bereavement support is available for family members or significant others of people living with HIV.</p>
Local Service Category Definition:	<p><b>Individual Therapy/counseling</b> is defined as 1:1 or family-based crisis intervention and/or mental health therapy provided by a licensed mental health practitioner to an eligible person living with HIV.</p> <p><b>Family/Couples Therapy/Counseling</b> is defined as crisis intervention and/or mental health therapy provided by a licensed mental health practitioner to a family or couple (opposite-sex, same-sex, transgendered or non-gender conforming) that includes an eligible person living with HIV.</p> <p><b>Support Groups</b> are defined as professionally led (licensed therapists or counselor) groups that comprise people living with HIV, family members, or significant others for the purpose of providing emotional support directly related to the stress of caring for people living with HIV.</p>
Target Population (age, gender, geographic, race, ethnicity, etc.):	People living with HIV and affected individuals living within the Houston HIV Service Delivery Area (HSDA).
Services to be Provided:	Agencies are encouraged to have available to PLWH all modes of counseling services, i.e., crisis, individual, family, and group. Sessions may be conducted in-home. Agency must provide professional support group sessions led by a licensed counselor.

<p>Service Unit Definition(s) <b>(TRG Only):</b></p>	<p><b>Individual Crisis Intervention and/or Therapy:</b> A unit of service is defined as an individual counseling session lasting a minimum of 45 minutes.</p> <p><b>Family/Couples Crisis Intervention and/or Therapy:</b> A unit of service is defined as a family/couples counseling session lasting a minimum of 90 minutes.</p> <p><b>Group Therapy:</b> A unit of service is defined as one (1) eligible PLWH attending 90 minutes of group therapy. The minimum time allowable for a single group session is 90 minutes and maximum time allowable for a single group session is 120 minutes. No more than one unit may be billed per session for an individual or group session.</p> <p>A minimum of three (3) participants must attend a group session in order for the group session to eligible for reimbursement.</p> <p><b>Consultation:</b> One unit of service is defined as 15 minutes of communication with a medical or other appropriate provider to ensure case coordination.</p>
<p>Financial Eligibility:</p>	<p>Income at or below 500% Federal Poverty Guidelines.</p>
<p>Eligibility for Services:</p>	<p>For individual therapy session, person living with HIV or the affected significant other of a person living with HIV, resident of Houston HSDA.</p> <p>Person living with HIV must have a current DSM diagnosis eligible for reimbursement under the State Medicaid Plan.</p> <p>PLWH must not be eligible for services from other programs or providers (i.e. MHMRA of Harris County) or any other reimbursement source (i.e. Medicaid, Medicare, Private Insurance) unless the PLWH is in crisis and cannot be provided immediate services from the other programs/providers. In this case, PLWH may be provided services, if the PLWH applies for the other programs /providers, until the other programs/providers can take over services.</p> <p>Medicaid/Medicare, Third Party Payer and Private Pay status of PLWH receiving services under this grant must be verified by the provider prior to requesting reimbursement under this grant. For support group sessions, PLWH must be either a person living with HIV or the significant other of person living with HIV.</p> <p>Affected significant other is eligible for services only related to the stress of caring for a person living with HIV.</p>
<p>Agency Requirements <b>(TRG Only):</b></p>	<p>Agency must provide assurance that the mental health practitioner shall be supervised by a licensed therapist qualified by the State to provide clinical supervision. This supervision should be documented through supervision notes.</p> <p>Keep attendance records for group sessions.</p> <p>Must provide 24-hour access to a licensed counselor for current PLWH with</p>

	<p>emotional emergencies.</p> <p>PLWH eligible for Medicaid or 3rd party payer reimbursement may not be billed to grant funds. Medicare Co-payments may be billed to the contract as ½ unit of service.</p> <p>Documentation of at least one therapist certified by Medicaid/Medicare on the staff of the agency must be provided in the proposal. All funded agencies must maintain the capability to serve and seek reimbursement from Medicaid/Medicare throughout the term of their contract. Potential PLWH who are Medicaid/ Medicare eligible may not be denied services by a funded agency based on their reimbursement status (Medicaid/Medicare eligible PLWH may not be referred elsewhere in order that non-Medicaid/Medicare eligible PLWH may be added to this grant). Failure to serve Medicaid/Medicare eligible PLWH based on their reimbursement status will be grounds for the immediate termination of the provider’s contract.</p> <p>Must comply with the State Services Standards of Care.</p> <p>Must provide a plan for establishing criteria for prioritizing participation in group sessions and for termination from group participation.</p> <p>Providers and system must be Medicaid/Medicare certified to ensure that Ryan White funds are the payer of last resort.</p>
<p>Staff Requirements:</p>	<p>It is required that counselors have the following qualifications: Licensed Mental Health Practitioner by the State of Texas (LCSW, LMSW, LPC PhD, Psychologist, or LMFT).</p> <p>At least two years’ experience working with HIV disease or two years’ work experience with chronic care of a catastrophic illness.</p> <p>Counselors providing family sessions must have at least two years’ experience in family therapy.</p> <p>Counselors must be covered by professional liability insurance with limits of at least \$300,000 per occurrence.</p>
<p>Special Requirements <b>(TRG Only):</b></p>	<p>All mental health interventions must be based on proven clinical methods and in accordance with legal and ethical standards. The importance of maintaining confidentiality is of critical importance and cannot be overstated unless otherwise indicated based on Federal, state and local laws and guidelines (i.e. abuse, self or other harm). All programs must comply with the Health Insurance Portability and Accountability Act (HIPAA) standards for privacy practices of protected health information (PHI) information.</p> <p>Mental health services can be delivered via telehealth and must follow applicable federal and State of Texas privacy laws.</p> <p>Mental health services that are provided via telehealth must be in accordance with State of Texas mental health provider practice requirements, see Texas Occupations Code, Title 3 Health Professions and <a href="#">chapter 111 for Telehealth &amp; Telemedicine</a>.</p>

When psychiatry is provided as a mental health service via telehealth then the provider must follow guidelines for telemedicine as noted in Texas Medical Board (TMB) guidelines for providing telemedicine, Texas Administrative Code, Texas Medical Board, Rules, Title 22, Part 9, Chapter 174, RULE §174.1 to §174.12

Medicare and private insurance co-payments are eligible for reimbursement under this grant (in this situation the agency will be reimbursed the PLWH's co-payment only, not the cost of the session which must be billed to Medicare and/or the Third-party payer). Extensions will be addressed on an individual basis when meeting the criteria of counseling directly related to HIV illness. Under no circumstances will the agency be reimbursed more than two (2) units of individual therapy per PLWH in any single 24-hour period.

Agency should develop services that focus on the most current Special Populations identified in the *Houston Area Comprehensive Plan for HIV Prevention and Care Services* including Adolescents, Homeless, Incarcerated & Recently Released (IRR), Injection Drug Users (IDU), Men who Have Sex with Men (MSM), and Transgender populations. Additionally, services should focus on increasing access for individuals living in rural counties.

Must comply with the Houston EMA/HSDA Standards of Care. The agency must comply with **the DSHS Mental Health Services Standards of Care**. The agency must have policies and procedures in place that comply with the standards *prior* to delivery of the service.

***FY 2024 RWPC “How to Best Meet the Need” Decision Process***

<b>Step in Process: Council</b>		Date: <b>06/08/2023</b>
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
<b>Step in Process: Steering Committee</b>		Date: <b>06/01/2023</b>
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
<b>Step in Process: Quality Improvement Committee</b>		Date: <b>05/2023</b>
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
<b>Step in Process: HTBMTN Workgroup #2</b>		Date: <b>04/19/2023</b>
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

## Modified Monitoring Process

Effective March 13, 2020 TRG enacted emergency response procedures due to COVID-19 pandemic. All monitoring was deferred/suspended in 2020 per DSHS and HRSA guidance.

In 2020, DSHS launched a burden reduction plan to reduce administrative burden by 50% for AA's and Subrecipients.

- This model requires subrecipient monitoring every other year (even years only).
- Per DSHS guidance, TRG is not required to complete monitoring in odd years
- In 2020, subrecipients that didn't have the ability to complete a remote review, were exempted from the 2020 Standards of Care chart review monitoring due to the COVID-19 State of Emergency.

## 2022 Monitoring

This year all subrecipients will be monitored, remotely if possible and in-person if necessary.

The monitoring period will cover calendar year 2021



Special chart review process is being evaluated for the RW Planning Council process during the "odd" years DSHS is not requiring monitoring (requires DSHS approval)

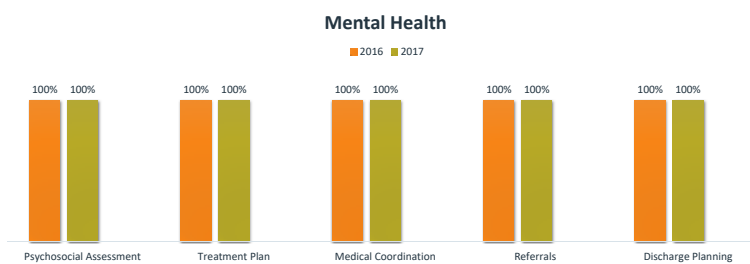
# Mental Health (MH)

NOT REVIEWED IN 2020 DUE TO NO REMOTE ACCESS

## Description of Service

Mental Health Services are treatment and counseling services offered to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services.

## Chart Review Highlights- 2018



Indicators reviewed in 2017 that were met at <50% were not reviewed in 2018. Only one indicator was reviewed in 2018, which was a new indicator





# The associations between HIV stigma and mental health symptoms, life satisfaction, and quality of life among Black sexual minority men with HIV

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Accepted: 3 January 2023

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## Abstract

**Purpose** With the advancement of antiretroviral therapy (ART), HIV/AIDS has become a manageable illness, similar to other chronic conditions. This study examined the associations between HIV stigma and patient-reported outcomes including mental health symptoms, life satisfaction, and quality of life among Black sexual minority men with HIV.

**Methods** We analyzed baseline data from a randomized comparison trial of a mobile app intervention aimed to address the social work and legal needs of Black sexual minority men with HIV in Los Angeles County. We used validated scales including the Berger HIV stigma scale, the Patient Health Questionnaire-9 & the General Anxiety Disorder-7, the Satisfaction with Life Scale, and the Ladder Scale to assess HIV stigma, depressive symptoms, anxiety, life satisfaction, and quality of life, and we conducted multivariable linear regression to examine their associations.

**Results** Participants experienced HIV stigma especially about disclosure concerns (e.g., 81.9% participants indicated “*I am very careful who I tell that I have HIV*”) and public attitudes (52.3% believed “*Most people with HIV are rejected when others find out*”). In the multivariable models, higher overall stigma scores were associated with higher likelihood of experiencing depression (adjusted  $b = 0.235$ ,  $p < 0.001$ ) and anxiety (adjusted  $b = 0.188$ ,  $p = 0.002$ ), and lower life satisfaction (adjusted  $b = -0.236$ ,  $p < 0.001$ ) and quality of life (adjusted  $b = -0.053$ ,  $p = 0.013$ ), adjusting for clinical characteristics including ART initiation, viral load suppression, and medication adherence. In addition, being attacked or harassed in the past year were significantly associated with lower life satisfaction and quality of life (adjusted  $b = -3.028$ ,  $p = 0.046$ ; adjusted  $b = -1.438$ ,  $p = 0.002$ ).

**Conclusion** Our findings highlight the need for focused HIV stigma reduction interventions to promote the overall well-being of Black sexual minority men with HIV. Strategies to promote the patient-reported outcomes may benefit from trauma-informed approaches.

**Keywords** HIV stigma · Depression · Anxiety · Life satisfaction · Quality of life · Black sexual minority men

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## Introduction

With the advancement of antiretroviral therapy (ART), HIV/AIDS has become a manageable illness, similar to other chronic conditions. People living with HIV (PLWH) who initiate ART and sustain virologic suppression now have a similar life expectancy as those in the general population [1, 2]. In the past decade, significant progress has been made toward the 95–95–95 target of ending the HIV/AIDS epidemic in 2030 [3]. This refers to 95% of PLWH who knowing their HIV status, 95% of PLWH receiving ART, and 95% of PLWH receiving ART achieving viral suppression [4]. This Fast-Track approach also includes ambitious

target for zero discrimination. Now researchers propose a ‘fourth target’—PLWH with viral suppression having good health-related quality of life, which entails attention to two domains—comorbidities and self-perceived quality of life [5]. The newly added target emphasizes the social and psychological well-being of PLWH beyond clinical treatment outcomes. In fact, there has been ongoing research on patient-reported outcomes (PROs) among PLWH in many settings, and it has been gradually recognized as an essential indicator of assessing the overall well-being of PLWH [6–8]. Such PROs include life satisfaction, mental health outcomes, weight and pain management, and self-efficacy [9].

In the past, researchers have examined and identified factors associated with patient-reported outcomes among PLWH, which include demographic characteristics and behavioral health factors [7, 10, 11]. Among these, one factor that plays a persistent role is HIV stigma [12, 13], which refers to prejudice and discrimination directed at people perceived to have HIV/AIDS and individuals, groups, and communities associated with the disease [14]. Herek (2002) noted that HIV stigma is a construct that explains both the negative attitudes toward people with HIV, often manifested by discrimination, and internalized negative beliefs, views, and feelings experienced by those living with HIV [15]. Turan et al. also emphasized that HIV stigma is a multi-dimensional phenomenon consisting of internalized, perceived, anticipated, and experienced stigma [16]. Indeed, prior studies have demonstrated that HIV stigma is a considerable barrier to accessing HIV treatment and prevention services and a major factor for the overall health-related quality of life among PLWH [17, 18]. For example, HIV stigma has been associated with never having received an HIV test, delayed ART initiation, and lower ART adherence and retention in HIV care [19, 20]. Moreover, stigmatization in different forms could also materialize into discriminative actions and pose obstacles that eliminate or exclude PLWH from accessing equal opportunities such as employment, education, and legal services [18]. A comprehensive systematic review and meta-analysis of the literature in the past 40 years suggested that HIV/AIDS stigma was negatively associated with well-being among PLWH and these associations were stronger among older PLWH [21]. In recent years, standardized measurement tools were also developed to assess stigma as a domain of quality of life among people living with HIV [22, 23]. Another recently published systematic review revealed despite the growing numbers of interventions on reducing stigma, there is a lack of well-designed interventions that documented stigma reduction among PLWH and few studies measured such effects on improving patient outcomes [18].

In the United States, Black sexual minority men living with HIV are disproportionately impacted by HIV and have poor treatment outcomes along the HIV care continuum

compared to their White and Latino counterparts [24]. For instance, compared to White sexual minority men, Black sexual minority men living with HIV have 8.2 times higher HIV incidence, and 6.5 times greater HIV mortality [25]. Studies also suggest that Black sexual minority men with HIV have lower retention in HIV care [26] and are less likely to be virally suppressed than their White counterparts [27, 28]. Individual and structural barriers, including HIV stigma, may increase morbidity, leading to worse patient outcomes among this population at the intersection of multiple vulnerabilities. Furthermore, the effects of HIV stigma may be pronounced among Black sexual minority men with HIV who also experience other forms of stigmatization and marginalization based on other identities, including sexual orientation and race, compared to the general population of PLWH.

### The current study

To better understand the mechanisms by which HIV stigma influences the social and psychological well-being of Black sexual minority men living with HIV and provide insights into the development of stigma reduction interventions, this study aims to document HIV stigma using a validated instrument, and to examine the associations between HIV stigma and patient-reported outcomes (PROs) in a sample ( $n=122$ ) of Black sexual minority men living with HIV in Los Angeles County, California. Specifically, we hypothesized that higher levels of HIV stigma would be associated with higher levels depression and anxiety, lower life satisfaction, and lower quality of life.

## Materials and methods

### Study procedures

We analyzed baseline data from a randomized comparison trial of a community-developed, web-based mobile app intervention that aimed to address the social work and legal needs of Black sexual minority men living with HIV, described elsewhere [29]. Briefly, Black sexual minority men living with HIV were recruited via online social media and community outreach events. To be eligible for the study, participants were required to: (1) be 18 years old or above, (2) self-identify male, (3) identify as Black/African American, (4) identify as gay, bisexual, or another sexual minority, and (5) and be living in Los Angeles County. Participants were also required to have a smartphone and be able to provide informed consent. Study procedures were reviewed and approved by the Institutional Review Board at the University of California Los Angeles. All respondents

provided informed consent and were offered monetary compensation of up to USD 130 for their participation in the research.

## Measures

**Sociodemographic and clinical characteristics.** Study participants were asked to report their age, birthplace, education and income level, number of children, and insurance status. In addition, participants were asked about their most recent CD4 and viral load, whether they were currently taking antiretroviral therapy (ART), and if so, how long they had received ART. Participants were also asked to self-report their ability to take all HIV medications as prescribed (options from very poor to excellent). See Table 1 for a complete list of demographic characteristics.

**HIV stigma.** HIV stigma was assessed using the adapted Berger HIV stigma scale [30]. This 10-item scale assessed four stigma subscales: (1) personalized stigma, (2) disclosure concerns, (3) negative self-image, and (4) public attitudes. All questions were rated on a five-point scale from “strongly disagree (0)” to “strongly agree (4)”, with a total possible score ranging from 0 to 40. A full description of the 10 items and distributions are presented in Table 2. The abbreviated scale was validated and showed good internal consistency in previous studies among PLWH [31, 32]. In the current sample internal consistency on the adapted Berger HIV stigma scale was also high (Cronbach’s alpha = 0.87).

## Patient-reported outcomes

**Depression.** We used the Patient Health Questionnaire-9 (PHQ-9) to measure depression [33]. This 9-item measure assessed how often the participant had experienced depressive symptoms over in the past 2 weeks, including “feeling down, depressed, or hopeless” and “Feeling bad about yourself—or that you are a failure or have let yourself or your family down?”. Response options included “not at all” (0), “several days” (1), “more than half the days” (2), and “nearly every day” (3). A total score was summed and presented from 0 to 27, and scores of 5, 10, 15, and 20 represent cut-off points for mild, moderate, moderately severe, and severe depression. To screen for depression, a PHQ-9 of 10 or greater is recommended for referral for further evaluation [33]. The Cronbach’s alpha for PHQ-9 among the study sample was 0.86.

**Anxiety.** The General Anxiety Disorder-7 (GAD-7) was used to measure anxiety among the participants<sup>30</sup>. The 7-item survey asked the participants questions about how often they were bothered by a list of anxiety-related symptoms over the past 2 weeks (e.g., *feeling nervous, anxious, or on edge*). A score of 10 or higher was considered

**Table 1** Characteristics of Black sexual minority men with HIV in Los Angeles County, California ( $n = 122$ )

	$n$ (%)
Social behavioral characteristics	
Age (range: 18 – 74; mean = 37.2; SD = 12.7)	
18–24	19 (15.6%)
25–34	43 (35.2%)
35–44	24 (19.7%)
45 and above	36 (29.5%)
Born in Los Angeles	53 (43.4%)
Born in the U.S	107 (87.7%)
Employment status	
Employed	44 (36.1%)
Unemployed	29 (23.8%)
Retired	6 (4.9%)
Disabled	40 (32.8%)
Decline to answer	3 (2.5%)
Income level	
< \$12,000	46 (37.7%)
≥ \$12,000	69 (56.6%)
Decline to answer	7 (5.7%)
Education	
College and above	18 (14.8%)
Some college	57 (46.7%)
High school and below	47 (38.5%)
Have at least one child	14 (11.5%)
Always have insurance in the past 5 years	91 (74.6%)
Did not get medical care when you needed it in the past year	15 (12.3%)
Did not get medication when you needed it in the past year	21 (17.2%)
Had been attacked or harassed in the past year	45 (36.9%)
Had been attacked with violence in the past year	28 (23.0%)
Had been a victim of any other crime in the past year	25 (20.5%)
Had been incarcerated in the past 5 years	31 (25.4%)
Clinical characteristics	
Receiving ART	115 (94.3%)
Started ART within 5 years	48 (41.7%) <sup>1</sup>
Viral load less than 200 copies/ml	71 (61.7%) <sup>1</sup>
Self-report very good medication adherence	82 (71.3%) <sup>1</sup>
Patient-reported outcomes	
Depression (PHQ9 > 9)	46 (37.7%)
Anxiety (GAD7 > 9)	45 (36.8%)
Satisfaction with Life (SWLS > 25)	35 (28.7%)
Quality of life (Cantril’s ladder scale)	
Thriving	61 (50.0%)
Struggling	45 (36.9%)
Suffering	16 (13.1%)

SD: standard deviation ART: antiretroviral therapy PHQ9: Patient Health Questionnaire-9 GAD7: General Anxiety Disorder-7 SWLS: Satisfaction with Life Scale

<sup>a</sup> Percentage among those who initiated ART

**Table 2** HIV stigma score among Black sexual minority men with HIV in Los Angeles ( $n = 122$ )

	Mean (SD)	Strongly agree or agree $n$ (%)
<i>Personalized stigma (range 0 – 12)</i>	5.148 (4.159)	
I have been hurt by how people reacted to learning I have HIV	1.943 (1.607)	56 (45.9)
I have stopped socializing with some people because of their reactions to my having HIV	1.828 (1.650)	51 (41.8)
I have lost friends by telling them I have HIV	1.377 (1.496)	35 (28.7)
<i>Disclosure concerns (range 0 – 8)</i>	5.779 (2.262)	
I am very careful who I tell that I have HIV	3.352 (1.149)	100 (81.9)
I worry that people who know I have HIV will tell others	2.426 (1.526)	69 (56.5)
<i>Negative self-image (range 0 – 12)</i>	2.893 (3.468)	
I feel that I am not as good a person as others because I have HIV	0.951 (1.316)	21 (17.2)
Having HIV makes me feel unclean	1.213 (1.506)	32 (26.3)
Having HIV makes me feel that I'm a bad person	0.730 (1.172)	15 (12.3)
<i>Public Attitude (range 0 – 8)</i>	4.574 (2.479)	
Most people think that a person with HIV is disgusting	2.148 (1.441)	58 (47.5)
Most people with HIV are rejected when others find out	2.426 (1.354)	65 (52.3)
<i>Total score (range 0 – 40)</i>	18.393 (9.760)	–

experiencing anxiety [34]. The Cronbach's alpha for GAD-7 among our study participants were 0.89.

**Life Satisfaction.** The Satisfaction With Life Scale (SWLS) was used to evaluate participants' global life satisfaction [35]. This 5-item measure assessed life satisfaction using questions that included, "In most ways my life is close to my ideal". Participants answered using a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The possible range of SWLS scores was 5–35. Based on prior literature [35], a SWLS score greater than 25 was used to indicate life satisfaction. The Cronbach's alpha of SWLS in the current sample was 0.83.

**Quality of Life.** Quality of life was measured using an abbreviated one-item Cantril Ladder Scale [36]. Specifically, participants were asked, "Suppose the top of the ladder represents the best possible life for you and the bottom of the ladder the worst possible life. Where on the ladder do you feel you stand at the present time?". Consistent with prior work, the 0–10 Likert scale was divided into three levels of well-being: *Thriving* (7–10), *Struggling* (5–6), and *Suffering* (< 5) [37]. Thriving indicates that well-being is strong, consistent, and progressing, and has been previously associated with fewer health problems and more happiness and enjoyment [36].

## Study covariates

We consider including study covariates given the evidence in the literature or the theoretical plausibility of their associations with the study exposures and outcomes. Social support has been previously associated with both HIV stigma and mental health outcomes among people with HIV

[38, 39] as have histories of victimization and incarceration [40, 41]. These variables were therefore included in the adjusted model.

**Social support.** Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) [42]. The MSPSS measures three different sources of support: (1) family, (2) friends, and (3) significant others, with questions like "There is a special person who is around when I am in need." and "My family is willing to help me to make decisions". Each item was measured on a 7-point Likert scale and all items were summed to create a total score where higher values indicated greater social support (range: 12–84). The Cronbach's alpha coefficient for the MSSPS in this sample was 0.92.

**Experiences of victimization and incarceration.** We assessed victimization by asking participants a set of questions including "Were you attacked or harassed", "Were you attacked with violence", and "have you been a victim of another crime" in the past year. We also asked if participants whether they had ever been incarcerated in the past 5 years. All four of these variables were coded 1 = yes and 0 = no, and each variable represented a history of victimization or incarceration.

## Statistical analysis

We used descriptive statistics to summarize the characteristics of the study participants. Bivariate correlation coefficients were calculated between HIV stigma, PROs, and other covariates. To assess the association between HIV stigma and each PRO, we conducted multivariable linear

regression controlling for sociodemographic and clinical characteristics and study covariates. All PROs were used as continuous variables. Results are reported as beta coefficient (*b*) with corresponding standard error (SE), and a *p*-value less than 0.05 was considered statistically significant.

## Results

### Characteristics

Among all participants (*n* = 122), the mean age was 37.2 (SD = 12.7, range: 18–74), and 43.4% were born in Los Angeles. About one-third (36.1%) were currently employed, and 37.7% had an annual income of \$12,000 or less. Over sixty percent (61.5%) had at least some college education. Nearly all (94.3%) were receiving ART, and over half of those participants (58.3%) had been on ART for more than 5 years. Less than two-thirds (61.7%) reported having a viral load of fewer than 200 copies/ml, and 71.3% indicated being excellent or very good at taking HIV medications. One in three (36.9%) reported being attacked or harassed in the past year, and over a quarter (25.4%) reported that they had been incarcerated in the past 5 years (Table 1).

### HIV stigma and associated factors

Participants scored high on HIV stigma measures (Table 2). Specifically, participants indicated high rates of *Disclosure Concerns*—a majority (81.9%) noted that they were very careful about to whom they tell their HIV status, and over half (56.5%) indicated that they worried that people who know they have HIV would tell others. Regarding *Public Attitude*, over half (52.3%) (strongly) agreed that most people with HIV are rejected when others find out. Nearly half (47.5%) noted that most people think that a person with HIV is disgusting; 45.9% indicated they had been hurt by how people reacted to learning that they had HIV; and 41.8% reported stopping socializing with some people because of their reactions to the participant’s HIV disclosure. The correlation coefficients of HIV stigma and all other study key variables are presented in Table 3.

### Patient-Reported outcomes and associated factors

As presented in Table 1, more than one-third (37.7%) of participants screened positive for depression based on PHQ-9 score, and about the same percentage screened positive for anxiety (36.8%). Based on the SWLS, less than one-third (28.7%) of the participants reported being satisfied

**Table 3** Descriptive statistics and correlation matrix of main measures

	1	1a	1b	1c	1d	2	3	4	5	6	Skewness	Kurtosis	Mean (SD)
1 HIV stigma	–										0.31	–0.63	1.84 (0.98)
1a Personalized stigma	0.85**	–									0.16	–1.27	5.15 (4.16)
1b Disclosure concerns	0.69**	0.46**	–								–0.92	0.08	5.78 (2.26)
1c Negative self-image	0.78**	0.48**	0.36**	–							0.93	–0.26	2.89 (3.47)
1d Public Attitude	0.80**	0.57**	0.52**	0.53**	–						–0.29	–0.92	4.57 (2.48)
2 MSSPS	–0.02*	–0.14*	–0.21*	–0.18	–0.21*	–					0.74	0.31	8.07 (5.90)
3 PHQ9	0.44**	0.32**	0.22*	0.41**	0.41**	–0.25**	–				0.68	–0.26	8.31 (6.43)
4 GAD7	0.32**	0.25**	0.20*	0.26**	0.32**	0.74**	–0.21*	–			–0.08	–0.83	20.5 (7.63)
5 SWLS	–0.36**	–0.25**	–0.20*	–0.33**	–0.37**	–0.48**	–0.36**	0.20*	–		–0.46	0.47	6.46 (2.23)
6 Ladder Scale	–0.29**	–0.26**	–0.12	–0.23*	–0.29**	–0.47**	–0.43**	–0.58**	0.33**	–			

\**p* < 0.05; \*\**p* < 0.01

MSPSS: Multidimensional Scale of Perceived Social Support

PHQ9: Patient Health Questionnaire-9

GAD7: General Anxiety Disorder-7

SWLS: Satisfaction with Life Scale

**Table 4** Associations between HIV stigma and patient-reported quality of life measures among Black sexual minority men with HIV ( $n=122$ )

	PHQ-9		GAD-7		SWLS		Ladder scale	
	<i>b</i> (SE)	<i>p</i>	<i>b</i> (SE)	<i>p</i>	<i>b</i> (SE)	<i>p</i>	<i>b</i> (SE)	<i>p</i>
HIV stigma	<b>0.235 (0.054)</b>	<b>&lt;0.001</b>	<b>0.188 (0.061)</b>	<b>0.002</b>	<b>-0.236 (0.069)</b>	<b>&lt;0.001</b>	<b>-0.053 (0.021)</b>	<b>0.013</b>
Social support	-0.061 (0.035)	0.140	-0.067 (0.040)	0.122	0.131 (0.045)	0.069	0.011 (0.014)	0.658
Age								
18–24	–	–	–	–	–	–	–	–
25–34	1.419 (1.574)	0.230	1.633 (1.760)	0.301	4.012 (1.998)	0.094	0.368 (0.626)	0.918
35–44	2.181 (1.757)	0.144	2.464 (1.964)	0.185	1.369 (2.229)	0.702	-0.045 (0.699)	0.666
45 and above	1.625 (1.844)	0.196	-0.070 (2.06)	0.889	0.600 (2.339)	0.843	-0.158 (0.733)	0.357
Employment status								
Employed	–	–	–	–	–	–	–	–
Unemployed	-0.869 (1.371)	0.801	-1.548 (1.532)	0.405	-1.859 (1.739)	0.148	-0.320 (0.545)	0.228
Retired	2.613 (2.674)	0.463	3.686 (2.987)	0.265	3.854 (3.391)	0.164	1.232 (1.063)	0.113
Disabled	0.972 (1.381)	0.473	2.036 (1.542)	0.189	-0.660 (1.750)	0.697	0.033 (0.549)	0.950
Decline to answer	0.611 (3.398)	0.756	1.520 (3.797)	0.652	1.796 (4.310)	0.776	0.504 (1.352)	0.862
Income level								
<\$12,000	–	–	–	–	–	–	–	–
≥\$12,000	-1.216 (1.160)	0.270	0.251 (1.296)	0.862	0.781 (1.471)	0.556	0.140 (0.461)	0.693
Decline to answer	-0.807 (2.353)	0.742	-0.183 (2.629)	0.951	-3.967 (2.984)	0.175	0.471 (0.936)	0.621
Education								
College and above	–	–	–	–	–	–	–	–
Some college	3.058 (1.542)	0.069	1.000 (1.722)	0.862	-3.602 (1.955)	0.054	-0.532 (0.613)	0.305
High school and below	2.284 (1.651)	0.768	-0.511 (1.845)	0.951	0.061 (2.094)	0.957	-0.265 (0.656)	0.582
Had been attacked or harassed*	2.276 (1.188)	0.068	1.054 (1.346)	<b>0.435</b>	<b>-3.028 (1.503)</b>	<b>0.046</b>	<b>-1.438 (0.459)</b>	<b>0.002</b>
Had been attacked with violence*	0.222 (1.526)	0.768	-0.596 (1.704)	0.605	-0.346 (1.935)	0.777	-0.975 (0.606)	0.363
Had been a victim of any other crime*	2.156 (1.583)	0.310	2.882 (1.769)	0.147	-2.098 (2.008)	0.492	-0.745 (0.630)	0.508
Had been incarcerated**	0.801 (1.202)	0.339	0.566 (1.343)	-0.593	1.643 (1.525)	0.442	-0.073 (0.478)	0.525
Receiving ART	-2.819 (2.287)	0.263	<b>-5.251 (2.555)</b>	<b>0.048</b>	<b>4.960 (2.901)</b>	<b>0.001</b>	<b>1.965 (0.910)</b>	<b>0.042</b>
Virally suppressed	-0.239 (1.156)	0.818	-0.696 (1.291)	0.586	0.590 (1.466)	0.666	-0.450 (0.459)	0.327
Good adherence	0.214 (1.215)	0.718	1.237 (1.358)	0.329	0.918 (1.541)	0.684	0.552 (0.483)	0.379

Bold values are statistically significant  $p$  values of less than or equal to 0.05  $b$ : beta coefficient SE: standard error PHQ9: Patient Health Questionnaire-9 GAD7: General Anxiety Disorder-7 SWLS: Satisfaction with Life Scale

\*in the past year; \*\*in the past 5 years

or extremely satisfied with life. Meanwhile, half (50%) indicated *thriving* in terms of quality of life.

The associations between HIV stigma with PROs are presented in Table 4. In multivariable models, participants who experienced higher HIV stigma were more likely to experiencing depression and anxiety ( $b=0.235$ ,  $p<0.001$ ;  $b=0.188$ ,  $p=0.002$ ). Conversely, higher HIV stigma was also associated with lower life satisfaction and quality of life ( $b=-0.236$ ,  $p<0.001$ ;  $b=-0.053$ ,  $p=0.013$ ). Notably, in adjusted models, currently receiving ART was associated

with higher GAD-7 score ( $b=-5.251$ ,  $p=0.048$ ), higher life satisfaction and quality of life ( $b=4.960$ ,  $p=0.001$ ;  $b=1.965$ ,  $p=0.042$ ). In addition, being attacked or harassed in the past year were significantly associated with lower life satisfaction and quality of life ( $b=-3.028$ ,  $p=0.046$ ;  $b=-1.438$ ,  $p=0.002$ ). We tested multicollinearity by computing the variance inflation factors for the multivariable model with a cutoff point of 10 and we did not any violations.

## Discussion

This study examined the associations between HIV stigma with patient-reported outcomes among a sample of Black sexual minority men living with HIV. Findings revealed high levels of HIV stigma in this sample of Black sexual minority men living with HIV, which are comparable to those found in other studies examining stigma in the lives of PLWH [20, 43]. We also found that higher levels of HIV stigma were associated with higher likelihood of experiencing depression and anxiety, and lower life satisfaction and quality of life among Black sexual minority men living with HIV.

Participants expressed high levels of concern about HIV disclosure and public attitudes about HIV, similar to a study conducted Quinn et al. among young Black men who have sex with men [44]. Unlike experienced or enacted stigma (e.g., *I have been hurt by how people reacted to learning I have HIV*), both disclosure concerns and public attitudes are *perceived* or *anticipated* stigma, which refer to the degree to which individuals expect that they will experience prejudice, judgment, and discrimination from the community [17]. Another study in San Francisco also noted that compared to their White counterparts, African Americans living with HIV (97% of which were identified as men) were more likely to have higher disclosure and public attitude concerns. They also found that these stigmas were associated with poorer physical and mental health status [43].

The relationship between HIV disclosure stigma and HIV viral suppression is likely complicated and requires more study. For example, a study in South Texas among a primarily Hispanic sample, found that HIV disclosure stigma was positively significantly associated with viral suppression [45]. Future research should examine the effects of different types of HIV stigma on patient-reported outcomes among people with HIV from diverse racial/ethnic backgrounds and the mechanisms driving these associations. In this analysis, higher levels of HIV stigma were associated with adverse mental health outcomes, lower life satisfaction, and poor quality of life after controlling for clinical characteristics including ART initiation, viral load suppression, and medication adherence. These results suggest that HIV stigma may affect patient-reported outcomes independent of treatment outcomes and highlights the need for tailored stigma reduction interventions among Black sexual minority men with HIV. Given the high levels of HIV stigma experienced among Black sexual minority males living with HIV as well as its negative impact on PROs including mental health outcomes, life satisfaction and quality of life, there is an urgent need to design, test, implement, and evaluate tailored stigma reduction interventions among this population. Such interventions must consider the

intersectional stigma and discrimination that Black sexual minority males living with may encounter and integrate culturally specific components.

Black sexual minority men living with HIV in this study experienced high rates of mental health challenges. About one in three screened positive for depression and about the same proportion were screened for anxiety, similar to findings from two prior studies [46, 47]. Recent literature suggests that psychological distress such as depression and anxiety are associated with worse HIV treatment outcomes, such as lower medication adherence and likelihood of initiating ART [48, 49]. Therefore, it is critical to provide mental health screening and treatment services for Black sexual minority men with HIV in order to improve their overall mental well-being and minimize adverse HIV treatment outcomes [50]. Our results also suggest that only about a quarter of participants were satisfied with their current life, and half were struggling or suffering in terms of quality of life. These results signal the need to provide comprehensive support along HIV care continuum to address the physical, mental, and social needs of PLWH. Focusing on life satisfaction and quality of life reflect holistic HIV treatment and can be determined by multiple factors, from individual to societal. A longitudinal study conducted in five African countries also noted that increased HIV stigma was related to decreased life satisfaction over time [51]. While romantic partnership [52, 53], higher education and income level [10, 52], sleep quality [11], and social capital [54] have all been correlated with higher quality of life, these factors have not been well studied among Black sexual minority men with HIV. Notably, more than half of study participants received ART for more than 5 years. Future interventions must address these correlates of life satisfaction and quality of life.

The strengths of the current analysis include the unique characteristics of the study participants and the diversity of the patient-reported outcomes (PROs). However, our study has several important limitations. The small sample size may limit the statistical power. PROs were all self-reported and are subject to recall bias. However, researchers also argue that PROs have the advantage of providing a subjective view of patient's health [9]. Another limitation is that almost all participants in this study were receiving ART. Therefore, the results are not generalizable to Black sexual minority men living with HIV who have not initiated ART. Further studies may consider focusing more on those who do not receive ART as they may experience adverse health outcomes due to the natural progression of HIV/AIDS. In addition, the current study did not assess the intersectional effects such as the syndemics among this population. Future studies should consider applying intersectionality in HIV research among Black sexual minority men living with HIV. Finally, the cross-sectional nature of the study prevents causal inference.

Future longitudinal research is needed to examine the unique effect of HIV stigma on PROs among PLWH over time.

## Conclusions

HIV stigma is a painful reality in the lives of PLWH, and here, among Black sexual minority men living with HIV, it was statistically significantly associated with adverse patient-reported outcomes. Further research should focus on understanding the mechanisms by which HIV stigma impacts health outcomes among this population and to inform tailored stigma reduction interventions that take a holistic view of the health of Black sexual minority men living with HIV. Tackling stigma and reducing its effects are levers to improving patient outcomes, which is imperative to achieve the UNAIDS 4th 90% target among Black sexual minority men living with HIV.

**Acknowledgements** We would like to acknowledge the contributions of our community advisory board (CAB) members, many of whom are Black LGBTQ individuals. We would also like to thank the community partners, including APLA Health and the AMAAD Institute for their assistance in coordinating the study. We would also like to thank UCLA staff and affiliates for their assistance in coordinating the study and assisting with outreach and engagement, including Robert Gamboa, Kelly Gluckman, Gerald Garth, Terry Smith, Maynard Hearn, Shellye Jones, Gregory Victorienne, Giselle Ruballos, Elizabeth S.C. Wu, Nina Young, Rosalia Alvarado, Sidra Rashid, Christian Paneda, Rae Jones, Sharon Lau, Tiffany Luu, Heliud Garcia, Arthur Sun, Paulette Orhii, and Jack Hjerpe. We also want to thank Dr. Laura Wray-Lake and Dr. Latoya Small for this critical feedback.

**Author contributions** CH conceptualized the research questions, conducted the literature review, analyzed the data, and written up the manuscript. IWH and AOM are the principal investigators of the project. All other authors provided feedback on data analysis, analysis interpretation, and manuscript revisions. All authors provided intellectual content to the paper and reviewed and approved the final manuscript.

**Funding** This study is supported by the California HIV/AIDS Research Program (HD15-LA-061) and the Center for HIV Identification, Prevention and Treatment Services (CHIPTS). California HIV/AIDS Research Program, HD15-LA-061, Ian W. Holloway, HD15-LA-061, Ayako Miyashita Ochoa

**Data availability** The data supporting this study's findings are available from the senior author upon reasonable request.

## Declarations

**Conflict of interest** All authors declared no conflict of interest.

**Ethical approval** Study procedures were reviewed and approved by the Institute of Review Board at the University of California Los Angeles.

**Informed consent** All participants agreed to participate after reviewing the study's informational letter and provided informed consent.

**Consent for publication** Not applicable.

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## ORIGINAL PAPER

# Changes in Mental Health Among People with HIV During the COVID-19 Pandemic: Qualitative and Quantitative Perspectives

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Accepted: 22 November 2021

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## Abstract

People with HIV (PWH) are at risk for adverse mental health outcomes, which could be elevated during the COVID-19 pandemic. This study describes reasons for changes in mental health among PWH during the pandemic. Data come from closed- and open-ended questions about mental health changes from a follow-up to a cohort study on PWH in Florida during part of the COVID-19 pandemic (May 2020–March 2021). Qualitative data were analyzed using thematic analysis. Among the total sample of 227 PWH (mean age 50.0, 49.7% men, 69.2% Black/African American, 14.1% Hispanic/Latino), 30.4% reported worsened mental health, 8.4% reported improved mental health, and 61.2% reported no change. The primary reasons for worsened mental health were concerns about COVID-19, social isolation, and anxiety/stress; reasons for improved mental health included increased focus on individual wellness. Nearly one-third of the sample experienced worsened mental health. These results provide support for increased mental health assessments in HIV treatment settings.

**Keywords** HIV · People with HIV (PWH) · COVID-19 · Mental health

## Introduction

Since the first cases of coronavirus disease 2019 (COVID-19), caused by the novel SARS-CoV-2 virus, were identified in December 2019, life has not been the same for many as social distancing guidelines and mandatory mask orders have been implemented, daily lives have been disrupted, and behaviors and overall health have changed worldwide. Mental health in particular has been significantly impacted by COVID-19 [1]. Studies in Europe have found that quality of life and symptoms of depression and anxiety have worsened among the general population since the start of the pandemic, while the prevalence of mental health problems has increased [2–4]. In the United States, 42% of Americans reported symptoms of depression or anxiety in December 2020 compared with 11% the previous year [5]. There is

also evidence that changes in mental health due to COVID-19 may differ by racial/ethnic groups and by gender [6, 7].

People with HIV (PWH) report a higher prevalence of mental health conditions than the general population, and mental health conditions can increase not only the risk for acquiring HIV but also the risk for negative health outcomes at each step along the cascade of HIV care; this includes measures such as being on antiretroviral therapy (ART) and being virally suppressed [8–12]. It is possible that, as in the general population, the COVID-19 pandemic could have severely impacted the mental health of this already susceptible population. PWH might experience negative health outcomes associated with a COVID-19 diagnosis and from pandemic safety measures such as social distancing measures and closed provider offices that may interrupt healthcare access [13–20]. Previous studies have found marked changes in mental health [20, 21] and increases in substance use [22] among PWH during the pandemic. Negative economic consequences of the pandemic have also caused stress and worsened mental health outcomes for some PWH [19, 20, 23]. Additionally, factors that can influence the health and wellness of PWH in normal conditions such as self-efficacy [24], perceived stress [25–27], resilience [28, 29], and social

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support [30, 31] could have been impacted by the COVID-19 pandemic and indirectly led to changed mental health outcomes [32]. Understanding the impact of individual attributes on mental health in the pandemic could inform interventions aimed at strengthening positive attributes.

Prior studies of COVID-19 have examined changes in mental health and reasons behind the changes; however, they have primarily been surveys without great opportunity for qualitative data collection. For example, an anonymous online survey of PWH in Buenos Aires, Argentina found that the COVID-19 pandemic caused economic disruption, loneliness, reduced ART adherence, and disrupted mental health and substance use treatment for many [23]. Another web-based survey in Turkey found that anxiety and stress increased among PWH during the pandemic, and this was associated with having a preexisting psychiatric disorder, worrying about COVID-19 in the environment, uncertainty about the correct preventive procedures, and having a household member with a chronic disease [21]. Despite existing information about changes in mental health experienced during the pandemic, there are gaps in our knowledge about the exact experiences PWH are having that might influence their mental health and how they do so. Qualitative data from open-ended questions could fill these gaps. Answers from open-ended questions in addition to quantitative survey questions have more detail and nuance than survey responses alone [33]. Open-ended questions can offer opportunities for new, unexpected insights from PWH through providing additional information on reasons for changes in mental and physical health and experiences with barriers to health and well-being. Moreover, to our knowledge there are few studies looking at PWH's responses to the COVID-19 pandemic qualitatively through open-ended survey responses combined with quantitative survey questions.

Assessing and understanding the aspects of the pandemic that were most responsible for changes in mental health among PWH, and realizing why some PWH are resilient in a crisis and why others struggle, could provide important insights into how to address the current and future health needs of PWH. The objectives of this study are to (1) describe self-reported changes in the mental health of a sample of PWH in Florida due to the COVID-19 pandemic, (2) identify demographic and behavioral variables associated with these changes, and (3) understand the reasons behind these changes through an analysis of open-ended questions. These findings can assist public health programs, clinics, or programs such as Ryan White in offering better support for specific issues that are affecting mental health for their patients with HIV. These findings might also allow researchers and providers to learn from those PWH who do well in public health crises to inform new and existing interventions.

## Methods

### Study and Study Participants

This study analyzed data from the Marijuana Associated Planning and Long-Term Effects (MAPLE) study, a prospective cohort study with a focus on determining the long-term health effects of marijuana on PWH. As of July 2021, there were 300 PWH enrolled in the cohort. Since October 2018, participants have been recruited through clinics at county Departments of Health, infectious disease clinics, community healthcare centers, and flyers placed in three recruitment settings in Florida. Participants who do and who do not use marijuana are eligible for the study, with planned enrollment targeting three participants who use marijuana for every one participant who does not. At the baseline, each participant completed a survey, a blood test, and a urine test to establish marijuana use status. All participants also received a brief telephone-based follow-up survey every 3 months and an in-person follow-up visit every 12 months. During a peak period of the COVID-19 pandemic, between May 2020 and March 2021, the research team added several additional questions to the existing 3-month telephone-based follow-up that aimed to evaluate changes in mental health. This paper presents the analysis of a sub-cohort of 227 PWH, from the larger cohort of 300 PWH (response rate: 75.7%), who responded to the 3-month follow-up brief telephone survey with questions related to the COVID-19 pandemic. The foci of this analysis are the changes in mental health and the reasons for the changes experienced by this sub-cohort.

### Measures

At baseline, collected between 2018 and 2020, all participants completed a survey that assessed their age, sex, race, ethnicity, income, education (scored on a three-tier scale of less than high school, high school or equivalent, and more than high school), and health behaviors such as ART medication usage and adherence, current marijuana use (confirmed with a positive urine test of Tetrahydrocannabinol), and self-reported past-year alcohol use. Baseline depression was measured using the PHQ-8 [34]. In the 3-month follow-up call, age was collected again. The researchers explained that questions in the follow-up pertained to the "coronavirus situation," the COVID-19 pandemic which was defined as beginning in Florida on March 1, 2020. Self-reported changes in mental health were assessed using the following question: "When considering your mental health, how would you say your mental health has changed since before the coronavirus situation until today?" The answer options were on a Likert scale

from “1-much better” to “5-much worse”, with a higher score indicating a worsened degree of mental health. If participants indicated a positive or negative change in mental health, they were asked a follow-up, open-ended question, “What would you say is the main reason for that change?” Participants could give as many reasons as they felt appropriate and as many details as they wished in their response or skip the question entirely, although no participants who indicated a change in mental health skipped the open-ended follow-up question. Only two participants (0.9%) had a positive COVID-19 test and thus COVID-19 diagnosis was not analyzed further in the results.

## Analysis

A descriptive analysis of participants’ sociodemographic characteristics and behaviors was done in SAS 9.4 (SAS Institute, Cary NC). Descriptive statistics were calculated to evaluate the frequency of reported changes in mental health and significant differences by key sociodemographic variables were determined using chi-sq/Fisher’s exact or ANOVA depending on the variable and sample size. Additional logistic regression analyses, controlling for variables significantly associated with changes in mental health, were conducted. Two logistic regression models were made to investigate the predictive effects of the significant variables on either a worsening of or an improvement in mental health compared with no change.

Thematic analysis adapted for our data was used for the open-ended questions [35, 36]. Qualitative data from the open-ended question about reasons for changes in mental health were compiled in Microsoft Excel and manually coded by two independent coders using a codebook created by the primary author. Additional codes were generated by the coders as new themes emerged from the participant responses. The coding was done by two independent coders who discussed the codebook before coding began, met after completing the coding to compare results, and reviewed any disagreements before coming to a shared conclusion. Codes were categorized under broader themes to understand reasons for changes in mental health, with separate sets of codes created for people who indicated an improvement in their mental health and those who indicated a worsening of their mental health.

## Results

### Participant Characteristics

Table 1 presents the study participants’ characteristics. The current average age of the participants was

50.0 years (SD = 11.1). Sixty-one percent of the participants were 50 years or older and 50.2% of the participants were female. Most of the participants were Black/African American (69.1%), followed by White (22.4%), and other race (8.4%). Of the total participants, 14.1% were Hispanic. Over one-quarter (29.1%) had less than a high school education and 70.0% made less than \$20,000 per annum. Most of the participants (94.3%) were currently taking ART medication. At baseline, nearly one-third of the sample had mild depression while 27.8% had moderate or severe depression. Additionally, 80.2% of the sample currently used marijuana and 76.2% had past-year alcohol use.

Sixty-nine participants (30.4%) indicated their mental health worsened due to the pandemic compared with 19 (8.4%) who indicated improvement and 139 (61.2%) who reported no change. Beyond baseline depression measured by PHQ-8 score ( $p = 0.004$ ) and education level ( $p = 0.020$ ), there were no statistically significant differences in changes in mental health by baseline characteristics. Over half of those with moderate depression experienced worsened mental health compared with 42.9% of those with severe depression, 28.8% of those with mild depression, and 16.5% of those with minimal or no depression. Nearly 40% of those with greater than a high school education experienced worsened mental health compared with only 27.3% of those with a high school education and 22.7% of those with less than a high school education.

Levels of education and depression had a significant predictive relationship in the logistic regression models. Having more than a high school education was associated with increased odds of reporting worsened mental health (odds ratio: 3.47, 95% confidence interval 1.52–7.90,  $\chi^2$ : 8.77,  $p = 0.003$ ), rather than no change in mental health; having less than a high school education was not significantly associated with worsened mental health. Similarly, having mild (OR: 2.29, 95% CI 1.02–5.17,  $\chi^2$ : 3.98,  $p = 0.046$ ), moderate (OR: 8.00, 95% CI 3.00–21.31,  $\chi^2$ : 17.30,  $p < 0.001$ ), or severe depression (OR: 4.15, 95% CI 1.51–11.38,  $\chi^2$ : 7.65,  $p = 0.006$ ) compared with having no or minimal depression was also associated with increased odds of reporting worsened mental health. Participants with more than a high school education had increased odds of reporting improved mental health, rather than no change in mental health, compared with those who had less than a high school education (OR: 5.72, 95% CI 1.34–24.44,  $\chi^2$ : 5.55,  $p = 0.019$ ), as did those with moderate depression (OR: 4.88, 95% CI 1.07–22.24,  $\chi^2$ : 4.20,  $p = 0.040$ ) compared to those with no or minimal depression. These results can be seen in the Supplementary materials (Supplementary Tables I and II).

**Table 1** Participant characteristics, N = 227

	Total cohort N = 227	Worsened mental health N = 69 (30.4%)	Improved mental health N = 19 (8.4%)	No change in mental health N = 139 (61.2%)	Chi-Sq or F-test statistic	P-value
Mean age (SD)	50.0 (11.1)	49.8 (10.7)	45.2 (13.5)	50.8 (10.9)	F = 1.15	0.257
<i>Age groups</i>						
18–29	14	2 (14.3%)	4 (28.6%)	8 (57.1%)	$\chi^2 = 12.34$	0.263
30–39	3	12 (40.0%)	3 (10.0%)	15 (50.0%)		
40–49	45	15 (33.3%)	2 (4.4%)	28 (62.2%)		
50–59	96	27 (28.1%)	7 (7.3%)	62 (64.6%)		
60 and older	42	13 (18.8%)	3 (7.1%)	26 (18.7%)		
<i>Gender assigned at birth</i>						
Men	113	34 (30.1%)	11 (9.7%)	68 (60.2%)	$\chi^2 = 0.55$	0.760
Women	114	35 (30.7%)	8 (7.0%)	71 (62.3%)		
<i>Race</i>						
White	51	23 (45.1%)	3 (5.9%)	25 (49.0%)	$\chi^2 = 6.83$	0.145
Black/African American	157	41 (26.1%)	14 (8.9%)	102 (65.0%)		
Other	19	5 (26.3%)	2 (10.5%)	12 (63.2%)		
<i>Ethnicity</i>						
Hispanic or Latino	32	12 (37.5%)	2 (6.3%)	18 (56.3%)	$\chi^2 = 0.90$	0.638
Non-Hispanic or Latino	194	57 (29.4%)	16 (8.3%)	121 (62.4%)		
<i>Education</i>						
Less than High School	66	15 (22.7%)	3 (4.6%)	48 (72.7%)	$\chi^2 = 11.71$	0.020*
Completed High School or Equivalent	77	21 (27.3%)	5 (6.5%)	51 (66.2%)		
Greater than High School	84	33 (39.3%)	11 (13.1%)	40 (47.6%)		
<i>Income</i>						
Less than \$5,000	42	15 (35.7%)	3 (7.1%)	24 (57.1%)	$\chi^2 = 4.66$	0.589
\$5,000–\$19,999	117	31 (26.5%)	9 (7.7%)	77 (65.8%)		
\$20,000–\$49,999	59	19 (32.2%)	7 (11.9%)	33 (55.9%)		
\$50,000 or more	8	4 (50.0%)	0 (0.0%)	4 (50.0%)		
<i>Baseline Depression Scores (PHQ-8)</i>						
0–4, none/minimal	79	13 (16.5%)	6 (7.6%)	50 (76.0%)	$\chi^2 = 9.00$	0.004*
5–9, mild	73	21 (28.8%)	6 (8.2%)	46 (63.0%)		
10–14, moderate	35	18 (51.4%)	4 (11.4%)	13 (37.1%)		
15 or greater, severe	28	12 (42.9%)	2 (7.1%)	14 (50.0%)		
<i>Current ART medication</i>						
Yes	214	62 (29.0%)	18 (8.4%)	134 (62.6%)	$\chi^2 = 2.48$	0.289
No	12	6 (60.0%)	1 (8.3%)	5 (41.7%)		
<i>Current marijuana use</i>						
Yes	182	57 (31.3%)	18 (9.9%)	107 (58.8%)	$\chi^2 = 3.69$	0.158
No	45	12 (26.7%)	1 (2.2%)	32 (71.1%)		
<i>Past-year alcohol use</i>						
Yes	173	55 (31.8%)	16 (9.3%)	102 (59.0%)	$\chi^2 = 1.75$	0.417
No	54	14 (25.9%)	3 (5.6%)	37 (68.5%)		

Ns in each of the categories might not add up to 227 due to missing data

\*Significant differences between groups ( $p < 0.05$ ) were detected by chi-square test for categorical variables and F-test for continuous variables

**Table 2** Coding framework and frequency of reasons for worsened mental health (n=69)

Theme	Code	Definition	N (%)
<i>Maintaining Health</i>	Health Concerns	Health concerns related or due to a non-COVID health condition	3 (4.3%)
	Medical Care or Medication Adherence	Changes in medical care or treatment, medical care access changes, or medication/adherence changes	4 (5.8%)
<i>Activities</i>	Exercise and Activities	Changes in the ability to partake in regular hobbies, activities, or exercise	5 (7.2%)
<i>Family Emotion</i>	Caring for Loved Ones	Caring for loved ones or friends	1 (1.4%)
	Anxiety/Stress	Anxiety/nervousness or stress, or being unable to relax or calm down	23 (33.3%)
<i>Social Factors</i>	Anger	New or changed feelings of anger or frustration	3 (4.3%)
	Fear	Feelings of fear	4 (5.8%)
	Sadness	Sadness or self-described depression	11 (15.9%)
	Isolation	Social distancing and isolation; also described as feeling lonely	19 (27.5%)
	Paranoia/Worries About Other People	Worries about coming into contact with other people or self-described paranoia	6 (8.7%)
	Know People Who Died	Knowing people who died and associated feelings of grief and loss	3 (4.3%)
	Loved Ones	Changes in social support or not being able to see friends and family	6 (8.7%)
<i>Life Events</i>	Life Events	Negative or cancelled life events	2 (2.8%)
	Career	Concerns about career or a change in employment status	5 (7.2%)
	Cabin Fever	Feeling trapped or confined at their lockdown location	8 (11.6%)
	Money	Financial changes or problems	5 (7.2%)
<i>Productivity</i>	Productivity	Changes in motivation, productivity, and/or focus	1 (1.4%)
<i>Virus Exposure</i>	Virus Exposure	Worries about virus exposure and/or the effectiveness of virus safety measures	9 (13.0%)
<i>Preexisting Mental Health Condition</i>	Mental Health Condition	New or pre-existing mental health condition	7 (10.1%)
<i>Worrying About COVID-19</i>	Worrying About COVID-19	Worrying about the pandemic, getting COVID-19, or loved ones getting COVID-19	19 (27.5%)
<i>Increased Substance Use</i>	Increased Substance Use	Increased substance use during the pandemic	1 (1.4%)

N does not sum to 69 because people could give multiple reasons why their mental health worsened

## Reasons for Changes in Mental Health

### Worsened Mental Health

Table 2 describes the codes and the frequency of reasons for worsened health among the study participants. Sixty-nine participants (30.4%) indicated that their mental health worsened; however, the reasons as to why mental health worsened varied. Over one-quarter of participants indicated that their mental health worsened because of worrying about their risk or a loved one's risk of contracting COVID-19. Some participants had public-facing jobs that required them to interact with the public, creating more opportunities for COVID-19 exposure which caused constant worry leading to worsened mental health. Other participants expressed concerns about whether COVID-19 was real or if it was a conspiracy theory.

- “Since I had to go back to work [at a coffee shop], I started to see a lot of people, and deal with a lot of people, especially homeless people who are becoming more concentrated in the location where I work after the coronavirus, and I have to deal with vandalism and customer services. This all has made me very stressed.” (51-year-old White woman)
- “I am more paranoid mostly about getting COVID or if it is even real.” (36-year-old Black and Hispanic woman)

Additionally, 13.0% of participants felt that their risk of COVID-19 exposure was beyond their control. Some cited a lack of trust in their community members to follow COVID-19 guidelines, such as social distancing and wearing masks. Some participants also believed the COVID-19 guidelines

would not protect them from COVID-19, instilling a sense of hopelessness that worsened their mental health.

- “It feels like the community is not taking COVID seriously like with wearing masks.” (25-year-old White and Hispanic man)
- “I am irritated more now especially with the back and forth on masks, we have to wear them and then don’t have to wear them. I believe masks will not help. They aren’t effective and it’s like putting pants on to cover up a fart. They won’t prevent the virus from coming in.” (55-year-old multiracial man)

Worries about contracting COVID were often cited alongside PWH’s beliefs that they were at higher risk for COVID-19. Some were unsure whether their HIV status would put them at greater risk for contracting COVID-19 or developing complications. About 6% of participants expressed trouble with their medical care or access, or limited knowledge about accessing care with the COVID-19 restrictions, that worsened their mental health.

- “I am concerned because I am immunocompromised, so I am worried about being around others and going out.” (46-year-old Black woman)
- “I do not know how to go about going to the doctor’s office.” (56-year-old Black woman)

Adding to these concerns, many PWH were unable to adhere to their medication or receive their regular care. Others had another comorbid condition they were unable to receive regular or proper care for that put them at enhanced risk for negative COVID outcomes. One participant also stated that while telehealth and phone appointments were available for them to receive their usual care, those appointment methods were not ideal for them due to the anxiety they caused.

- “Instead of being seen in person, an ARNP changed my medication and was not as thorough as my usual provider, causing the removal of my medication.” (51-year-old multiracial female)
- “My psychiatrist wants to talk over the phone which gives me panic attacks.” (25-year-old White Hispanic man)

Seven participants had preexisting mental health conditions that were exacerbated by pandemic conditions.

- “I am bipolar and experiencing a lot of anxiety and a lot more downs.” (52-year-old Black woman)
- “I generally suffer from depression, I have been isolating myself even before the coronavirus problem started. Lately,

there has been a lot of negativity surrounding me, and people are becoming unraveled, the problem of the pandemic, politics, and a lot of crazy stuff going on, people are weird. I even left Facebook.” (51-year-old White woman)

Many expressed concerns about the wellbeing of family and friends, since they could not meet or check in with them regularly. Others lost their loved ones and were feeling sad from their loss.

- “I am worried, I haven’t been able to see my sister.” (71-year-old White man)
- “I am taking it one day at a time. My mother passed away last week.” (52-year-old Black woman)

Five participants experienced worsened mental health due to being unable to make their ends meet financially. This may have been because of unexpected medical or other expenses that they were experiencing during the pandemic. Additionally, five people indicated that a change in their career status, such as suddenly losing their job or being furloughed, worsened their mental health.

- “I am not able to make ends meet with no work.” (33-year-old Black woman)
- “I am not working and staying at home. It is mainly because of the loneliness, and money issues. It has affected me emotionally, I feel stressed, and it just goes along with my depression.” (25-year-old White man)

Staying in was another prominent factor that reportedly worsened mental health for the participants. Being isolated at home with “cabin fever” and in general having to stay away from others contributed to worse mental health for eight participants. Not being able to do usual activities that brought the participants joy or helped them maintain their mental and physical health, such as going to the gym, religious gatherings, or meeting with friends in person also worsened mental health for five participants.

- “I go in a room and stay by myself because of worries of bringing COVID back to my family.” (63-year-old Black man)
- “I usually go to the gym quite frequently and have not been able to and can feel it affected my mind.” (57-year-old White man)

One participant reported that having their kids at home and out of school, along with the increased responsibilities of remote learning, led to increased feelings of stress.

- “I have 5 kids and they are not having social interactions with peers; they are not able to do the activities they



used to do. Some of them are reverting, and I have a kid who is on the autistic spectrum. This change in my kids' schedules is causing me a lot of stress because I need to be in charge of their education, and I am trying to find some activities for them to do safely. It is tough to be responsible for teaching, especially for my kid who is on the autistic spectrum, and I myself had difficulties in learning while growing up, so it is harder for me to teach my children. Because I am worried about a wave of people testing positive ... when schools open, I decided to keep my kids at home for the first 9 weeks of school. It is a very stressful situation." (32-year-old White woman)

### Improved Mental Health

Table 3 describes the frequency of reasons for improved health among the study participants. Nineteen participants (8.4%) indicated that their mental health improved during the pandemic. Many said that this was because of the stay-at-home orders that required them to stay home, which gave them an opportunity to do activities that brought them joy or engage in other coping mechanisms.

- "For a while, I wasn't working because of COVID, so I had more time for myself. I took a little break. I had more time to sleep more, relax, and I started journaling because I have more time." (24-year-old Black woman)
- "I am doing more artwork, and staying in." (60-year-old White man)

Many indicated that the pandemic made them more mindful. Several participants also indicated that they felt comfortable with their knowledge about COVID-19 health and

safety measures and their ability to follow them, which made them feel safer and more in control of their living situation during the pandemic.

- "I am more aware of my body daily, what I do to it, and what I put in." (25-year-old Black man)
- "Everyone is talking to us and giving us information about different ways to protect our health. I feel like I am ready and have the knowledge needed. COVID information is making things less stressful." (52-year-old Black man)

Some participants reported that renewed faith and religiosity helped not only with coping but also with improving their outlook on life and overall mental health.

- "This [the pandemic] has given me a lot more spiritual strength and belief." (59-year-old Black man)

Additionally, others indicated that, while they may have had worse mental health at the start of the pandemic, they have adapted to the situation and now feel their mental health is better than it was at the beginning of or even before the pandemic. A few participants also indicated that their resilience or a "new perspective" led to improved mental health overall.

- "I am more relaxed and at peace with the COVID-19 situation." (54-year-old White and Hispanic man)
- "I am adapting to new perspectives due to coronavirus." (27-year-old multiracial Hispanic man)

Several participants also experienced significant social support or various positive experiences such as finding a

**Table 3** Coding framework and frequency of reasons for improved mental health (n = 19)

Theme	Code	Definition	N (%)
<i>Maintaining Health</i>	Health Conscious	Increased health awareness and activities	8 (42.1%)
	Medical Care or Medication Adherence	Improved medical care or treatment, medical care access changes, or medication/adherence changes	3 (15.8%)
<i>Activities</i>	Exercise and Activities	Increased participation in hobbies, activities, or exercise	2 (10.5%)
<i>Social Support</i>	Social Support	Changes in social support. They may have improved or reduced social support	1 (5.2%)
<i>Coping</i>	Coping	Changes in perspective, spirituality, or life outlook	3 (15.8%)
	Knowledge	Improved knowledge of COVID-19 and safety practices. They may feel comforted by their knowledge of COVID-19 and precautions	2 (10.5%)
<i>Life Events</i>	Life Events	Experiencing positive life events or celebrations	2 (10.5%)
<i>Productivity</i>	Productivity	Improvements in mental health due to changes in work, motivation, productivity, and/or focus	4 (21.1%)
<i>Staying In</i>	Staying In	Feeling good due to social distancing/isolation, staying in, and/or being away from others	3 (15.8%)
<i>No Reason</i>	No Reason	Generally feeling better without a specific reason	1 (5.2%)

N does not sum to 19 because people could give multiple reasons why their mental health improved

new partner or celebrating important anniversaries and birthdays, which brought them joy.

- “I have better support. I found a new partner.” (37-year-old Black woman)
- “I celebrated my 20th anniversary with my husband.” (43-year-old White woman)

## Discussion

This study aimed to understand the changes in mental health experienced by a cohort of PWH in Florida due to the COVID-19 pandemic and the reasons behind those changes. The information from this study adds to previous research with this sample that quantitatively examined changes in mental health and its associated factors [37] by providing much-needed context to the reported changes in mental health. To the best of our knowledge, this is the first study using open-ended questions and combined quantitative and qualitative methods to explore how the COVID-19 pandemic has impacted mental health in PWH. Our findings on the underlying reasons for mental health changes in PWH can potentially inform interventions that aim to improve mental health among this population.

This study found that, while over 30% of the sample experienced worsened mental health, there was no significant difference in the frequency of changes in mental health by age, race, ethnicity, gender, income, or alcohol or marijuana use status, factors that had great potential to be associated with changes in mental health. The only significant differences, controlled for in additional logistic regression analyses, were that people with greater than a high school education and those who had moderate depression were more likely to experience improved mental health while those with greater than a high school education and those with any level of depression (mild, moderate, or severe) were more likely to experience worsened mental health. It is interesting that those with greater than a high school education and those with moderate depression were more likely to experience any change in mental health, worsened or improved. Perhaps these populations are more likely to be aware of their mental health status and report a change, or experienced stressful situations differentially.

The results of this study support previous findings in the literature, using a variety of methods, about reasons why PWH have experienced changes in mental health. For example, participants reported worrying about COVID-19 [23, 38, 39], not trusting information about COVID-19 or following preventive protocols [40, 41], reduced access to healthcare [19, 42], worsening of psychological symptoms such as anxiety and depression [1, 38, 42, 43], isolation and a lack of social support [39, 44–46], not being able to do

regular and meaningful activities [47, 48], worrying about themselves or loved ones [21, 49], and financial difficulties [19, 50] as reasons why they experienced worsened mental health, all of which have been tied in the literature to the COVID-19 pandemic among both the general population and PWH. Of note, while some issues noted in the literature and by the PWH in this study might have unique causes or consequences for PWH such as reduced viral suppression, the concerns cited most often by PWH in this study apply to the general population as well. This shows that while PWH do have unique health concerns, the experiences they had during the pandemic and corresponding changes in mental health were largely like anyone else's. This shows potential for being targeted for interventions not only at HIV care centers but at primary care and general community or online locations as well.

A strength of this study is that the open-ended questions allowed for more particular reasons for changes in mental health to be stated by the participants. For example, participants in this study reported that being isolated from specific locations such as the gym or church worsened their mental health, rather than just discussing general disruptions to their routine. These also give more concrete targets for future interventions; perhaps increasing access to online church services or workout classes, or social-distancing safe meet-ups with community members from those locations, could help PWH in similarly isolating and disruptive public health crises.

Findings from this study also highlight the factors that contribute to improved mental health among PWH during the pandemic. The most frequently mentioned factors that brought happiness and calmness among the participants were having adequate social support, occurrence of a positive life event, using the pandemic as an opportunity to focus on their health and wellbeing, pursuing activities they enjoy or have wanted to be involved in, turning to their faith, and becoming overall more resilient. This supports evidence in the literature that found that higher resilience reduced the impact of the COVID-19 pandemic on mental health among PWH [23].

A common theme that arose in the analysis was the differentiation between things that participants could control and things they could not control. Many of the items that people said worsened their mental health were beyond their individual control, while those who stated improved mental health often cited increasing their resilience, engaging in mindfulness practices and activities that brought them joy, or focusing on positive events in their lives. This may have contributed to an increased sense of control in their lives, even though those participants likely dealt with similarly stressful items as those with worsened mental health. Further research with those who improved or simply maintained their mental health during

the pandemic could provide insight into effective strategies for individuals to stay well in stressful situations such as the COVID-19 pandemic and beyond.

These findings highlight the importance of a clear understanding regarding the factors that improve resilience and improve mental health among PWH during public health emergencies and future pandemics. It might be advised that for future public health emergencies, services that improve mindfulness and resilience should be more accessible to PWH, and perhaps be connected to them through services they already use such as their primary care or HIV provider. It might also be recommended that PWH stay involved in activities they enjoy and/or they recognize as being critical to maintaining their mental health, whether that be exercise, art, faith-related activities, or staying connected with their friends through whatever medium possible, even if they are not able to maintain it to the extent they are used to or must complete it from their home. For example, programs that aim to safely connect PWH to others in their social network, perhaps via technology, to prevent loneliness and isolation could be impactful for this population, as could interventions such as online workout or hobby groups that allow people to do activities they enjoy and relieve stress. Mindfulness interventions that aim to improve people's attention and awareness to their present experience have been shown to reduce incidence of depression and other psychological symptoms and improve the quality of life among PWH [51], and this could be an impactful intervention to improve mental health among PWH during public health emergencies. Involving PWH's regular providers, who likely have the best understanding of their patients' individual needs could help in this effort. Telemedicine has become a valuable tool in the pandemic for treating PWH by greatly enhancing healthcare access [52–54]. In general, telemedicine has had high clinician support throughout the pandemic [55], providing more potential feasibility and sustainability for regular use during and after the pandemic. However, as one participant in this study noted, telemedicine might not be a viable option for those who have anxiety about communicating on the phone or via videocall. Keeping people engaged in their healthcare by the method most preferable and accessible to them can improve both physical and mental health outcomes, as it can help people stay in their routines and have regular contact with others.

### Limitations

While a strength of the study was the wide coverage from participants around Florida, many participants were recruited for the study at clinics and other healthcare locations. This, as well as the fact that these participants have agreed to partake

in a long-term cohort study, means that this sample could be more attuned to their healthcare and health needs and have improved health outcomes compared with the general PWH population or PWH who are not in regular care. To improve this limitation in future research using this cohort, the research team is making concerted efforts to recruit participants who are underrepresented and who might not have regular access to care.

Additionally, while our response rate of 75.7% was high, there could be a representativeness issue if those who did not respond were experiencing disproportionately worsened, improved, or maintained mental health. We would not know the experiences of these participants without their responses, and in the regularly scheduled upcoming follow-up sessions the research team will aim to successfully recruit these participants.

Depression was measured by an objective baseline item and changes in mental health were measured as a subjective single item, and not as a formal objective change in scores over time. Later, during the next cycle of follow-ups, we will have data that will allow us to compare the scores on depression before and after the pandemic and further investigate changes in mental health, but at this point, only baseline information and 3-month follow-up information exist.

The questions used in this study were written in May 2020, before the COVID-19 vaccine was available to the general public. Due to this, the survey questions do not ask about vaccines and issues surrounding vaccine uptake and hesitancy. Future studies with this population could examine this serious topic, as vaccine hesitancy remains a primary barrier to ending the COVID-19 pandemic.

Finally, this was not a formal qualitative interview, but a single open-ended question following a Likert-scale type question on subjective changes in mental health. Therefore, we lack comprehensive understanding of the spectrum of reasons that people might have had worsened mental health and only know the primary reasons that the person first thought of during the interviews. With a full interview, we might have gotten richer details on the participants' experiences, setbacks, and triumphs. Future research involving more in-depth qualitative interviews could provide more information to fill the gaps in our knowledge.

### Conclusion

The COVID-19 pandemic has had a substantial yet varied impact on the mental health of PWH for a range of reasons. Over 30% of a sample of PWH in Florida said that their mental health worsened during the pandemic, while a small but not negligible percentage (8.4%) said their mental health improved. Understanding the reasons behind both worsened and improved mental health in this

population can provide specific targets for potential interventions to maintain or even improve mental health among PWH in public health emergencies.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s10461-021-03547-8>.

**Acknowledgements** We would like to thank all the participants and study staff who donated their time to make the MAPLE study possible.

**Author contributions** CP conceptualized the paper, created the qualitative codebook, analyzed the data, and wrote the manuscript; DV conceptualized the paper and contributed to manuscript preparation; YW conceptualized the paper and contributed to manuscript preparation; KV contributed to manuscript preparation; GEI contributed to manuscript preparation; LC analyzed the data and contributed to manuscript preparation; RLC contributed to the study design and manuscript preparation.

**Funding** This study is funded by the National Institute on Drug Abuse (Grant Nos. R01DA042609 and R01DA042609-04S1). C.P is funded by the National Institute on Alcohol Abuse and Alcoholism (Grant No. T32AA025877).

**Data Availability of Data and Material (Data Transparency)** Not applicable.

**Code Availability** Not applicable.

## Declarations

**Conflict of interest** The authors report no conflicts of interest or competing interests.

**Ethics Approval** The MAPLE study was approved by the University of Florida Institutional Review Board and the Florida Department of Health Institutional Review Board, with other participating institutions approving under a reciprocity agreement.

**Consent to Participate** Not applicable.

**Consent for Publication** Not applicable.

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

# The impact of mental health across the HIV care continuum

## The HIV Landscape in 2018

The world has seen remarkable medical advances in HIV prevention and treatment since the discovery of the virus that causes AIDS and the very beginning of the HIV pandemic. What was once a terminal illness for most people infected with HIV, is now considered to be a chronic illness for most people living with HIV. Nevertheless, there is currently no cure. Thus, all people living with HIV are challenged with having to take combination antiretroviral treatment (cART) on a daily basis for the remainder of their lives. Further, even in the context of highly effective cART, there is ongoing immune activation with accompanying comorbid conditions that can impair daily functioning and contribute to a diminished quality of life. Given this reality, prevention of HIV infection and providing optimal treatment for those living with HIV continue to present significant individual-level and also public health challenges.

In recent years, there has grown an excitement and enthusiasm for the potential of ending the HIV epidemic, with the current biological treatments that exist. Pre-exposure prophylaxis (PrEP) has been shown to be highly effective in protecting individuals exposed to HIV via bodily fluids from acquiring HIV, if such individuals are taking and adhering to PrEP regimens [Fonner et al., 2016]. Further, people living with HIV who adhere to cART and achieve sustained viral suppression are nearly incapable of transmitting the virus to sexual and needle-sharing partners, as well as from mother-to-child through pregnancy and delivery [Bavinton et al., 2018]. Theoretically, if HIV incidence can be brought down to very low levels (i.e., less than one percent worldwide) the epidemic could be ended.

Given the HIV prevention and treatment advances in the field, there are concerted efforts in multiple jurisdictions to end the HIV epidemic through scale-up and implementation of PrEP for uninfected individuals vulnerable to acquiring HIV, and cART for people living with HIV. The UNAIDS goals of “90-90-90” are for 90 percent of people living with HIV to be diagnosed, with 90 percent of them initiating cART, and 90 percent of people initiating cART to achieve and sustain viral suppression through adherence to the treatment [UNAIDS, 2014]. Such goals are indeed aspirational, though many believe achievable with focused resources and concerted efforts on the part of many. However, these gains will not be achieved without addressing the many barriers to access to adequate and sustained healthcare which is driven by social determinants of health such as HIV-related stigma, racism, homophobia, discrimination, sexism, housing instability, and food insecurity [Aidala et al., 2016; Feller & Agins, 2017; Gupta, Parkhurst, Ogden, Aggleton & Mahal, 2008]. Along with these challenges and inequities, mental health and substance use problems, among people vulnerable to

acquiring HIV and those living with HIV, have been shown to be among the most significant barriers to achieving the 90-90-90 UNAIDS targets.

### **Mental health and HIV acquisition**

Mental health problems, including mental health and substance use disorders, play a critical role in HIV acquisition across populations, increasing the risk of HIV acquisition by four to ten-fold [CDC, 2015, [Hobkirk, Towe, Lion & Meade, 2015](#)]. In the US, the prevalence of HIV is substantially higher among adults with serious mental illness (SMI) – ranging from 2 percent in rural areas to 6 percent in large metropolitan areas – compared to the general population (0.5 percent) [[Blank et al., 2014](#); CDC, 2015, [Himmelhoch et al., 2011](#)]. Mental health problems can also interfere with efforts to prevent HIV infection, including regular HIV testing and adherence to PrEP [[Mangurian et al., 2017](#); [Senn & Carey, 2009](#), [Mehrotra et al., 2016](#)]. In the iPrEx and iPrEx OLE trials, studying implementation and efficacy of PrEP to prevent HIV acquisition among men who have sex with men (MSM) and transgender women, participants with higher depression scores had lower levels of detectable PrEP medication (emtricitabine and tenofovir disoproxil fumarate) and higher levels of condomless receptive anal intercourse.

### **Prevalence of mental health disorders among people living with HIV (PLWH)**

Many studies have shown that PLWH have higher rates of mental health disorders than that of the general population [[Bing et al., 2001](#); [Do et al., 2014](#); [Kendall et al., 2014](#); [O’Cleirigh, Magidson, Skeer, Mayer & Safren, 2015](#)]. For example, in a U.S. multi-site study with just over 2,800 PLWH from 1996, 36 percent had major depression, and 15.8 percent had generalized anxiety disorder. The prevalence of major depression in the US general population is 6.7 percent and 2.1 percent for generalized anxiety disorder [[Center for Behavioral Health Statistics and Quality, 2017](#)]. Other studies from North America have shown similarly higher rates of mental health disorders among PLWH. In Ontario, Canada, using available electronic medical records, [Kendall et al. 2014](#) found the prevalence of any mental health condition to be 41 percent among PLWH and 22 percent for non-HIV infected adults. A recent study by [Blank et al. 2014](#), conducted HIV tests with over 1,000 people who were seeking mental health care at university-based psychiatric inpatient units, intensive case-management programs, and community mental health centers. They found that 4.8 percent had confirmed positive HIV tests – much higher than the HIV prevalence rate in the general US population [[Blank et al., 2014](#)]. Further, data from across the globe also indicates elevated rates of mental health disorders among PLWH compared to the general population.

### **Mental health impairment impact on outcomes along the HIV care cascade**

There is substantial evidence that impairment in mental health leads to negative health outcomes at



each step in the HIV care continuum, starting with being diagnosed with HIV, all the way to achieving viral suppression. Not being diagnosed is problematic for the person living with HIV since we now know that there are optimal health outcomes when a person is treated with cART as soon as possible after infection. And it is also detrimental to the public health since a substantive proportion of new HIV infections are the consequence of transmission from a person who is not aware of his/her HIV status. Mental health impairment, whether due to having a mental health disorder (e.g., major depression, alcohol or other substance use abuse or dependence) or significant levels of psychiatric distress (e.g., elevated depressive, anxiety, or PTSD symptoms) can interfere with HIV testing and learning one's HIV status, successfully linking to HIV healthcare, staying in care, initiating cART, and remaining adherent to cART to achieve HIV viral suppression [[Antelman et al., 2007](#); [Bemelmans et al., 2016](#); [Gonzalez, Batchelder, Psaros & Safren, 2011](#), [Krumme et al., 2015](#); [Uthman, Magidson, Safren & Nachega, 2014](#)].

### **Screening and treatment for mental health problems**

Given the strong evidence for the contribution of mental health and behavioral problems to poor HIV health outcomes, there is an obvious need for increased mental health screening and mental health treatment to be integrated into ongoing HIV care. There exists a wide array of mental health screening tools that are being used in clinical care as well as in research, and they have been validated across many regions of the world, including in low- and middle-income countries [[Ali, Ryan & De Silva, 2016](#)]. Similarly, there exists a wide-range of effective mental health treatments including psychopharmacological treatment, and several types of psychotherapies (e.g., psychodynamic, cognitive-behavioral therapy, motivational enhancing therapy, and interpersonal therapy), stress reduction and mindfulness treatments, and harm reduction and abstinence treatments. And many of these have been manualized and tailored across languages and cultures [[Sherr, Clucas, Harding, Sibley & Catalan, 2011](#); [Sikkema et al., 2015](#); [van Luenen et al., 2018](#); [Lofgren, Nakasujja & Boulware, 2018](#)].

### **Mental and behavioral health treatments in HIV care**

There have been large systematic reviews and meta-analyses of mental and behavioral health interventions for PLWHA [[Sherr, Clucas, Harding, Sibley & Catalan, 2011](#); [Sikkema et al., 2015](#); [van Luenen et al., 2018](#); [Lofgren, Nakasujja & Boulware, 2018](#)]. In 181 studies across low-, middle-, and high-income countries, with over 20,000 participants representing diverse populations, many types of studies have been examined, including randomized controlled trials, pilot and feasibility studies, and quasi-experimental designs. The interventions had a duration range from 1-30 hours, 1-54 weeks, and 1-48 sessions, with a follow-up of outcomes ranging from 1-17 months. Interventions included pharmacological interventions, symptom-oriented interventions (e.g., cognitive and/or behavioral

therapy, stress management, motivational interviewing, interpersonal therapy), supportive interventions (e.g., support, psycho-education), and meditation interventions (e.g., mindfulness, meditation, relaxation). Overall, there were small to moderate positive effects on mental health, with a reduction in depression and anxiety, and improved quality of life and psychological well-being. The largest positive effects were seen among those interventions with lengthier and multi-level interventions, and those that were integrated into community-based health care settings. Interventions that included family interactions and peer support, and ones that were primarily focused on mental health and also delivered by mental health care professionals were among the most effective. Also, psychological interventions with cognitive-behavioral components were consistently effective. And finally, psychotropic and HIV-specific health psychology interventions were generally effective, but findings were mixed.

## **Summary**

Mental health problems (ranging from distress to SMI) are elevated among people at-risk for HIV and those living with HIV. Such mental health problems contribute to HIV acquisition and poor outcomes along the HIV treatment continuum. We have the necessary assessment (screening) tools and efficacious treatments. However, we need to prioritize mental health treatment with appropriate resources to address the current gap. In the HIV context, promising advances have been made integrating mental health care into primary care. These need to be further scaled-up in all HIV testing and treatment settings.

## Review article

# Mental health challenges among adolescents living with HIV

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### Abstract

**Introduction:** Mental health is a critical and neglected global health challenge for adolescents infected with HIV. The prevalence of mental and behavioural health issues among HIV-infected adolescents may not be well understood or addressed as the world scales up HIV prevention and treatment for adolescents. The objective of this narrative review is to assess the current literature related to mental health challenges faced by adolescents living with HIV, including access to mental health services, the role of mental health challenges during transition from paediatric to adult care services and responsibilities, and the impact of mental health interventions.

**Methods:** For each of the topics included in this review, individual searches were run using Medline and PubMed, accompanied by scans of bibliographies of relevant articles. The topics on which searches were conducted for HIV-infected adolescents include depression and anxiety, transition from paediatric to adult HIV care and its impact on adherence and mental health, HIV-related, mental health services and interventions, and the measurement of mental health problems. Articles were included if the focus was consistent with one of the identified topics, involved HIV-infected adolescents, and was published in English.

**Results and Discussion:** Mental and behavioural health challenges are prevalent in HIV-infected adolescents, including in resource-limited settings where most of them live, and they impact all aspects of HIV prevention and treatment. Too little has been done to measure the impact of mental health challenges for adolescents living with HIV, to evaluate interventions to best sustain or improve the mental health of this population, or to create healthcare systems with personnel or resources to promote mental health.

**Conclusions:** Mental health issues should be addressed proactively during adolescence for all HIV-infected youth. In addition, care systems need to pay greater attention to how mental health support is integrated into the care management for HIV, particularly throughout lifespan changes from childhood to adolescence to adulthood. The lack of research and support for mental health needs in resource-limited settings presents an enormous burden for which cost-effective solutions are urgently needed.

**Keywords:** Adolescents; HIV; mental health; transition; stigma; mental health disorders

**Received** 9 September 2016; **Accepted** 14 February 2017; **Published** 16 May 2017

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### Introduction

#### Mental health issues and adolescents with HIV

Mental health is a neglected global health priority, particularly for children and adolescents [1–3]. Mental health disorders, including psychiatric disorders, general psychological distress, emotional, and behavioural problems, are a leading cause of health-related disability, affecting 10–20% of children worldwide [4], and are predictive of mental health disorders and other morbidities in adulthood [5,6]. Research on mental health among children and adolescents lags considerably behind that of adults, particularly in resource-limited settings (RLS) [7,8]. A 2007 review of 11,501 intervention trials for the treatment or prevention of mental health disorders found that few targeted children and adolescents; the little research with children primarily focused on interventions

for developmental disabilities [9]. Furthermore, less than 1% of the studies of drug and psychological interventions for treating mental health disorders were conducted in “low-income” countries, with only 10% in “lower-middle-income” countries [9].

The need for a better understanding of mental health is especially important when its assessment and treatment are compounded by other comorbidities. Children and adolescents living with HIV may face an increased burden of mental and behavioural health disorders. The objective of this narrative review is to assess the current literature related to mental health challenges faced by adolescents living with HIV, including access to mental health services, the role of mental health challenges during transition from paediatric to adult care services and responsibilities, and the impact of mental health

interventions. This review focuses on adolescents who are themselves infected with HIV, with particular attention to: (1) the developmental phase of adolescence, and (2) to the specific challenge of transitioning primary responsibility of their medical care.

## Methods

Individual searches were run using Medline and PubMed for each of the topics included in this review. The topics on which searches were conducted included the following: (1) depression and anxiety among HIV-infected adolescents, (2) transition from paediatric to adult HIV care and its impact on adherence and mental health, (3) HIV-related stigma and mental health, (4) mental health services for adolescents in RLS and interventions for HIV-infected adolescents, and (5) the measurement of mental health problems in adolescents with HIV.

Exact text and MeSH headings for search terms are available from the authors on request (also see Table 1.). Articles on measuring mental health problems in adolescents with HIV were taken from the preliminary results of an ongoing systematic review on the use of mental health screening instruments among HIV-infected, paediatric and adolescent populations in Africa.

Articles from these searches were included if the focus of the study or review was consistent with one of the identified topics, the study or studies reviewed involved adolescents, and the article was published in English. We then identified additional articles meeting our inclusion criteria from the bibliographies of articles identified in our searches, as well as by using the “cited by” function through PubMed. From each article identified, we extracted

information on the study design, population, geographical context, measurement methods, and study outcomes from each study.

## Results and discussion

### Prevalence of mental health challenges in HIV-infected children and adolescents: high-income countries

Studies from high-income settings generally suggest that children and adolescents with HIV face an increased burden of mental health challenges. HIV-infected children and youth are at higher risk of psychiatric hospitalizations, compared with the general paediatric population [10]. A 2013 systematic review of the literature on the mental health of adolescents living with HIV found few studies describing the prevalence of psychiatric diagnoses in HIV-infected adolescents, but the existing studies suggest that psychiatric disorders such as depression and anxiety are more prevalent among perinatally infected adolescents compared to non-infected adolescents [11]. With the advent of antiretroviral therapy (ART), despite a significant decline in the incidence of severe, AIDS-defining neurocognitive diseases like HIV encephalopathy [12,13], HIV-infected children may still experience neurocognitive complications, such as deficits in cognitive, speech, gross motor and fine motor functioning, that can substantially impact their quality of life (QoL), social relationships, academic achievements, and risks for abuse and substance use [14–18]. These complications can be seen despite early ART treatment and viral suppression [19]. Moreover, HIV-infected adolescents are growing up and developing in a milieu that includes exposure to biomedical, genetic, familial, economic, and social or environmental factors that may increase their risk for mental health problems [20].

**Table 1. Search terms to identify articles.**

Main topic	Specific search terms	Additional inclusion criteria/Steps
Depression and anxiety	<i>depression, mood disorders, depressive disorder, anxiety, anxiety disorders, HIV, HIV infections, adolescent</i>	
Transitioning to adult HIV care	<i>transition, transition to adult care, HIV, HIV infections</i>	Addressed mental health impact or impact on adherence to antiretroviral medication regimens
HIV stigma	<i>HIV, stigma, mental health, adolescents</i>	
Mental health services for adolescents in resource-limited settings	<i>mental health services, adolescent, resource-limited, low- and middle-income country</i>	
Mental health interventions for HIV-infected adolescents	<i>HIV, HIV infection, adolescent, mental health, intervention</i>	
HIV-infected adolescents	<i>HIV, HIV infections, depression, mood disorders, depressive disorder, anxiety, anxiety disorders, validation studies, reproducibility of results, predictive value of tests, sensitivity and specificity, psychometrics, mass screening, surveys and questionnaires, Africa</i>	Searched PsychINFO, EMBASE, Medline; Reviewed titles, followed by Abstract review

An older review of the prevalence of DSM psychiatric disorders among HIV-infected children and adolescents found prevalence of 29% for Attention Deficit Disorder, 24% for anxiety disorders, and 25% for depression; however, appropriate control groups were infrequently used [21]. In a large longitudinal cohort study of youth in New York who were perinatally exposed to HIV, 61% were found to have psychiatric disorders other than substance use on the Diagnostic Interview Schedule for Children (DISC-IV), but only the prevalence of ADHD was different between the HIV-infected and HIV-exposed groups [22]. Prevalences of anxiety, mood, and other behavioural disorders were the same between the HIV-exposed groups, with no inclusion of a non-HIV-exposed comparison group. A 2000 study in the United States found that among HIV-positive adolescents, 53% had received psychiatric diagnoses prior to HIV treatment, and 44% experienced ongoing depressive disorders [23].

Many of the studies of mental health in HIV-infected children and adolescents conducted to date lack comparison groups, which makes it difficult to compare the prevalence of mental health challenges in this population to the general population or to draw conclusions about the potential contribution of HIV on the observed rates of mental health challenges [11]. Due to the complexity of the effects of HIV, appropriate comparison groups could include adolescents who were perinatally exposed to HIV, but remain HIV uninfected, as well as adolescents without any history of HIV exposure, but from similar communities and backgrounds. Available studies that compare perinatally infected, HIV-positive adolescents with those perinatally exposed to HIV, but uninfected largely suggest that there are not significant differences in the rates or types of psychiatric disorders between these groups in comparison with those with no HIV exposure [11,22,24,25].

#### **Prevalence of mental health challenges in HIV-infected children and adolescents: low- and middle-income countries**

Most studies evaluating the prevalence of mental health challenges for HIV-infected adolescents have been done in the United States, rather than in the RLS where most of the world's HIV-infected adolescents live [11]. Fewer data are available on mental health among HIV-infected adolescents in RLS [11,26], which may be partially related to a lack of validated instruments for these contexts, lack of attention to or resources for mental health in resource-constrained healthcare settings, and additional stigma related to mental health conditions [27]. Despite these challenges, accumulating evidence from RLS does suggest that adolescents living with HIV also face particular emotional, behavioural, and mental health challenges.

Most studies of mental health challenges among adolescents living with HIV in low- and middle-income countries are cross-sectional and do not include comparison groups; however, they do indicate the need to address mental health within care systems addressing HIV or primary care. In a study of 162 HIV-infected children and adolescents in Kenya, 49% were reported to have at least one

psychiatric diagnosis or suicidality, with anxiety disorders most common (32.3%), followed by major depressive disorder (17.8%) [28]. A cross-sectional study of 562 HIV-infected adolescents from Malawi found a depression prevalence of 18.9% [29,30]. Within another study in Rwanda examining 100 HIV-infected children ages 7–14 years, the prevalence of depression reported was 25% [31]. A cross-sectional study of 82 HIV-infected adolescents ages 10–18-years old in Kampala, Uganda found that 51.2% had scores indicating significant psychological distress, 17.1% had attempted suicide in the past year, 19.5% had ever attempted suicide, and 30.5% had experienced psychotic symptoms in the past [32].

A cross-sectional study of 692 HIV infected, treated children ages 8–17 years in Botswana using a culturally-adapted and translated version of the Pediatric Symptom Checklist found that higher scores on the PSC (indicating psychosocial dysfunction) were associated with virologic failure, suggesting a critical link between psychosocial function and clinical outcomes [33]. In Tanzania, a cross-sectional study of 182 HIV-infected adolescents between 12 and 24 years old found multiple suggestions of mental health challenges in this group [34].

The few studies that use comparison groups in these settings do suggest certain increased risks of mental health challenges for those living with HIV. A study of 683 children ages 10–17 years of age in Rwanda compared a group with either HIV infection themselves (HIV-infected) or who were HIV affected (living with an HIV-infected caregiver or had a caregiver who had died from HIV) to a control group that was neither HIV infected nor living with anyone HIV infected [35]. Twenty per cent of the HIV-infected or HIV-affected adolescents were reported to have attempted suicide or engaged in self-harm in the past 6 months, compared to 13% of HIV-uninfected, unaffected children, with child-reported HIV-related stigma significantly increasing the risk of suicidal ideation and behaviours [27]. The HIV-infected or affected group of children also had significantly increased risks of depression, anxiety, and conduct problems compared to the HIV-uninfected/HIV-unaffected adolescents, but this did not differ whether the youth were themselves infected or had a HIV-infected caregiver or caregiver who had died from HIV [26]. In another study comparing HIV-positive Zambian adolescents with a control group from a British community sample, the HIV-infected Zambian adolescents had significantly higher reports of emotional symptoms, hyperactivity, and peer problems [36]. These combined studies suggest that, while HIV-infected adolescents in RLS are also at risk of developing mental health problems such as depression, anxiety, and ADHD, the aetiology extends beyond their HIV infection or health status and is likely impacted by the full range of their biopsychosocial experiences.

#### **Measurement of mental health among adolescents: high-income settings**

Measuring mental and behavioural health for adolescents remains a critical challenge that must be addressed in order

for mental health to be supported and improved. A 2015 systematic review examined depression screening instruments used to detect major depressive disorder in children and adolescents generally, for those ages 5–18 years [37]. The vast majority of studies evaluating the reliability and validity of depression measurement for children and adolescents have been conducted in the United States and Europe [37]. Four screening instruments, the Children's Depression Inventory (CDI), the Beck Depression Inventory (BDI), the Center for Epidemiological Studies – Depression Scale (CES-D), and the Reynold's Adolescent Depression Scale (RAD), were identified as the most commonly used tools and all were found to be reliable measures of Major Depressive Disorder in children and adolescents [37]. These four screening instruments are also commonly used to assess depression among HIV-infected adolescents in high-income countries. Though more often used with adults, the Patient Health Questionnaire (PHQ)-9 is a brief, well-validated screening measure that is available in more than 60 languages [38].

#### **Measurement of mental health among adolescents: low- and middle-income settings**

Few instruments to evaluate mental and behavioural health outcomes have undergone rigorous evaluation and validation for adolescents in RLS [39]. Research in these settings typically employs instruments and criteria developed in high-income settings that, if culturally inappropriate in a certain context, could lead to erroneous or misleading results [40,41]. The appropriateness of concepts and instruments may vary across different cultures [42] and across populations such as children and adolescents [43]. Betancourt *et al.* conducted a validation study to test the validity of the CES-DC as a depression screen for a general population sample of 367 children and adolescents in Rwanda, which included translation and cognitive testing of the screening items [44]. They found the CES-DC to be a valid screening tool, with a sensitivity of 81.9% and specificity of 71.9%, and made a recommendation that similar research efforts validate measures according to how well the measure items fit with local characterizations of mental health problems [44,45].

There is even more limited evidence for how to examine mental health outcomes among HIV-infected adolescents in RLS. Kim *et al.*, Mutumba *et al.*, and Binagwaho *et al.* tested the validity of these existing mental health measurement instruments within Malawi, Uganda, and Rwanda, respectively [29,31,46]. In Malawi, the validation findings suggested that the BDI-II had greater internal consistency and showed greater concordance with the CDRS-R results for this population [29]. The studies from Uganda and Rwanda highlighted the need for a process of cultural adaptation, such as included translation, expert panel review, cognitive interviewing, and pilot testing, followed by full evaluation to modify these instruments and generate sufficient sensitivity for use [31,46]. These studies highlight the importance of cross-cultural modification of instruments and local validation, while also demonstrating the need to employ rigorous measurement of mental health symptoms

for HIV-infected populations of children and adolescents in the RLS where most of these children live.

#### **Mental health and sex-based differences across income settings**

Sex-based differences in mental health challenges among HIV-infected youth have not been consistently identified although there seems to be a suggestion that females are at higher risk [47,48]. As Mellins *et al.* noted in their 2013 systematic review, some studies have found that, among HIV-infected youth, female sex is a risk factor for depression and anxiety, while male sex is a risk factor for behavioural problems [11]; however, other studies have had mixed or inconsistent results regarding gender differences.

There is more variation in the findings related to biological sex among HIV-infected adolescent in low-income settings. One study found male sex to be associated with a greater risk of depression than female sex in Kenya [28], while another found female sex to be associated with higher BDI-II scores in Malawi [30]. Another study found depression rates to be higher among HIV-infected adolescent females than males in Rwanda, but this difference was not significant [31], while another found no significant association between sex and suicidal ideation or behaviour in Rwanda [35].

#### **Mental health associated with adolescents' ART adherence across income settings**

Adherence to ART is critical to maintaining viral suppression and avoiding morbidity and mortality among HIV-infected patients. Among HIV-infected children and adolescents, depression and anxiety symptoms have been associated with lower adherence to ART [49–51] and higher substance abuse and risky sexual behaviours [52]. In a longitudinal study of 294 perinatally HIV-infected children and adolescents in the US and Puerto Rico, children with anxiety were 40% less likely to have unsuppressed viral load compared to other children [53]. Mental health disorders may be exacerbated by social exclusion and HIV stigma, which are associated with delayed HIV testing [54,55] and decreased treatment adherence [56]. Stigmatizing aspects of HIV infection or treatment, such as lipodystrophy, may also negatively impact mental health outcomes like depression and adherence to ART among adolescents, particularly during this developmental period when body image and the social desirability to “fit in” are strong motivators of behaviour [57]. Behaviourally HIV-infected youth who experience a combination of individual challenges such as low levels of self-efficacy and mental health disorders, in combination with environmental challenges such as homelessness or a history of time in detention facilities, have greater issues with maintaining adherence [58,59].

Based on a qualitative study of perinatally infected adolescents in Canada, how medication adherence is interpreted may be the key to whether the adolescent begins to take responsibility for his/her own HIV care, including adherence [60]. A positive mental framework towards adherence may be associated with autonomy and control over the adolescent's health and wellbeing. Conversely, a negative mental framework views adherence as a reminder of HIV infection,

difference from peers, and stigmatization. This interplay of mental health, adherence, and the adolescents' psychosocial environment suggests a critical role for mediating these risk factors and boosting mental and emotional health resilience for these adolescents.

#### **HIV-related stigma and adolescent mental health across income settings**

HIV-related stigma is a key issue that impacts adolescents living with HIV across country-income settings by affecting quality of life, healthcare access, and health outcomes. Stigma and discrimination experienced by HIV-infected youth through the broader community, as well as in clinical encounters, are significant barriers to HIV treatment, often leading to negative consequences and poor health outcomes [34,61]. Furthermore, HIV-related stigma is often intertwined with other sources of stigma, including those associated with mental health and/or substance use disorders. Research that investigates these impacts upon public health can guide the development of service delivery and provision of optimal healthcare appropriate for the resource setting. Such interventions to combat barriers due to stigma are especially relevant for adolescents transitioning their medical care to adult care settings, as the burden and interplay of physical, emotional, and social stressors during this vulnerable, developmental period increase. For example, due to the expectations of increased independence in navigating the healthcare systems, adolescents with HIV may need increased social support from family and friends. However, the availability and level of social support for adolescents and young adults living with HIV may be complicated by mental health issues, many of which may be emerging during this time, as well as stigma and disclosure [62]. Services to address stigma, social support, and mental health overall, are scarce, especially in low-resource settings [62,63]. Additional evidence on the impact of stigma, HIV related, as well as mental health related, on the transition process for adolescent to adult care settings and resultant health outcomes is needed.

#### **Mental health within the transition from paediatric to adult medical care: high-income settings**

Adolescents' mental health must be considered throughout the process of transitioning to adulthood with HIV, both in the general sense of their transition to adult, autonomous management of their disease as well as specific changes that may occur in the provision of their medical care. One of the first steps in adolescents' transition to managing their own HIV care is being informed of their own HIV status, also referred to as child HIV disclosure. Decisions around when to disclose HIV status to children are often impacted by caregivers' beliefs about the impact of disclosure on the child's mental health [64]. Studies suggest that disclosure of their own HIV status to children causes stress [65], but whether the disclosure process has a lasting negative impact on mental health is not clear [36,66]. In settings with higher HIV-related social exclusion and stigma, disclosure of HIV status to adolescents is also likely to be delayed [67].

In addition to this period of developmental transition from childhood to adulthood, adolescents may experience a physical transition in who provides their HIV care or where they receive medical services. Transitions that include an entirely new environment in which to receive medical care, potentially with fewer psychosocial supports, a new set of providers, or less "protective" HIV care compared to child-centred programmes, may create feelings of fear and anxiety for adolescents, even among those without any pre-existing mental health conditions [68]. In qualitative work, adolescents report feeling unprepared for transition and anxious about transitioning [69,70]. In addition to adjusting to new providers and care settings, the mental and emotional stressors may include the stress of disclosing their HIV status to providers within the new care system, the possibility of facing new HIV-related stigma or discrimination, and retelling their often-traumatic life story once again [65]. In addition, the new care systems in which adolescents find themselves may not provide care tailored to adolescents' specific needs, which may include sexual and reproductive healthcare, addressing specific populations such as young men who have sex with men, and adolescents' concerns about disclosing either their HIV status or sexual health issues to family members [65].

Mental health challenges likely complicate the navigation of these changes in medical care. In a systematic review of studies of HIV-infected youth transitions into adult care, the combined barriers to transition anticipated by providers and the adolescents included feelings of loss when separating from the paediatric provider, anxiety about increasing autonomy, and the logistic challenges of navigating the adult healthcare system – all of which may colour the mental and emotional health state of the adolescents [71]. A majority of providers of adolescent HIV care surveyed in the United States expressed concern that those adolescents who do have mental health problems or substance use issues would be at risk for being lost to care in the process of transition, especially as the adult care services might not follow the same multidisciplinary and integrated care models often seen in the paediatric HIV care models in this setting [72]. The preparedness of adult providers to address a population with higher rates of cognitive impairment, mental health problems, and adherence difficulties may be a challenge throughout the healthcare transition [65]. In a qualitative study of American HIV care providers, the following indicators of successful transition to adult care were identified: medication adherence, adherence to clinic visits, taking ownership of medical care, viral load, and CD4 count [73]. Adolescents with mental health problems or struggling with the multiple relational and environmental factors that make them more prone to mental health symptoms may be less likely to have these characteristics. In another qualitative study of clinical and programme staff providing adolescent HIV care at 12 clinical sites across the United States, the identified barriers to successful transition included mental health issues, substance abuse, paediatric providers being hesitant to transition care, and issues with insurance coverage [74].

### **Mental health within the transition from paediatric to adult medical care: low- and middle-income settings**

Very few studies have examined the barriers and facilitators of transition in RLS, with even less data regarding potential mental health challenges. In many RLS, particularly in sub-Saharan Africa, there are not separate paediatric specialty services for HIV-infected children, nor is there specialized care for adolescents (with or without HIV), and so HIV-infected adolescents may not experience any changes in providers or care systems in these settings. One qualitative study in Thailand, which employed semi-structured interviews of users of ART services, policymakers, and caregivers of orphaned children, concluded that adherence, drug resistance, and psychosocial issues were important in caring for HIV-infected children long term, that services to help adolescents to transition into adult care were largely lacking, and that physicians did not have adequate skills or comfort to aid in this transition. However, mental health needs or issues were not considered in depth [75].

### **Mental health service access for adolescents: high-income countries**

Considering how to ensure access to resources for mental health services for HIV-infected adolescents is a critical consideration [69]. A 2011 study used the World Health Organization Assessment Instrument for Mental Health Systems (WHO-AIM) in 13 low-, 24 lower-middle, and 5 upper-middle income countries. One indicator from this instrument included the treated child and adolescent prevalence in all mental health facilities for a one-year period. It found a one-year median treated prevalence for children and adolescents of 159 per 100,000 patients treated compared to 664 per 100,000 in adults, with greater differences in the low- and lower-middle-income countries than upper-middle-income countries [76]. Children were more likely to be treated in outpatient facilities and made up 12% of the mental health outpatient population, but none of the other facilities surveyed (e.g. inpatient facilities, day treatment) had any facilities devoted to children [76]. Even in resource-rich settings, there may be important disparities in mental health service access for minority populations; in the U.S. Adolescent Treatment Network, Black HIV-infected youth were less likely to receive care for mental health symptoms than non-Black youth [77]. Among 164 HIV-infected adolescents in 3 U.S. cities enrolled in the Adolescent Impact study, 31% had symptoms of psychopathology, but almost one-third of those reporting clinically significant symptoms did not receive care despite the availability of psychiatric medications, hospitalizations, counselling, or psychotherapy [78].

### **Mental health service access for adolescents: low- and middle-income countries**

Mental health services for children and adolescents in resource-limited countries are extremely limited according to existing estimates, and thus, lead to severe limitations in not only access to, but also uptake of mental health services [76]. The availability of providers may be extremely limited; only 1% of schools in low- and middle-income countries had mental health professionals as

staff members, and less than 1% of professionals had attended any training on child and adolescent psychiatry in the last year [76]. Ratios of available psychiatrists are estimated at 1 psychiatrist per 4 to 5 million children in resource-limited countries, and training for mental health workers are limited and often out-of-date [79]. Qualitative inquiry among key education personnel and teachers in Nigeria suggests that, in some settings, these deficits in services may be further hampered by stigmatizing beliefs about mental health disorders, disbelief that children can have a mental illness, and overtly discriminating or derogatory language and treatment used in regards to mental illness [80]. Access to mental health services in low- and middle-income countries may also be affected by concerns regarding the use of psychotropic medications in conjunction with ART. Options to extend mental health services through alternative modes of delivery such as teleconsultations and telepsychiatry may offer particular benefits for RLS with adolescents in need of mental health screening and treatment [79]. An integrated mental healthcare approach within the primary HIV care setting to address gaps in mental health service access and treatment is another option worth investigating [81].

### **Mental health interventions for HIV-infected adolescents: high-income countries**

Few mental health interventions, specifically for HIV-infected adolescents, have been studied. One pilot study from a resource-rich setting used health and wellness cognitive behavioural therapy for 8 HIV-infected participants aged 16–24 years and found significant improvement in depression symptoms as measured over 14 sessions by the Quick Inventory of Depressive Symptomatology-Clinician measure, as well as improved self-reported adherence [82]. In a literature review of studies evaluating the impact of service delivery interventions to improve the health of perinatally HIV-infected adolescents, the overall conclusion from the 12 studies examined was that youth-focused health services and individual-level interventions would improve adherence and retention in care; however, these were small studies with limited follow-up times, and the impact of the service delivery interventions on mental health were largely unexamined [83].

### **Mental health interventions for HIV-infected adolescents: low- and middle-income countries**

Interventions to promote mental health show significant promise generally to improve child and adolescent mental health and wellbeing in RLS. A systematic review of mental health interventions and their effectiveness for adolescents in resource-limited studies identified 14 studies of school-based interventions and 8 studies of community-based interventions [84]. The majority of the school-based interventions led to improvements in student emotional and behavioural wellbeing, self-esteem, and coping skills [84]. Similarly, community-based interventions also showed significant improvements in youth mental health



and social wellbeing [84]. Cognitive-behavioural group therapy has been shown to improve externalizing symptoms and anxiety in low- and middle-income countries, though not depressive symptoms or quality of life [85]. Very few mental health interventions have been studied specifically for HIV-infected adolescents in RLS.

## Conclusions

This review of the literature related to mental health, HIV-infected adolescents, and transition raises the critical importance of considering mental health as an integral component to adolescent care and to the transition process. While mental health disorders are often prevalent in this population, too little has been done to measure the impact of these disorders for adolescents, to evaluate interventions to best sustain or improve the mental health of this population, or to create healthcare systems with personnel or resources to promote mental health. Evidence-based studies confirming the link between poor mental health and deleterious health outcomes are still needed within the growing population of HIV-infected adolescents to inform guidelines and policies for HIV healthcare.

For the low- and middle-income countries in which the majority of the world's HIV-infected adolescents live – and the exact settings in which the rates of adolescent HIV-related deaths are a major concern – the absence of screening for mental health disorders, the lack of evidence for how to intervene to prevent or improve mental health problems, and the minimal healthcare infrastructure to address mental health are enormous obstacles. These limitations for mental health are all too-often complicated by HIV-related stigma, mental health-related stigma, sex and gender disparities, and the broader set of psychosocial challenges faced by adolescents living with HIV. Any effort to provide long-term care for these youth and to effectively support their transition into adulthood must address the adolescents' mental health. Validating mental health screening tools that can be used in routine care settings in RLS should be a priority research area.

Mental health is also likely critical for adolescents' successful transitions within the specific realm of medical care services as they face the long-term challenges of remaining in medical care, sustaining medication adherence, and achieving viral suppression. Further research to assess these connections and how to sustain them is urgently needed for this population, particularly in low- and middle-income countries. For transition processes to meet the full range of adolescents' mental health and emotional health needs, transition plans need to consider HIV-infected adolescents' risk of mental health disorders and psychiatric illness, the specific needs of adolescents, and the key issues of HIV-related stigma, HIV disclosure to others, adherence issues, and the range of factors that may increase or decrease resilience in the face of transitions in care [69]. For example, detailed recommendations for the medical transition process from the Johns Hopkins University HIV Clinical Guidelines Program (2000–2016) in the United

States emphasize the need for creating a plan for each adolescent that does the following: (1) "Address the individual barriers for each patient that may be preventing him/her from acquiring skills, such as anxiety, depression" and (2) Provide HIV care "in settings where patients can receive all services in one location from a multidisciplinary team. If a multidisciplinary team is not available, mental health and psychosocial support services should be available onsite or in an easily accessible location" [86]. A multidisciplinary team approach to the screening of mental health disorders, followed by an integrated treatment approach with primary HIV care along the transition continuum could improve access to and uptake of mental health services and interventions.

This review offers an update on previous systematic reviews of mental health challenges and interventions, which have focused on the more general population of children and adolescents [4,7,8], by assessing emerging work of those infected with HIV from RLS [11]. While this was not a traditional systematic review, we did use a standardized search strategy that could be replicated and have attempted to provide both a broad and thorough summary of the current literature. Many of the primary studies included within the review are limited by small sample sizes without comparison groups, in addition to the relative dearth of investigation from the settings where the bulk of HIV-infected children and adolescents live, particularly sub-Saharan Africa. We have tried to make clear these limitations when describing each study or content area, and to highlight the gaps in the existing research with recommendations for further investigation (Table 2). Our review emphasizes the need for mental health issues to be addressed proactively for all HIV-infected youth, and integrated into their overall HIV care.

**Table 2.**

### Key Areas for Future Mental Health Research and Practice Improvement for HIV-Infected Adolescents

- Reliable and valid screening and assessment instruments of mental health that are culturally-appropriate for children and adolescents in resource-limited settings
- Measurement instruments, mental health interventions, and mental health services for HIV-infected adolescents must be patient centered and adapted to specific cultural and environmental contexts
- Longitudinal studies inclusive of perinatally infected and behaviourally infected youth with HIV to effectively monitor mental health outcomes across the lifespan
- Evidence-based models linking the importance of mental health to treatment adherence and physical health outcomes for HIV populations
- Integration of mental health services and interventions within adolescent-friendly healthcare services as youth with HIV transition to adult care
- Incorporation of factors such as stigma and disclosure of illness to access to mental health services during the transition process

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#### Competing interests

The authors (RV, BM, and SL) have no financial relationships or other conflicts of interest relevant to this article to disclose.

#### Authors' contributions

RV provided the scientific leadership, conceptualized this review article, guided the literature review, led the drafting of the manuscript, and supervised all revisions. BM conducted the literature review, summarized relevant literature, and participated in the editing of the manuscript. SL provided additional scientific leadership, drafted sections of the manuscript, and edited the manuscript. All authors have read and approved the final manuscript and meet international criteria for authorship.

#### Acknowledgements

RV's contribution was supported in part by a grant entitled "Stigma in AIDS Family Inventory" (3R01MH099747-01S1) to Dr. Rachel Vreeman from the National Institute of Mental Health, Bethesda, MD, USA. The views expressed in this article are those of the authors and do not necessarily represent the view of the Indiana University School of Medicine, Moi University School of Medicine, or the National Institutes of Health.

#### Funding

This work was supported by the Stigma in AIDS Family Inventory; [3R01MH099747-01S1]; National Institute of Mental Health.

#### List of abbreviations

ART, antiretroviral therapy; BDI, beck depression inventory; CES-D, center for epidemiological studies – depression scale; CDI, children's depression inventory; HIV, human immunodeficiency virus; QoL, quality of life; RLS, resource-limited settings; RAD, reynold's adolescent depression scale

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