

Mental Health Services	Pg
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PowerPoint: 2022 Mental Health Chart Review Update, TRG Due to a new modified monitoring process 2020 was the last monitoring year. These update slides are included since most information can't be updated at this time.	6
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Changes in Mental Health Among People with HIV During the COVID-19 Pandemic: Qualitative and Quantitative Perspectives – Springer Science, January 2022	15
HIV and Mental Health – National Institutes of Health, August 2021	27
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Local Service Category:	Mental Health Services
Amount Available:	To be determined
Unit Cost	
Budget Requirements or Restrictions (TRG Only):	Maximum of 10% of budget for Administrative Cost.
DSHS Service Category Definition	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. 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. Mental health services include: • Mental Health Assessment • Treatment Planning • Treatment Provision • Individual psychotherapy • Family psychotherapy • Conjoint psychotherapy • Group psychotherapy • Psychiatric medication assessment, prescription and monitoring • Psychotropic medication management • Drop-In Psychotherapy Groups • Emergency/Crisis Intervention 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.
Local Service Category Definition:	Individual Therapy/counseling 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. Family/Couples Therapy/Counseling 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. Support Groups 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.
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.

Service Unit Definition(s) (TRG Only):	Individual Crisis Intervention and/or Therapy: A unit of service is defined as an individual counseling session lasting a minimum of 45 minutes. Family/Couples Crisis Intervention and/or Therapy: A unit of service is defined as a family/couples counseling session lasting a minimum of 90 minutes. Group Therapy: 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. A minimum of three (3) participants must attend a group session in order for the group session to eligible for reimbursement. Consultation: One unit of service is defined as 15 minutes of communication with a medical or other appropriate provider to ensure case coordination.
Financial Eligibility:	Income at or below 500% Federal Poverty Guidelines.
Eligibility for Services:	For individual therapy session, person living with HIV or the affected significant other of a person living with HIV, resident of Houston HSDA. Person living with HIV must have a current DSM diagnosis eligible for reimbursement under the State Medicaid Plan. 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. 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. Affected significant other is eligible for services only related to the stress of caring for a person living with HIV.
Agency Requirements (TRG Only):	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. Keep attendance records for group sessions. Must provide 24-hour access to a licensed counselor for current PLWH with

	emotional emergencies. 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. 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. Must comply with the State Services Standards of Care. Must provide a plan for establishing criteria for prioritizing participation in group sessions and for termination from group participation. Providers and system must be Medicaid/Medicare certified to ensure that Ryan White funds are the payer of last resort.
Staff Requirements:	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). At least two years' experience working with HIV disease or two years' work experience with chronic care of a catastrophic illness. Counselors providing family sessions must have at least two years' experience in family therapy. Counselors must be covered by professional liability insurance with limits of at least \$300,000 per occurrence.
Special Requirements (TRG Only):	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. Mental health services can be delivered via telehealth and must follow applicable federal and State of Texas privacy laws. 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 chapter 111 for Telehealth & Telemedicine.

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 2023 RWPC “How to Best Meet the Need” Decision Process

Step in Process: Council		Date: 06/09/2022
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Steering Committee		Date: 06/02/2022
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Quality Improvement Committee		Date: 05/03/2022
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: HTBMTN Workgroup #2		Date: 04/19/2022
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)

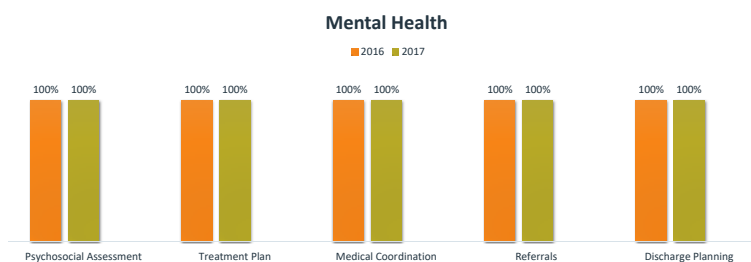
Mental Health (MH)

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



MENTAL HEALTH SERVICES
2019 CHART REVIEW

PREFACE

DSHS Monitoring Requirements

The Texas Department of State Health Services (DSHS) contracts with The Houston Regional HIV/AIDS Resource Group, Inc. (TRG) to ensure that Ryan White Part B and State of Texas HIV Services funding is utilized to provide in accordance to negotiated Priorities and Allocations for the designated Health Service Delivery Area (HSDA). In Houston, the HSDA is a ten-county area including the following counties: Austin, Chambers, Colorado, Fort Bend, Harris, Liberty, Montgomery, Walker, Waller, and Wharton. As part of its General Provisions for Grant Agreements, DSHS also requires that TRG ensures that all Subgrantees comply with statutes and rules, perform client financial assessments, and delivery service in a manner consistent with established protocols and standards.

As part of those requirements, TRG is required to perform annual quality compliance reviews on all Subgrantees. Quality Compliance Reviews focus on issues of administrative, clinical, data management, fiscal, programmatic and quality management nature. Administrative review examines Subgrantee operating systems including, but not limited to, non-discrimination, personnel management and Board of Directors. Clinical review includes review of clinical service provision in the framework of established protocols, procedures, standards and guidelines. Data management review examines the Subgrantee's collection of required data elements, service encounter data, and supporting documentation. Fiscal review examines the documentation to support billed units as well as the Subgrantee's fiscal management and control systems. Programmatic review examines non-clinical service provision in the framework of established protocols, procedures, standards and guidelines. Quality management review ensures that each Subgrantee has systems in place to address the mandate for a continuous quality management program.

QM Component of Monitoring

As a result of quality compliance reviews, the Subgrantee receives a list of findings that must be address. The Subgrantee is required to submit an improvement plan to bring the area of the finding into compliance. This plan is monitored as part of the Subgrantee's overall quality management monitoring. Additional follow-up reviews may occur (depending on the nature of the finding) to ensure that the improvement plan is being effectively implemented.

Scope of Funding

TRG contracts with two Subgrantees to provide hospice services in the Houston HSDA.

INTRODUCTION

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. **Individual Therapy/counseling** 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 HIV positive or HIV/AIDS affected individual. **Support Groups** are defined as professionally led (licensed therapists or counselor) groups that comprise HIV positive individuals, family members, or significant others for the purpose of providing emotional support directly related to the stress of caring for an HIV positive person.

Tool Development

The TRG Mental Health Services Tool is based upon established local standards of care.

Chart Review Process

All charts were reviewed by Bachelors-degree registered nurse experienced in treatment, management, and clinical operations in HIV care of over 10 years. The collected data for each site was recorded directly into a preformatted computerized database. The data collected during this process is to be used for service improvement.

File Sample Selection Process

Using the ARIES database, the file sample was created from a provider population of 216 who accessed mental health services in the measurement. The records of 51 clients were reviewed, representing 24% of the unduplicated population. The demographic makeup of the providers was used as a key to file sample pull.

NOTES: DSHS modified their review process to exclude indicators that were <51% in last years this year. As a result, only one (1) indicator was reviewed in 2018. The results listed below are from 2017, with the exception of the one (1) indicator reviewed.

Demographics- Mental Health

2018 Annual		
Total UDC: 216		
Age	Number of Clients	% of Total
Client's age as of the end of the reporting period		
Less than 2 years	0	0.00%
02 - 12 years	0	0.00%
13 - 24 years	4	1.85%
25 - 44 years	73	33.80%
45 - 64 years	127	58.80%
65 years or older	12	5.55%
Unknown	0	0.00%
	216	100%
Gender	Number of Clients	% of Total
"Other" and "Refused" are counted as "Unknown"		
Female	20	9.26%
Male	196	90.74%
Transgender FTM	0	0.00%
Transgender MTF	5*	2.31%
Unknown	0	0.00%
	216	100%
Race/Ethnicity	Number of Clients	% of Total
Includes Multi-Racial Clients		
White	138	63.89%
Black	73	33.80%
Hispanic	38*	17.59%
Asian	2	0.93%
Hawaiian/Pacific Islander	0	0.00%
Indian/Alaskan Native	1	0.46%
Unknown	2	0.93%
	216	100%

From 01/01/18 - 12/31/18

2019 Annual		
Total UDC: 282		
Age	Number of Clients	% of Total
Client's age as of the end of the reporting period		
Less than 2 years	0	0.0%
02 - 12 years	0	0.0%
13 - 24 years	9	3.2%
25 - 44 years	139	49.2%
45 - 64 years	119	42.2%
65 years or older	15	5.3%
Unknown	0	0.0%
	282	100%
Gender	Number of Clients	% of Total
"Other" and "Refused" are counted as "Unknown"		
Female	42	14.9%
Male	240	85.1%
Transgender FTM	0	0.00%
Transgender MTF	9*	3.19%
Unknown	0	0.00%
	282	100%
Race/Ethnicity	Number of Clients	% of Total
Includes Multi-Racial Clients		
White	160	56.7%
Black	115	40.8%
Hispanic	66*	23.4%
Asian	0	0.0%
Hawaiian/Pacific Islander	1	0.35%
Indian/Alaskan Native	2	0.70%
Multi/Unknown	4	1.4%
	282	100%

From 01/01/19 - 12/31/19



RESULTS OF REVIEW-2018

Psychosocial Assessment

Psychosocial Assessment completed no later than third counseling session.

	Yes	No	N/A
Clients with psychosocial assessment completed no later than the 3 rd appt.	59	-	-
Client records reviewed that included in this measure.	59	-	-
Rate	100%	-	-

Psychosocial Assessment: Required Elements

Psychosocial Assessment included assessment of all elements in the Mental Health Standards.

	Yes	No	N/A
Clients with assessment completed no later than the 3 rd appt.	59	-	-
Client records reviewed that included in this measure.	59	-	-
Rate	100%	-	-

Treatment Plan

(NEW 2018) Documentation of detailed treatment plan and services provided within client's primary record.

	Yes	No	N/A
Treatment plan and services detailed in client record.	38	12	1
Client records reviewed that included in this measure.	50	50	51
Rate	76%	24%	2%

Treatment Plan completed no later than third counseling session.

	Yes	No	N/A
Clients with treatment plans completed no later than the 3 rd counseling session.	52	-	7
Client records reviewed that included in this measure.	52	-	59
Rate	100%	-	12%

Treatment Plan: Signed by Therapist

Treatment Plan was signed by the mental health professional who rendered service.

	Yes	No	N/A
Clients with treatment plans signed by the mental health professional rendering service.	52	-	7
Client records reviewed that included in this measure.	52	-	59
Rate	100%	-	12%

Treatment Plan: Reviewed/Modified

Treatment Plan was reviewed and/modified at least every ninety (90) days.

	Yes	No	N/A
Clients with treatment plans reviewed/modified every 90 days.	50	2	7
Client records reviewed that included in this measure.	52	52	59
Rate	96%	4%	12%

Services Provided: Required Elements

Treatment included counseling covering all elements outlined in the Mental Health Standards.

	Yes	No	N/A
Clients who received counseling covering all elements.	59	-	-
Client records reviewed that included in this measure.	59	-	-
Rate	100%	-	-

Services Provided: Psychiatric Evaluation

Treatment included psychiatric evaluation was conducted/referral completed if needed.

	Yes	No	N/A
Clients who psychiatric evaluation was conducted/referral completed if needed.	1	-	58
Client records reviewed that included in this measure.	59	-	59
Rate	100%	-	-

Services Provided: Psychiatric Medication

Treatment included psychotropic medication management services, if needed.

	Yes	No	N/A
Clients who documented psychotropic medication management service was provided if needed.	-	-	59
Client records reviewed that included in this measure.	59	-	59
Rate	0%	-	100%

Services Provided: Progress Notes

Progress notes completed for each counseling session and contained all elements outlined in the Mental Health Standards.

	Yes	No	N/A
Clients with progress notes complete and containing all elements.	59	-	-
Client records reviewed that included in this measure.	59	-	-
Rate	100%	-	-

Services Provided: Medical Care Coordination

Evidence that care was coordinated as appropriate across all medical care coordination team members.

	Yes	No	N/A
Clients with care coordinated across team.	59	-	-
Client records reviewed that included in this measure.	59	-	-
Rate	100%	-	-

Referrals: Referrals Made as Needed

Documentation that referrals were made as needed to specialized medical/mental health providers/services.

	Yes	No	N/A
Clients with referral needed and made.	27	-	32
Client records reviewed that included in this measure.	27	-	59
Rate	100%	-	-

Referrals: Referrals Outcome

Documentation is present in client's record of the referral and the outcome of the referral.

	Yes	No	N/A
Clients with referral document with outcome of referral.	27	-	32
Client records reviewed that included in this measure.	27	-	59
Rate	100%	-	-

Discharge Planning

Documentation is present that discharge planning was completed with the client.

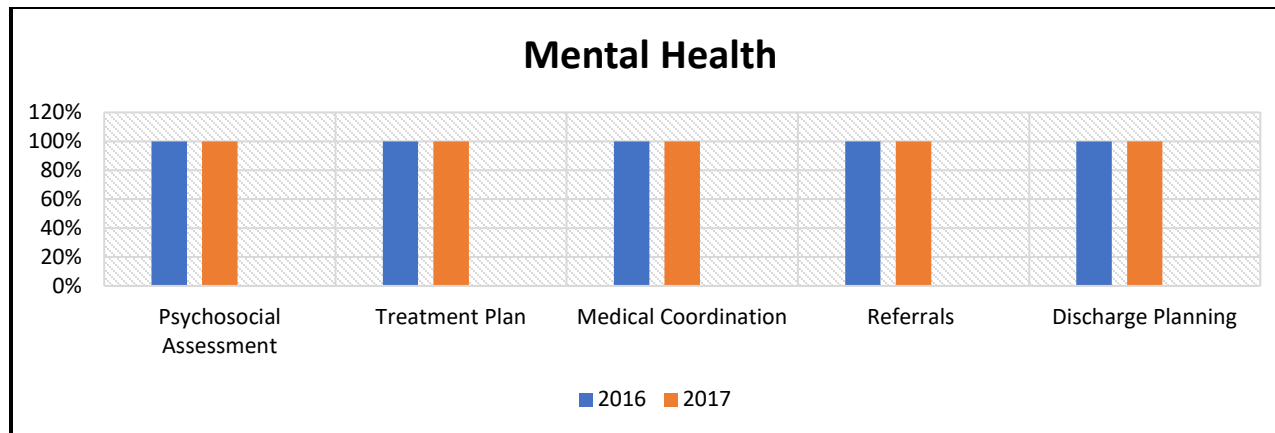
	Yes	No	N/A
Clients with documented discharge planning.	26	-	33
Client records reviewed that included in this measure.	26	-	59
Rate	100%	-	-

Discharge

Documentation is reason for discharge is located in the client's record and is consistent with agency policies.

	Yes	No	N/A
Clients with documented reason for discharge.	23	-	36
Client records reviewed that included in this measure.	23	-	59
Rate	100%	-	-

HISTORICAL DATA



CONCLUSION

Quality of mental health services continues to excellent. All clients reviewed (100%) completed a psychosocial assessment no later than the third counseling session, all clients had a treatment plan and medical care coordination was appropriate across all medical care coordination team members. Eleven data elements were met at 100%.



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

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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, χ^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, χ^2 : 3.98, $p = 0.046$), moderate (OR: 8.00, 95% CI 3.00–21.31, χ^2 : 17.30, $p < 0.001$), or severe depression (OR: 4.15, 95% CI 1.51–11.38, χ^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, χ^2 : 5.55, $p = 0.019$), as did those with moderate depression (OR: 4.88, 95% CI 1.07–22.24, χ^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 men- tal health N = 69 (30.4%)	Improved mental health N = 19 (8.4%)	No change in men- tal 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</i>	Caring for Loved Ones	Caring for loved ones or friends	1 (1.4%)
<i>Emotion</i>	Anxiety/Stress	Anxiety/nervousness or stress, or being unable to relax or calm down	23 (33.3%)
	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%)
<i>Social Factors</i>	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.

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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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Living with HIV

HIV and Mental Health

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Key Points

- Mental health refers to a person's overall emotional, psychological, and social well-being. Good mental health helps people make healthy choices, reach personal goals, develop healthy relationships, and cope with stress.
- For people with HIV, taking care of both physical and mental health are important.
- People with HIV have a higher risk for some mental health conditions than people who do not have HIV.
- Mental health conditions are treatable, and people with mental health problems can recover.

What is mental health?

Mental health refers to a person's overall emotional, psychological, and social well-being. Mental health affects how people think, feel, and act. Good mental health helps people make healthy choices, reach personal goals, develop healthy relationships, and cope with stress.

Poor mental health means people find it difficult to manage how they feel, think, act, or cope with stress. Poor mental health is not the same as mental illness. Mental illnesses are mental, behavioral, or emotional disorders that may not result in any impairment or may result to mild, moderate, or severe impairment that may limit or interfere with function in one or more areas of life. Mental illnesses include many different conditions, such as post-traumatic stress disorder (PTSD), bipolar disorder, and schizophrenia.

A person can have poor mental health and not have a diagnosed mental illness. Likewise, a person with a mental illness can still enjoy mental well-being.

If you are living with HIV, it is important to take care of both your physical health and your mental health.

Are people with HIV at risk for mental health conditions?

Anyone can have mental health problems. Mental health conditions are common in the United States. According to the [National Institute of Mental Health \(NIMH\)](#), in 2019, about one in five American adults experienced a mental health issue.

People with HIV are at high risk of some mental health conditions because of the stress associated with living with HIV. For example, people living with HIV are twice as likely to have depression as people who do not have HIV.

It is important to remember that mental health conditions are treatable and that people who have mental health problems can recover.

What can cause mental health problems in people with HIV?

The following factors can increase the risk of mental health problems in anyone:

- Major life changes, such as the death of a loved one or the loss of a job
- Negative life experiences, such as abuse or trauma
- Biological factors, such as genes or brain chemistry
- A family history of mental health problems

In addition to these factors, the stress of having a serious medical illness or condition, like HIV, may also negatively affect a person's mental health. Situations that can contribute to mental health problems in people with HIV include:

- Difficulty in telling others about an HIV diagnosis
- [Stigma](#) and discrimination associated with HIV

- Loss of social support and isolation
- Difficulty in getting mental health services

In people with HIV, HIV infection and related [opportunistic infections](#) can affect the brain and the rest of the nervous system. This may lead to changes in how a person thinks and behaves. In addition, some medicines used to treat HIV may have side effects that affect a person's mental health.

What are the warning signs of a mental health problem?

Changes in how a person feels or acts can be a warning sign of a mental health problem. For example, potential signs of depression include:

- Losing interest in activities that are usually enjoyable
- Experiencing persistent sadness or feeling empty
- Feeling anxious or stressed
- Having suicidal thoughts

If you have any signs of a mental health problem, it is important to get help.

What should people with HIV do if they need help for a mental health problem?

People with HIV can talk to their health care provider about how they are feeling. They can also tell their health care providers if they are having any problems with drugs or alcohol.

Health care providers will consider whether any HIV medicines may be affecting the person's mental health. They can also help people with HIV find a mental health care provider, such as a psychiatrist or therapist.

Here are additional ways that people with HIV can improve their mental health:

- Join a support group.
- Try meditation, yoga, or deep breathing to relax.
- Get enough sleep, eat healthy meals, and stay physically active.

To find mental health treatment services, use these resources from [NIMH](#) and the [Substance Abuse and Mental Health Services Administration](#).

This fact sheet is based on information from the following sources:

From the Centers for Disease Control and Prevention:

- [About Mental Health](#)
- [Stigma and Mental Health](#)

From MentalHealth.gov:

- [What Is Mental Health?](#)

From NIMH:

- [HIV/AIDS and Mental Health](#)

From the U.S. Department of Veterans Affairs:

- [Mental Health and HIV](#)
- [Mental Illness](#)

Also see the [HIV Source](#) collection of HIV links and resources.

COMMENTARY

Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence

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Abstract

Introduction: As adolescents transition from childhood to adulthood, they experience major physical, social and psychological changes, and are at heightened risk for developing mental health conditions and engaging in health-related risk behaviours. For adolescents living with HIV (ALHIV), these risks may be even more pronounced. Research shows that this population may face additional mental health challenges related to the biological impact of the disease and its treatment, the psychosocial burdens of living with HIV and HIV-related social and environmental stressors.

Discussion: Psychosocial interventions delivered to adolescents can promote positive mental health, prevent mental health problems and strengthen young people's capacity to navigate challenges and protect themselves from risk. It is likely that these interventions can also benefit at-risk populations, such as ALHIV, yet there is little research on this. There is an urgent need for more research evaluating the effects of interventions designed to improve the mental health of ALHIV. We highlight four priorities moving forward. These include: generating more evidence about preventive mental health interventions for ALHIV; including mental health outcomes in research on psychosocial interventions for ALHIV; conducting intervention research that is sensitive to differences among ALHIV populations; and involving adolescents in intervention design and testing.

Conclusions: More robust research on promotive and preventive mental health interventions is needed for ALHIV. Programmes should be informed by adolescent priorities and preferences and responsive to the specific needs of these groups.

Keywords: adolescents; interventions; public health; social support; mental health; psychosocial interventions

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1 | INTRODUCTION

As adolescents transition from childhood to adulthood, they undergo major physical, social and psychological changes [1]. Physical changes, which include puberty and rapid brain development, take place in the context of newly developing autonomy, responsibility and decision-making abilities. This transition is also influenced by a complex set of socio-economic factors, including family and cultural environments, which interact with each other and shape adolescents' health trajectories and vulnerabilities [2]. During this dynamic yet precarious life stage, adolescents are at heightened risk for developing mental health conditions (such as depression and anxiety) and engaging in health-related risk behaviours. As many as 10% to 20% of people will develop mental health conditions during adolescence, and it is estimated that up to 50% of all mental health conditions start before the age of 14 [3]. Self-harm, which includes suicidal behaviours, is among the top three causes of death for 15- to 19-year-old boys and girls globally [4].

Furthermore, mental health conditions during this period are associated with a range of risk behaviours, including tobacco and alcohol use, drug misuse, risky sexual behaviours and violence [5,6], the effects of which may persist throughout the life course.

Adolescents living with HIV (ALHIV) are at an even greater risk of developing mental health conditions and risk behaviours [7]. Worldwide, an estimated two million adolescents are living with HIV, with over 80% of them residing in sub-Saharan Africa [8]. Depression, anxiety, hopelessness and fear for the future are common in this population, which makes mental health a vital area of concern for ALHIV [9]. Research shows that these risks are manifold, related to the biological impact of the disease and its treatment, the psychosocial burden of living with HIV and HIV-related social and environmental stressors. From a biological perspective, for adolescents who acquired HIV perinatally, the effects of the virus on brain development persist into adolescence [10], and there is mixed evidence on whether highly active antiretroviral therapy can

slow or reverse damage to the developing brain [11,12]. ALHIV also face numerous psychosocial challenges. Many young people with perinatally acquired HIV first learn they are living with HIV during adolescence, which can be highly stressful and create familial tensions if they blame their parents for their condition [13]. Relatedly, ALHIV may also experience grief from losing one or both parents, or other caregivers, contributing to their own expectations and fears of illness and death [9,14]. Social and environmental stressors include experiencing heightened stigma and isolation; adolescents may also be increasingly required to manage their own treatment adherence [15,16]. ALHIV engaging in romantic and sexual relationships for the first time need to grapple with how to disclose their status to partners and protect against potential fears of rejection [17]. Additionally, adolescents living in vulnerable households with others who are also living with HIV may have additional mental health needs that intersect with experiences of poverty and illness [18].

There is additional evidence that the mental health of ALHIV affects other domains of their health and wellbeing. In general, clinical outcomes for adolescents tend to be worse than those of adults, and adolescents have poorer levels of adherence to antiretroviral therapy (ART) and thus higher viral loads [19,20]. Evidence from adult populations reveals a complex relationship between mental health and HIV, including poor physiological and psychological outcomes related to factors such as disease progression, medication side effects, social isolation and the financial burden of being ill [21]. The same mechanisms that can contribute to poor health in adults living with HIV are likely to affect ALHIV; however, improving mental health can also foster better HIV outcomes such as adherence and retention in care [22], especially for adolescents [23].

2 | DISCUSSION

Adolescence is thus a critical time to intervene with this vulnerable group – to prevent mental conditions, to promote positive mental health and to strengthen young people's capacity to navigate challenges and protect themselves from risk. Psychosocial interventions have been identified as beneficial when delivered to universal, or general, adolescent populations: these interventions adopt a psychological, behavioural, and/or social approach to improve psychosocial wellbeing and reduce the risk of poor mental health outcomes [24]. Our meta-analysis found that psychosocial interventions that included specific components (emotional regulation, interpersonal skills, mindfulness, assertiveness training, problem solving, stress management, and alcohol and drug education) were associated with more successful programme outcomes for adolescent mental health [24].

However, there is less research about the impact of these types of interventions among targeted groups, such as ALHIV, who are likely to have specific, additional psychosocial support needs. From an equity perspective, it is critical to consider if and how psychosocial interventions might benefit special populations, including ALHIV. The same skills taught and practiced in a psychosocial intervention for a universal population of adolescents – for example, navigating changing peer dynamics or setting goals – may take on new significance as they help ALHIV disclose their status to a trusted peer, or conceptualise a healthy, fulfilling adult life. With a growing number of adolescents globally – including the largest

number of children born with HIV to survive into adolescence – this imperative is even greater.

Helping Adolescents Thrive (HAT), a joint initiative between the World Health Organization and UNICEF, represents one such attempt to provide more evidence for both universal and targeted interventions for adolescent mental health. A 2019 evidence review linked with HAT, conducted in preparation for the development of the WHO Guidelines on Mental Health Promotive and Preventive Interventions for Adolescents, found only three randomised controlled trials targeting mental health outcomes for ALHIV ages 10 to 19 [25–27], shown in Table 1. As the burden of HIV and mental health continues to persist among this population, there is an urgent need for research evaluating the effects of interventions designed to improve the mental health of ALHIV. Drawing primarily on this review, we have distilled four recommendations to guide future research in this area.

2.1 | Invest in high-quality research to test the effectiveness of interventions to prevent mental health conditions and promote positive mental health for ALHIV

There is a clear need to invest in more research about the mental health of ALHIV. Increased HIV-related research on adolescents regarding new strategies for biomedical treatment and adherence, given their unique risk profile and susceptibility to worse HIV outcomes, is promising [28]. However, there are glaring omissions in the evidence on mental health for ALHIV. Mental health, as a critical foundation for overall wellbeing and quality of life, must be prioritised in research and interventions with ALHIV. We argue that there should be an equally robust approach to generating evidence about how best to promote positive mental health, and prevent mental conditions and risk behaviours, in this population. Integrating services that consider and address mental health into existing HIV services that adolescents routinely access is one way to bridge this gap. Recent reviews have identified the need for integrating mental health services into HIV care in high-burden settings [29], especially for adolescents [7]. Integrated models, which might consist of multidisciplinary teams coordinating care in a “one-stop shop”, or service providers managing two-way referrals between HIV and mental health care, have been found to be both feasible and acceptable in high-burden, low-resource settings [30,31].

There is also a need to build process data into studies evaluating effectiveness, to give stakeholders and funders a multi-dimensional understanding of the complexity of programming with ALHIV. Process measures might include attendance, dosage and coverage of sessions; delivery characteristics; delivery and participation costs; content relevance; contextual barriers and enablers; implementer competence; and implementer soft skills. For adolescents who are more difficult to reach, more innovative engagement methods may be necessary. These include adolescents who do not access clinical care or HIV treatment consistently, those in age-disparate relationships, those living in vulnerable family circumstances and those who are involved in sex work or transactional relationships [32,33]. Research using process data holds important lessons for understanding why certain interventions may be easier to implement in given populations, or why some interventions may show limited evidence of effectiveness.

Table 1. Summary of studies included in review

Author and year	Article name	Country	Programme Intent	Total sample (N), % girls	Age (mean, sd)	Study population description	Mental health outcomes measured ^a	Summary of findings as reported by authors
Bhana et al. (2014)	The VUKA family programme: piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa	South Africa	RCT to prevent depression and anxiety; promote communication and mental wellbeing	65, 49.2%	11.57, n/s	Recruited children between 10 and 14 years old enrolled in HIV care at the hospital and aware of their HIV status at two clinical sites in KwaZulu-Natal	- Positive mental health (mental wellbeing and mental functioning) - Mental disorders (depression and anxiety)	At 3 months post-intervention, intervention participants showed a significant improvement in positive mental health (youth/caregiver communication comfort, $\beta = 0.796$, $p = 0.002$ and communication frequency, $\beta = 0.478$, $p = 0.09$). Mental disorders showed a non-significant reduction in symptoms (depression, $\beta = 0.736$, $p = 0.417$).
Webb et al. (2018)	Mindfulness instruction for HIV-infected youth: A randomized controlled trial	United States	RCT to prevent stress, aggression and lower CD4 count; promote mindfulness, mental functioning, life satisfaction and adherence	72, 45.8%	18.71, 2.31	Adolescent participants were eligible if they received their medical care at one of the clinics, did not have any significant cognitive, behavioural, or psychiatric disorders and had a current CD4 count above 200	- Mental disorders (depression and anxiety) - Positive mental health (mental wellbeing and mental functioning) - Adherence to antiretroviral treatment - Aggressive, disruptive and oppositional behaviours (aggression, $\beta = -0.89$, 95%CI [-1.41, to 0.37], $p = 0.002$).	At three months post-intervention, intervention participants showed significant improvements in positive mental health (mindfulness, $\beta = 0.65$, 95%CI [0.06, 1.24], $p = 0.03$, problem-solving coping $\beta = 0.49$, 95%CI [0.05, 0.92], $p = 0.03$, and life satisfaction, $\beta = 0.57$, 95%CI [0.01, 1.13], $p = 0.05$) and aggressive, disruptive and oppositional behaviours (aggression, $\beta = -0.89$, 95%CI [-1.41, to 0.37], $p = 0.002$).

Table 1. (Continued)

Author and year	Article name	Country	Programme Intent	Total sample (N), % girls	Age (mean, sd)	Study population description	Mental health outcomes measured ^a	Summary of findings as reported by authors
Willis <i>et al.</i> (2019)	Effectiveness of community adolescent treatment supporters (CATS) interventions in improving linkage and retention in care, adherence to ART and psychosocial wellbeing: a randomized trial among adolescents living with HIV in rural Zimbabwe	Zimbabwe	RCT to promote adherence, self-esteem and quality of life	94, 59.6%	10 to 15, n/s	Adolescents living with HIV, receiving ART at three selected clinic sites	- Positive mental health (mental wellbeing) - Adherence to antiretroviral treatment	At 12-month follow-up, intervention participants reported significant increases in positive mental health (confidence, self-esteem and self-worth, point difference = 0.49, 95%CI [0.313, 0.667], $p < 0.001$) and adherence to ART (OR = 3.934, 95%CI [1.404, 11.02], $p = 0.0087$). Significant increases in quality of life were reported for both intervention participants (point difference = 0.29, 95%CI [0.031, 0.549], $p = 0.028$) and control participants (point difference = 0.26, 95%CI [0.061, 0.459], $p = 0.011$).

^aThese measures are worded accordingly to the outcome specifications in the review.
 RCT = randomised controlled trial

2.2 | Include mental health outcomes in studies of the effectiveness of psychosocial interventions to promote HIV treatment adherence and reduce risk behaviours

There is a large body of evidence relating to behavioural and psychosocial interventions for ALHIV; however, these studies rarely report on mental health outcomes specifically, often focusing on treatment adherence and sexual and reproductive health outcomes [34–37]. Existing interventions tend to be specifically designed to promote adherence to ART and prevent risky sexual behaviours such as unprotected intercourse [38], which are seen as essential to supporting adolescent health and preventing onward transmission. At the same time, these interventions tend to employ content and delivery mechanisms that are also likely to benefit mental health, such as decision-making skills, self-esteem, coping skills, support networking, psychoeducation and peer support [35,39,40].

As such, it is critical that measures that capture self-reported or parent-reported mental health are included in these types of studies as primary or secondary outcomes. In the absence of these measures and accompanying data, it is impossible to know whether psychosocial interventions have positive, null, or potentially negative effects on participants' mental health. Similarly, the effectiveness of adherence and risk behaviour interventions may be mitigated by underlying mental health outcomes that are not being accurately considered or incorporated into analysis: for example, the impact of self-harm or suicidal ideation on non-adherence. Embedded within this recommendation is a note of caution about context. As psychosocial interventions for ALHIV are increasingly implemented in sub-Saharan African settings, selecting the appropriate mental health measures and ensuring their validity among the research population is essential to gathering high-quality data [41].

2.3 | Conduct intervention research that is sensitive to individual differences and specific needs among heterogeneous populations of ALHIV

While many ALHIV share a common set of vulnerabilities, acknowledging the diversity and complexity of this group is critical when considering how to design and implement programmes. Differences in mode of infection, age group (younger versus older) and gender, as well as additional adolescent comorbidities, may affect how adolescents engage with an intervention. Evidence shows that as children born with HIV transition into adolescence, the way that they relate to their HIV status and engage in treatment behaviours may change, as they gain autonomy, come to terms with their illness and take control of their own health care-seeking [42,43]. Adolescents who acquire HIV later in their teens may experience a different set of challenges that complicate their ability to initiate care, with underlying mental health problems contributing to poorer health and adherence outcomes [44]. Depending on mode of infection – and on the duration of their illness, access to social support networks and other intersecting life stressors and risk behaviours – ALHIV may have ways of relating to their illness that are diverse. Research that is attuned to differences by mode of HIV infection could provide a more nuanced approach to improving mental health and could identify means of engaging and retaining adolescents in these interventions.

2.4 | Involve and empower adolescents in intervention development and testing

Actively involving and engaging adolescents throughout the conceptualisation and implementation stages of interventions is important for ensuring interventions are acceptable and relevant – and ultimately effective. Special considerations should be made to develop adolescent-friendly interventions that actively include adolescents at all stages, and not to retrofit interventions used with adult populations. Co-production strategies, such as adolescent advisory boards, allow adolescents to drive how content is delivered and what messages are emphasised [45,46]. As this field develops, adolescents should take a lead role in crafting interventions that speak to their distinct needs and are also informed by cutting-edge evidence.

3 | CONCLUSIONS

ALHIV are faced with many potential risks to their mental health, yet there are few evaluations of promotive and preventive mental health interventions for this group. This group is a critical population to engage further through more frequent, robust research that can inform the development of new interventions. We call for more high-quality research into interventions for ALHIV that is informed by adolescent priorities and preferences and responsive to the specific needs of this group.

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COMPETING INTERESTS

The authors declare no competing interests.

AUTHORS' CONTRIBUTIONS

CAL conceptualized and drafted the manuscript, and coordinated further writing and editing among the co-authors. SS led the team that conducted the systematic reviews in collaboration with the WHO. SG, OAO, NA, MB, AB, SD and GJMT, along with CAL, all worked on the systematic review team and made important contributions to identifying eligible articles, extracting data, assessing risk of bias, analysing data, and conducting literature reviews to contextualise findings. MT, CS, TD and DAR provided leadership and input to the review team throughout the duration of the project and supported in conceptualising the manuscript. All authors reviewed the manuscript and provided feedback at various stages, and read and approved the final manuscript.

ABBREVIATIONS

ALHIV, adolescents living with HIV; ART, antiretroviral therapy; HIV, human immunodeficiency virus; WHO, World Health Organization.

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