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Longitudinal impacts of the COVID-19 pandemic on adolescents living with HIV in New York City

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ABSTRACT

Adolescents living with HIV (ALWH) are particularly susceptible to disruptions in care, which may lead to poor HIV-related health outcomes. Here, we report the results of a longitudinal phone-based study investigating impacts of the COVID-19 pandemic on ALWH in New York City. Participants ($N = 10$, mean age 21.2 years, 50% female) demonstrated substantial COVID-19 knowledge and identified Instagram as their primary source of COVID-19 information. Nearly all participants reported loss of income, and 50% reported experiencing food insecurity as a result of the pandemic. These findings highlight existing vulnerabilities among ALWH that may threaten the continuum of care.

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Introduction

In March 2020, in response to the COVID-19 pandemic, New York City (NYC) experienced its first shutdown of all non-essential businesses and gatherings, including routine medical care services, with concomitant unprecedented social, economic and healthcare disruptions (Saqib et al., 2020). For people living with HIV (PLWH), who rely on antiretroviral therapy (ART), the COVID-19 pandemic presents exceptional challenges.

Barriers to the care continuum are of particular concern for adolescents living with HIV (ALWH), who have the lowest rates of viral suppression of any age group in the United States (US), and account for 21% of new HIV diagnoses nationwide (National Center for HIV/AIDS, 2016). ALWH face particular challenges maintaining ART adherence, and experience high rates of mental health challenges and substance use (Chenneville et al., 2017).

Specific impacts of the COVID-19 pandemic on ALWH in the US are largely unknown; understanding impacts on this vulnerable group will inform care strategies for this population. We describe self-reported impacts of the COVID-19 pandemic on the health and well-being of a small sample of ALWH living in NYC.

Methods

We conducted longitudinal, phone-based assessments of COVID-19 pandemic-related impacts on socio-economic status, health-related behavior and mental health for ALWH in NYC. Phone-based assessments were conducted at initial assessment (July–August 2020), and at three (October–November 2020) and six months (January–February 2021). The study team adapted a questionnaire for the NYC setting from a tool provided by the NIH-funded East Africa International Epidemiology Databases to Evaluate AIDS Consortium to investigate impacts of the COVID-19 pandemic on PLWH (National Institute of Child Health and Human Development, 2020). Survey questions were primarily closed-ended with a few open-ended questions (Enane et al., 2021). The survey included validated questionnaire items: the Patient Health Questionnare-2 (PHQ-2) screened for symptoms of depression; the Generalized Anxiety Disorder-2 (GAD-2) screened for symptoms of anxiety; and a questionnaire assessed self-reported ART adherence (Enane et al., 2021; Kroenke et al., 2010; Monahan et al., 2008; Plummer et al., 2016; Vreeman et al., 2015, 2018, 2019). It probed COVID-19 knowledge and preparedness, housing, ART access and adherence, health status and health-seeking behavior, and mental health

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(Kroenke et al., 2001; Plummer et al., 2016; Vreeman et al., 2019). Additionally, the study team extracted clinical data from participant electronic health records (EHR), including the route of HIV infection, ART and viral load (VL) history, comorbidities and mental health diagnoses.

This study was conducted at the Mount Sinai Health System's Jack Martin Fund Clinic (JMC), which provides care to children, adolescents and young adults living with HIV. Participants were eligible to participate if they were 12–24 years old, living with HIV, receiving care at JMC and had at least one clinic visit within 18 months of enrollment. Descriptive analyses were conducted to summarize survey responses and clinical data.

Ethical approvals

This study was approved by the Institutional Review Board at the Icahn School of Medicine at Mount Sinai (STUDY-20-00766). Informed consent was obtained electronically from participants prior to completing study assessments.

Results

Participant demographics

A total of 10 participants were enrolled in the study; eight participants completed all three assessments (Table 1). All participants had at least one comorbid condition (in addition to HIV) documented prior to enrollment.

Housing, income and food insecurity

Over 75% of participants remained in their residence with immediate family during the study. Four out of five participants who were earning an income prior to the pandemic lost their income during the pandemic. At initial assessment, five participants reported new food insecurity, which improved for the majority at follow-up. New enrollment in a nutrition assistance program increased by 27% from initial assessment to six-month follow-up.

Mental health

Mental health symptomology fluctuated over the study period. Though no participants had prior diagnoses of anxiety, some participants experienced anxiety symptomology across the study period. One participant had a prior diagnosis of depression. Three participants

Table 1. Cohort characteristics at initial assessment ($N = 10$).

	Value *N* (%)
Age, mean (*SD*)	21.2 (1.7)
Sex (% female)	5 (50%)
Gender identity (% cis-gender)	10 (100%)
*Racial identity**	
Black, Afro-Caribbean, African American	6 (60%)
Latino or Hispanic	5 (40%)
Other	1 (10%)
Years since HIV diagnosis, Mean (*SD*)	18 (6)
Route of infection	
Perinatal	8 (80%)
Heterosexual contact	1 (10%)
MSM	1 (10%)
Comorbidities	
Asthma	5 (50%)
Obesity	1 (10%)
Hepatitis C	1 (10%)
Other	6 (60%)
Documented mental health diagnoses pre-pandemic	
Depression	1 (10%)
Substance use	1 (10%)
Other Mood disorder	2 (20%)
ADHD/ADD	1 (10%)

*Participants were instructed to select all racial identities that apply.

Table 2. COVID knowledge and preparedness.

	Baseline *N* = 10	Three month, *N* = 8	Six month, *N* = 9
COVID-19 Literacy: reported known symptoms of COVID-19			
Fever	8 (80%)	6 (75%)	6 (67%)
Cough	6 (60%)	6 (75%)	4 (44%)
Shortness of breath	2 (20%)	2 (25%)	2 (22%)
Headache	2 (20%)	0 (0%)	1 (11%)
Body aches	3 (30%)	0 (0%)	1 (11%)
Loss of taste or smell	5 (50%)	3 (38%)	2 (22%)
Vomiting	1 (10%)	1 (13%)	2 (22%)
Diarrhea	1 (10%)	2 (25%)	2 (22%)
Sore throat	1 (10%)	2 (25%)	3 (33%)
Proper behavior should one feel sick with symptoms of COVID-19			
Isolate from others	7 (70%)	6 (75%)	7 (78%)
Manage symptoms at home if able	2 (20%)	3 (38%)	4 (44%)
Contact/visit healthcare facility	8 (80%)	6 (75%)	6 (67%)
Other	3 (30%)	4 (50%)	3 (33%)
Safety measures used to avoid COVID-19 transmission			
Washing hands more frequently	9 (90%)	6 (75%)	9 (100%)
Wearing face covering	8 (80%)	8 (100%)	9 (100%)
Avoiding people who are sick	7 (70%)	2 (25%)	6 (67%)
Avoiding visitors and social gatherings	8 (80%)	5 (63%)	6 (67%)
Avoiding public transportation	6 (60%)	4 (50%)	4 (44%)
Avoiding public spaces	6 (60%)	7 (88%)	4 (44%)
Staying home from work	1 (10%)	1 (13%)	3 (33%)
Avoiding hanging out with friends in-person	3 (30%)	2 (25%)	2 (22%)
Sources of COVID-19 information			
TV news	3 (30%)	3 (38%)	6 (67%)
Internet news source	3 (30%)	5 (63%)	3 (33%)
Facebook	4 (40%)	2 (25%)	4 (44%)
Instagram	6 (60%)	4 (50%)	6 (67%)
Twitter	2 (20%)	2 (25%)	2 (22%)
Family	4 (40%)	2 (25%)	1 (11%)
Healthcare Provider/Clinic	2 (20%)	2 (25%)	3 (33%)
Self-reported reasons for leaving home during pandemic			
Going to work	6 (60%)	4 (50%)	4 (44%)
Getting food/household supplies	9 (90%)	7 (88%)	7 (78%)
Picking up medicine/ accessing medical care	3 (30%)	4 (50%)	5 (56%)
Caring for others	2 (20%)	1 (13%)	2 (22%)

reported depressive symptomology at initial assessment, which decreased to none at six-month follow-up.

COVID-19 knowledge and preparedness

The majority of participants identified at least one COVID-19 symptom and appropriate steps to take if experiencing symptoms (Table 2). Identified symptoms changed over the study, with increasing identification of gastrointestinal symptoms and sore throat. Over 50% of participants used social media to access COVID-19 information.

HIV outcomes

At initial assessment, participants skipped doses due to concerns about running out (20%), missed at least one dose in the past seven days (30%), and/or reported greater difficulty accessing care (40%); these outcomes improved over time. At study completion, no participants reported missing doses due to fear of running out; missing at least one dose in the past week and having greater difficulties accessing care were each reported for one participant. All participants had an HIV viral load test prior to the pandemic; four were virally suppressed (<20 copies/mL). Eight had VL tests during the pandemic, and four were virally suppressed. One participant experienced HIV viral rebound, and another experienced viral suppression after having prior non-suppression (>200 copies/mL) at initial assessment.

Discussion

The COVID-19 pandemic disrupted the social lives, clinical care and livelihoods of ALWH in NYC. While this study examines a very small sample of participants, it provides insight into the experiences of ALWH in NYC during the COVID-19 pandemic. The majority of participants came from communities of color, groups disproportionally impacted by HIV and the COVID-19 pandemic and by barriers to healthcare access. Thus, the findings of this study do not only reflect impacts of the COVID-19 pandemic, but also pre-existing structural deficiencies in healthcare delivery systems (CDC, 2019; Yancy, 2020). Participants reported increased food insecurity and loss of income, highlighting needs for economic support and food service integration into clinical facilities (Koible, 2020).

The pandemic has caused mental health challenges nationwide, highlighting needs for ongoing mental health assessment and care access (Guessoum et al., 2020). Mental health symptomology fluctuated throughout the study, potentially related to the dynamic changes of the pandemic, such as the rapid development of COVID-19 vaccines, declines in mortality from the early crisis in NYC, resumption of services and activities, and adjustment to new realities.

Accurate COVID-19 knowledge remained consistent across the study period. Participants most commonly received COVID-19-related information from Instagram and least commonly from healthcare providers. Social media provides avenues for both accurate information and misinformation, including about COVID-19 risks, vaccines and treatments. Healthcare providers should consider expanding social media outreach, to guide patients towards more reliable information. Social media may also be a useful tool for ensuring access to telehealth HIV care services (Dourado et al., 2020; Rovetta & Bhagavathula, 2020).

Participants reported challenges accessing care and adhering to ART at initial assessment. Barriers to initial care access may have included fear of COVID-19 exposure; challenges in the emergency transition to telehealth and limitations to its accessibility; inability to drop in for un-scheduled clinic appointments; and disruptions to social lives and schedules that facilitate adherence. Poor mental health and disruptions to routines are also associated with decreased medication adherence among ALWH, highlighting the need for increased adherence counseling during emergencies, and mitigation of health impacts of these disruptions (Chenneville et al., 2017).

Challenges accessing medical care, refilling prescriptions and maintaining ART adherence improved over the study, which may reflect adolescent resilience and adaptation, ultimately effective transitions to telehealth services, and returns to in-person services. The clinic was open for urgent visits only until late March 2020, closed completely during April and reopened in early May for urgent visits. It opened for routine visits on June 1, with gradual return to in-person services. Clinic staff provided outreach to patients via phone and text messages to reschedule visits and facilitate care re-engagement. The rapid transition to telehealth was effective for providing adolescent healthcare, including HIV care, during the COVID-19 pandemic (Wood et al., 2020). However, as clinics continue to utilize telehealth, providers should consider the needs of patients with less access to these platforms, or who may have needs necessitating in-person evaluations.

Limitations

There are several limitations to this study. This was a small study of 10 older adolescents enrolled in a private HIV clinic connected by effective public transportation

and pharmacies, which limits generalizability to younger adolescents and those in rural or lower-resourced settings. In order to gain more in-depth and holistic understandings of experiences of ALWH, future research should include qualitative interviews. This study did not include assessments in the earliest months after onset of the pandemic, or assessment of potential long-lasting impacts; however, it provides a snapshot of pandemic-related impacts over six months.

Conclusion

The COVID-19 pandemic and concomitant social and economic disruptions impacted the lives of ALWH in NYC. Participants demonstrated high COVID-19 literacy and engagement in protective behaviors, losses of income, food insecurity, mental health and ART adherence challenges, and difficulties accessing clinical services. We observed improvements in depression symptomology and ART adherence over a six-month period. Future research is needed to better understand the experiences of ALWH as the pandemic evolves, and to assess longer-term impacts of the pandemic for this group.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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