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Hardships and Perceived Barriers to Medical Care Among Newly Diagnosed People With HIV During the COVID-19 Pandemic

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Abstract

Purpose of the research: A major consequence of the COVID-19 pandemic was a disruption of medical care in the United States. Using cross-sectional data from an ongoing randomized clinical trial, we examined severity of COVID-related hardships and other factors that might have influenced newly diagnosed people with HIV's (PWH's) receipt of care during the initial years of the pandemic (2020–22).

Major findings: In a sample of 29 newly diagnosed PWH presenting for care at three geographically diverse medical clinics in the United States, results showed that most patients (72.4%) reported that obtaining an HIV medical appointment during the pandemic was "easy." Correlational analyses found that COVID-related hardships were significantly related to overall health and functioning, as well as experiences of discrimination.

Conclusions: Taken together, these findings align with previous results to show that already vulnerable populations were particularly affected by service disruptions, but that many patients were able to access care despite the pandemic.

Plain Language Summary

Challenges faced by newly diagnosed patients with HIV during the initial years of the COVID-19 pandemic related to their medical care

In this study, we asked newly diagnosed patients with HIV about challenges they might have faced in accessing medical care and hardships related to the COVID-19 pandemic. Most patients reported that they were able to obtain a medical appointment despite the pandemic. However, patients with worse health issues and lower functioning reported more COVID-related hardships.

Keywords

HIV, COVID-19, retention

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Introduction

On March 11, 2020, the World Health Organization (WHO) declared COVID-19 a global pandemic,[1] leading governments across the globe to mandate lockdowns to mitigate the spread of the disease. One of the major consequences of such a mandate was a disruption of outpatient medical services. In the United States (U.S.) healthcare system, two-thirds of hospital leaders ($n = 588$) reported that patients in outpatient care had reduced access to services.[2] While some patients pivoted to online outpatient services through virtual encounters (ie, telehealth), patients with access barriers or other limitations sought care in overflowing emergency rooms.[3] With hospitals surpassing max capacity,

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telehealth seemed like a viable option, but these encounters only covered a small fraction of outpatient appointment needs.[4] In sum, despite many clinical sites adapting to offer services during the pandemic, treatment options were reduced and many patients likely faced access barriers.

The COVID-19 pandemic exacerbated already present inequalities in the U.S. healthcare system, particularly among marginalized groups.[5] Many patients avoided seeking services due to fear of COVID-19 exposure.[6] Moreover, some patients de-prioritized seeking care due to acute needs related to hardships associated with the pandemic (eg, unemployment, food insecurity).[7] With COVID-19 being a respiratory infection targeting the immune system, it was suggested that people with HIV (PWH), a marginalized and stigmatized group,[8–11] could be particularly at-risk for negative outcomes. Indeed, numerous steps in the HIV care continuum were disrupted by the pandemic. Access to HIV testing was highly disrupted in the early months of the pandemic, dropping by 31.9% in early 2020[12]; testing did not fully rebound to pre-pandemic levels for a number of months.[13] Interestingly, in a report by the U.S. Centers for Disease Control and Prevention (CDC), the incidence and prevalence of HIV might have decreased during the initial year of the pandemic. Specifically, U.S. HIV incidence went from about 11.1 diagnoses per 100 000 people in 2019 to 9.2 diagnoses per 100 000 in 2020.[14] However, the pandemic might have skewed these numbers due to disruptions in HIV testing. In terms of outpatient care for HIV, a study performed in Washington DC found that nearly half of local HIV clinics reduced clinical hours, thereby limiting service offerings.[15] These disruptions in testing and service provision were extremely concerning given the adverse outcomes for those who do not obtain consistent HIV medical care, particularly for newly diagnosed patients.[16]

Adequate retention rates have been difficult to maintain across populations with HIV. In fact, according to the most recent CDC HIV Surveillance Supplemental Report, only 54 out of every 100 of those diagnosed with HIV in the United States in 2021 were retained in care.[17] Modern antiretroviral therapy (ART) has prolonged survival and made HIV a manageable, chronic illness.[18] However, an inconsistent connection to medical care compromises an individual's likelihood of timely ART initiation.[19] Once ART is initiated, suboptimally retained patients are less likely to be medication adherent, increasing the risk for viral drug resistance[20] and HIV transmission.[21] In fact, PWH who are not retained in medical care are more likely to transmit HIV.[22] Overall, poorly retained PWH are responsible for more HIV transmissions than the population in care and the undiagnosed population combined.[22,23] Emerging data from the COVID-19 pandemic present a mixed picture of HIV service retention disruptions. In a recent systematic review,[24] results revealed that up to 46% of PWH missed medical appointments. Reasons for missed appointments ranged from healthcare provider cancelations to transportation issues. However, the provision of telehealth services appeared to buffer these disruptions, with some studies reporting very few missed appointments.[24,25]

A number of environmental and structural barriers have been shown to reduce entry and future retention in care for PWH, including housing instability and lack of transportation.[26] Further, new patients must also overcome a number of psychological hurdles to fully engage in care.[27] Compared to the general population, PWH have higher rates of co-occurring mental health diagnoses,[28] which often impede effective disease management.[29] Taken together, extant research shows that linkage to and longitudinal retention in care for HIV is challenging for a number of reasons. In the context of the pandemic, which created additional hurdles to overcome to receive HIV care, it is likely that newly diagnosed PWH had even more trouble receiving services. Yet, few studies have analyzed the effects of the COVID-19 pandemic on PWH's treatment-seeking behavior.

In this observational study, we examined perceived barriers to seeking medical care among newly diagnosed PWH during the COVID-19 pandemic. We analyzed the severity of COVID-related hardships and other factors that might have influenced newly diagnosed PWH's receipt of care. We hypothesized that patients would report that obtaining HIV care during the pandemic would be challenging. Additionally, we hypothesized that increased COVID-related hardships would be related to lower social support, worse depressive symptoms, increased alcohol use, lower overall health and functioning, and elevated experiences of discrimination.

Materials and Methods

Overview

These cross-sectional, baseline-only data were obtained from an ongoing randomized controlled trial of a brief behavioral intervention to increase medical care engagement among newly diagnosed PWH. Data were collected from December 2020 through December 2022. This study occurred in three academically affiliated HIV primary care, hospital-based, outpatient clinics in New Orleans, Louisiana; Minneapolis, Minnesota; and, Providence, Rhode Island. The protocol is further discussed here.[30] The reporting of this study conforms to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement.[31] The completed STROBE checklist for this study is available in Supplementary File 1.

Participant Eligibility

Inclusion criteria: (a) HIV+; (b) ≥18 years old; (c) entering HIV medical care services for the first time (that is, not

transferring HIV care from another location); (d) able to speak and read English at the seventh grade level to be able to complete the study procedures; and, (e) have telephone access. The only *exclusion criterion* was cognitive impairment, as determined by clinical staff.

Procedures

Study procedures were approved via a Single Institutional Review Boards protocol and all participants completed informed consent prior to participation. Staff recruited and screened eligible participants during routine intake procedures for new patients at each site with the priority of enrolling participants before their first appointment with a medical provider. Informed consent was obtained, and participants signed a release of information form so that study staff could review their medical records. Only baseline data were used here; participants were compensated up to $75 for completion of the assessment, which could be completed in-person or remotely.

Assessments

Demographic data were obtained from the sample and participants reported the number of weeks since they were diagnosed with HIV. To characterize possible delays in seeking HIV care due to the pandemic, participants were asked, "Did COVID-19 impact your decision to seek HIV care?" with answer choices being: (a) "As a result of the COVID-19 pandemic, I did not seek out care for my HIV," (b) "As a result of the COVID-19 pandemic, I delayed seeking out care for my HIV," or (c) "Despite the COVID-19 pandemic, I did seek out care for my HIV." To assess difficulty obtaining HIV care due to the pandemic, participants rated on a Likert scale ranging from "easy" to "hard," "How hard was it to get an HIV appointment?". To assess COVID-related hardships, we used items developed by Penedo and colleagues.[32] Examples of hardships assessed included: "I lost a job," and "I had to use savings as a result of the coronavirus pandemic." Alcohol use was assessed with the 3-item *Alcohol Use Disorder Test-C* (AUDIT-C[33,34]). A score ≥4 represents hazardous drinking. The *Patient Health Questionnaire-9* (PHQ-9[35]), a well-validated and reliable 9-item measure, was used to assess depressive symptoms. *The Multidimensional Scale of Perceived Social Support* (MSPSS[36,37]) was used to measure social support. The *Healthcare System Distrust Scale* (HSDS[38]) consists of 10-item measuring attitudes toward the healthcare system, including beliefs about healthcare system practices and motives. The *Everyday Discrimination* measure[39] was used to examine participants' perceived experiences of discrimination. This measure allows participants to rate their experiences of and perceived reasons for discrimination (eg, because of sexual orientation, because of HIV status, etc). The PROMIS measure was used to assess overall health and functioning.[40,41]

Statistical Analysis and Sample Size

This was a convenience sample drawn from a larger study. However, to provide context when interpreting study results, we explored the necessary sample size to detect a significant correlation between overall health and functioning and experiences of discrimination. These variables have previously been examined in cross-sectional research among PWH. Using a moderate to large effect size, as reported by Rueda and colleagues in their series of meta-analyses examining associations between HIV-related stigma and mental and physical health,[9] we estimated that $n = 72$ would be the minimum sample size to detect significant effects at 80% statistical power. Thus, our study is underpowered, suggesting significant relationships revealed in the analyses are particularly noteworthy. Descriptive statistics were used to characterize the sample. Given the small sample, we calculated Pearson correlation coefficients (r) among the variables of interest and did not correct for any possible source of bias.

Results

Participant Characteristics

In this sample of 29 newly diagnosed PWH, participants were mostly male ($n = 26$; 89.7%) and were an average of 31.2 years old (SD = 10.5). The sample was highly diverse, with nearly half being non-White ($n = 14$; 48.3%) and 24.1% ($n = 7$) self-identifying as Hispanic/Latinx. The sample was predominantly single ($n = 20$; 69.0%), employed ($n = 18$; 62.1%), and had at least some college education ($n = 23$; 79.3%). The average lag time between HIV diagnosis and first seeking medical care was 3.8 weeks (SD = 3.6). None of the participants met the cut-off for hazardous drinking on the AUDIT. In this sample, average depressive symptoms were mild. Social support was moderate to high in the sample. The most common reasons for experiencing discrimination, based on participant perception, were sexual or gender identity ($n = 9$; 31%) and ancestry or national origin ($n = 5$; 17.2%). See Table 1 for demographic summary.

Ease of Obtaining Medical Appointments, COVID-19 Hardships, and Correlational Analyses

Most participants reported that obtaining an HIV medical appointment, despite the pandemic, was "easy" ($n = 21$; 72.4%). Notably, only four participants (13.8%) reported not seeking or delaying seeking HIV care due to the COVID-19 pandemic. On average, participants reported

Table 1. Baseline Demographic Characteristics ($n = 29$). Engage Study (December 2020–22).

	n (%)	Mean (±SD)
Age (years)		31.2 (±10.5)
Gender		
Female	2 (6.9%)	
Male	26 (89.7%)	
Genderqueer	1 (3.4%)	
Race		
White	15 (51.7%)	
African American/Black	6 (20.7%)	
Native American/Alaskan Native	3 (10.3%)	
Other	5 (17.3%)	
Ethnicity (Hispanic/Latinx)	7 (24.1%)	
Marital status		
Single	20 (69.0%)	
In a relationship	7 (24.1%)	
Divorced/separated/widowed	2 (6.9%)	
Education		
High school or less	5 (17.2%)	
Some college	13 (44.8%)	
Higher education degree	10 (34.5%)	
Other	1 (3.5%)	
Full- or part-time employment	18 (62.1%)	
Weeks since tested HIV+		3.8 (±3.6)
COVID hardships		2.1 (±2.8)
AUDIT (hazardous alcohol use)		3.2 (±2.3)
PHQ-9 (depressive symptoms)		8.2 (±5.6)
MSPSS (perceived social support)		5.3 (±0.9)
PROMIS (overall health/functioning)		39.5 (±7.5)
Healthcare system distrust		22.3 (±5.8)
Discrimination experiences		9.2 (±8.3)

Note: AUDIT = Alcohol Use Disorders Identification Test (score range = 0-8); PHQ-9 = Patient Health Questionnaire (score range = 0-27); MSPSS = Multidimensional Scale of Perceived Social Support (score range = 1-7); PROMIS = Patient-Reported Outcomes Measurement Information System (score range = 9-55); Healthcare System Distrust (score range = 10-50); Discrimination Experiences (score range = 0-45).

2.1 (SD = 2.8) COVID-related hardships. The most common hardships attributed to the pandemic were as follows: cut down on recreational activities ($n = 12$, 41.4%), cut down on spending in general ($n = 9$, 31%), and used savings as a result of the pandemic ($n = 8$, 27.6%). In correlational analyses, COVID-19 hardships were significantly, inversely correlated with overall health and functioning ($r = -0.38$, $P = .044$), and positively, significantly correlated with experiences of discrimination ($r = 0.51$, $P = .005$). See Table 2 for the summary of correlational results.

Table 2. Product-moment Correlations ($n = 29$). Engage Study (December 2020–22).

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1) Age (Years)	1.00											
(2) Gender	−0.105	1.00										
(3) Ethnicity	−0.357	−0.032	1.00									
(4) Race	−0.097	−0.135	0.365	1.00								
(5) Education	0.028	0.288	0.216	0.260	1.00							
(6) COVID Hardships	0.152	0.202	−0.307	0.010	−0.243	1.00						
(7) AUDIT (hazardous alcohol use)	−0.256	−0.251	0.046	−0.127	−0.183	−0.216	1.00					
(8) PHQ-9 (depressive symptoms)	−0.376*	0.223	−0.036	−0.055	−0.307	0.362	−0.020	1.00				
(9) PROMIS (overall health/functioning)	0.019	−0.173	0.136	0.129	0.182	−0.377*	0.170	−0.799**	1.00			
(10) MSPSS (perceived social support)	−0.511**	0.292	0.051	−0.205	0.133	−0.186	0.173	−0.143	0.459*	1.00		
(11) Healthcare Distrust	−0.108	−0.201	0.140	−0.053	−0.310	0.162	−0.035	0.254	−0.311	−0.226	1.00	
(12) Discrimination Experiences	−0.240	0.122	−0.243	−0.120	−0.189	0.505**	0.111	0.573**	−0.538**	−0.082	0.365	1.00

Note: AUDIT = Alcohol Use Disorders Identification Test; PHQ-9 = Patient Health Questionnaire; MSPSS = Multidimensional Scale of Perceived Social Support; PROMIS = Patient-Reported Outcomes Measurement Information System.
*$P < .05$, **$P < .01$.

Discussion

In our study of 29 newly diagnosed PWH, we examined perceived access to HIV medical services during the COVID-19 pandemic, as well as factors associated with pandemic hardships. Contrary to our hypothesis, most patients (72.4%) reported that obtaining an HIV medical

appointment during the pandemic was "easy." On average, patients were diagnosed about one month prior to enrolling in this study. Because we recruited at the time of the first appointment at our HIV clinical sites, these data dovetail to suggest that HIV care was accessible to patients and that they could obtain a first appointment in a timely matter. These results are heartening because of the importance of rapid linkage to HIV services, including early initiation of ART.[42] Indeed, when newly diagnosed PWH start ART early in care and maintain adequate adherence, the likelihood of transmitting HIV to others is significantly reduced.[43] Yet, according to a recent systematic review of HIV treatment issues during the pandemic, 27% of PWH were unable to receive ART at some point during the pandemic, 34% of those who received ART did not achieve viral suppression, and about 19% of PWH were unable to receive a refill for ART during the pandemic.[44] Taken together, these findings plus extant data suggest that most PWH were likely able to access ART, but that it was challenging for a smaller, but nonetheless important group.

Our correlational analyses also showed noteworthy findings. Consistent with hypotheses, COVID-related hardships were significantly related to overall health and functioning, as well as experiences of discrimination. The list of assessed hardships mostly focused on financial challenges, such as job loss or spending cuts due to the pandemic. However, our measure also included items relevant to patients facing social determinants of health, including housing instability due to the COVID-19 pandemic as well as working in a setting in which one risked exposure to the virus (eg, service industry jobs). A wealth of data from the pandemic showed that individuals with lower health and functioning were particularly affected by the pandemic in terms of illness severity and risk of death.[45] These findings add to this literature by demonstrating that lower overall health and functioning were associated with hardships attributed to the COVID-19 pandemic. Moreover, it is not surprising that PWH who experienced discrimination also experienced more hardships. Data show that people of color were disproportionally impacted by the pandemic.[46] Within the LGBTQ+ community, of which most of our sample identified, data demonstrated that this population has been harder hit by the pandemic in terms of mental health and well-being.[47] Taken together, our findings align with previous results to show that already vulnerable populations were particularly affected by the pandemic. All other correlational results were not significant, although relationships were mostly directionally consistent with hypotheses (eg, depressive symptoms, social support).

Limitations

This was a small, cross-sectional sample. As such, we are unable to draw directional or causal conclusions. However, these results do align with extant literature and theory related to the impact of COVID-19. Additionally, the sample was likely biased as participants were patients who showed an ability to schedule and attend an HIV intake appointment. It is possible that newly diagnosed PWH who faced worse access barriers did not present to the clinic at all. Lastly, the measure used to assess COVID-19 hardships was novel. However, it showed good reliability in this sample.

Conclusions

One of the major issues that the pandemic brought to light was the lack of access to health care, especially among patients with chronic health conditions that require longitudinal engagement in care, such as HIV. The present findings add to the literature to show that despite these challenges, particularly related to ART and adherence, newly diagnosed PWH were able to access services.

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Statements and declarations

Ethical Considerations

This study was approved by the single IRB organization, Advarra (Protocol #Pro00059418).

Informed Consent

All participants provided written informed consent prior to enrollment in the study.

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Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

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