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“It’s never just about the HIV:” HIV primary care providers’ perception of substance use in the era of “universal” antiretroviral medication treatment

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Abstract

Antiretroviral therapy (ART) is recommended for all people living with HIV (PLWH), regardless of disease status. Substance use disorders (SUD) are common barriers to successful HIV treatment; however, few studies have comprehensively explored how HIV primary care providers take SUDs into account in the context of universal ART implementation. This study uses thematic analysis of qualitative interviews to explore providers’ (N=25) substance use assessment and factors associated with ART initiation. 64% of providers had 15 or more years of HIV treatment experience. Almost all providers agreed with the guidelines for universal ART initiation despite the presence of SUD. Still, identification and management of SUD is challenged by inconsistent assessment, providers’ misperceptions about SUD and patients’ willingness to discuss it, and lack of accessible treatment resources when SUD is identified. Greater guidance in systematic SUD assessment and management, combined with integrated addiction services, could enhance universal ART implementation among PLWH/SUD.

Keywords

HIV primary care; antiretroviral therapy; substance use disorders

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COMPLIANCE WITH ETHICAL STANDARDS

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INTRODUCTION

HIV, Antiretroviral Therapy, and Substance Use

In December 2011, the New York City Department of Health and Mental Hygiene (NYC DOHMH) began recommending that antiretroviral therapy (ART) be offered to all people living with HIV (PLWH) regardless of their CD4 count or other indicators of disease progression [1]. The Centers for Disease Control and Prevention (CDC) reinforced those recommendations in January 2016 by elevating the rating for universal ART guidelines [2] to an A1 level, indicating “the strongest recommendation based on the highest quality of scientific evidence”. The CDC’s strengthened HIV treatment guidelines were grounded in findings from The INSIGHT START, TEMPRANO ANRS, and HPTN 052 studies, which revealed various individual health and HIV prevention benefits (population health) of early ART initiation [3–5]. The most recent CDC guidelines continue to recommend ART for all HIV positive individuals irrespective of mental health status and drug or alcohol use [2].

The push for universal ART is rooted in “treatment as prevention”; providing all PLWH with ART bolsters viral suppression, reduces morbidity and mortality, and ultimately contributes to a vast reduction in the likelihood of HIV transmission to HIV negative individuals [6–9]. Although universal ART holds promise for preventing HIV transmission, it may be especially challenging to execute among individuals with problem substance use. Problem substance use contributes to increased risk of HIV transmission related to sexual and drug use risk behaviors (e.g. condomless sex under the influence of drugs and alcohol; needle sharing) [10–15]. Moreover, individuals who misuse substances are also less likely to link to HIV care [16–18], to be retained in care [19], and to maintain adequate adherence to ART [20, 21], essential for achieving and maintaining viral load suppression. Adherence barriers specific to individuals with substance use disorders can include both structural (e.g., unstable housing, treatment transitions from jail to community) [22] and personal impediments (e.g., cognitive impairment) [23].

Barriers to ART Initiation

When HIV providers are confronted with the decision of whether or not to initiate ART, many elect to defer treatment among patients reporting substance abuse [24], “active” [25–29] or “uncontrolled” use [30, 31]. HIV care providers may be hesitant due to concerns that patients’ lack of adherence could spur HIV drug resistance [25], and this practice has been especially prevalent for racial and ethnic minority patients [32]. Providers’ decisions to defer HIV treatment among substance users runs counter to the current CDC HIV treatment guidelines that promote universal ART irrespective of complicating factors [2]. Still, the guidelines also acknowledge the occasional need to delay ART treatment when adherence barriers are anticipated, highlighting providers’ responsibility to detect potential adherence obstacles and determine appropriate interventions to address them [2]. Without adequate training in addiction treatment, however, providers may be ill-equipped to sufficiently address drug and alcohol use among their PLWH [27].

Approaches to meeting the needs of PLWH vary, as does the accessibility and availability of such approaches. If patients are not ready or do not wish to cease substance use, providers

should collaboratively explore harm reduction strategies such as encouraging decrease in substance use and tempering the adverse effects of ongoing use on HIV treatment [33, 34]. Co-location of substance abuse treatment and HIV care has been shown to increase the likelihood of providers' initiating ART in patients with active substance use [29]. Coordination of substance use disorder treatment and HIV services has prompted optimism in some providers, but has caused doubt about effectiveness or patient acceptability in others [35].

Several studies of HIV providers' experiences with ART initiation in substance using patients have identified substance use as a potential deterrent to initiation [22, 36–38]; however, more nuanced factors, such as substance type or severity, have not been examined. In one quantitative study, 662 HIV providers were surveyed about working with injection drug users (IDUs); an inverse relationship was obtained between drug use (daily use vs. occasional use vs. current abstinence) and likelihood of prescribing ART. ART was less likely to be prescribed among IDUs with current and more frequent use [29]. In another probability sample of 1,234 HIV care providers who completed a quantitative survey, among providers who delayed ART initiation, 31.1% cited medical problems that could pose barriers to ongoing adherence—including substance use—as the primary reason for withholding ART [22]. Substance use-related stigma has also been noted as a factor in the maintenance of health disparities [39] and compromising delivery of comprehensive and integrated health services [40].

In addition to substance use, other patient-level factors have been cited as major barriers to providers' willingness to initiate ART. *HIV-related barriers* have included: level of acceptance of HIV status and motivation to initiate ART [26, 28, 30, 31, 37]; and whether or not patients have disclosed HIV status to family or friends [36]. *Psychosocial barriers* have included: mental health issues [22, 26, 27, 31, 37, 38]; level of social support [37]; and general instability [22, 26, 36–38, 41], leading to missed medical appointments. *Structural barriers* have included: unstable housing [22, 26, 37, 38]; and financial barriers, especially lack of insurance [22, 26, 28, 31].

Provider factors may also present impediments to early ART initiation, but evidence to date is mixed. Some studies have identified providers' perceptions of having insufficient time [36], prohibitively large caseloads [26, 30, 35], and lack of support staff for adherence counseling [36] as obstacles. However, other studies observed lack of an association between provider characteristics (e.g. age, gender, years of HIV treatment experience) [28, 30, 31, 36, 38], clinical setting (e.g. type or location of the clinic) [31, 36], or size of caseload [22, 28, 38] and ART initiation. Additional research has found that higher caseload was associated with greater likelihood of ART initiation [22, 41].

Provider Factors in ART Initiation among PLWH with Problem Substance Use

While the literature is suggestive, there are important gaps. First, most studies of provider factors in ART initiation among PLWH with problem substance use are solely quantitative [22, 26, 28–31, 36, 38, 41] using self-report questions with fixed answer options. Often, these have been large scale, mailed surveys of physicians [22, 26, 29, 32, 38]. Few studies have used qualitative interviews to elicit provider descriptions of their attitudes and values

underlying their ART decision-making and accounts of their ART-related interactions with substance using PLWH. Second, and perhaps most importantly, few studies have been conducted since the implementation of universal ART guidelines. One recently published study on provider obstacles to universal ART initiation was quantitative and did not explore specific components of substance use as potential barriers [22]. There is a clear need to obtain in-depth understanding of the drivers of provider decision-making and behavior about ART initiation with substance-using PLWH, particularly in the era of universal ART.

Purpose

From qualitative interviews with HIV primary care providers, this paper aims to explore: how providers identify and assess substance use; factors that influence providers' decisions to initiate or withhold ART with substance-using PLWH; provider characteristics that influence ART initiation practices; and program characteristics that influence ART initiation practices. These interviews were part of a larger, multi-method evaluation of the rollout of universal ART in New York City [42] which combined qualitative interview methods with providers and substance using PLWH, quantitative cohort studies of PLWH in drug and alcohol detoxification and NYC Department of Health and Mental Hygiene (NYCDOHMH) Sexual Health clinics, and geospatial analyses of NYCDOHMH HIV surveillance data.

METHODS

Participants

A total of 163 HIV primary care providers were contacted from the following sources: a) randomly selected from three publicly available lists (HIV Medicine Association [43], American Academy of HIV Medicine [44], and the New York State AIDS Institute [45]); b) consecutive recruitment from a convenience sample of providers in a pilot study of one of the investigators, and c) word of mouth. Eligible providers were 1) primary HIV medical care providers (i.e., physicians, nurse practitioners (NPs), or physicians' assistants) for at least one adult PLWH; 2) able to speak and understand English; and 3) based in NYC. Of 163 potential participants identified through the aforementioned sources, 112 did not respond to contact attempts or had inaccurate contact information. Of 51 who were reached by phone or email, 10 declined to participate; 7 were ineligible (2 of whom had no adult caseload of PLWH and 5 of whom were not based in NYC); 9 expressed interest but ultimately did not respond to scheduling attempts; and 25 were enrolled in the final sample (n=18 from the publicly available provider lists; n=4 from the convenience sample of providers in a pilot study of one of the investigators; and n=3 word of mouth). Providers were enrolled into the study between Fall 2014 and Spring 2016.

Procedures

Once identified, providers were mailed information about the study. On a follow-up phone call, research staff described the study, confirmed eligibility, determined interest in participating, and scheduled an interview. Written informed consent, including permission for audio recording, was obtained. Providers completed a brief survey (approximately 25 minutes) and qualitative interview (approximately 60 minutes; mean=53 minutes, range=28–115 minutes). Most interviews took place in the providers' office; a smaller number took

place at other convenient locations and two took place over the phone. Providers received \$60 for completing the interview. The study was approved by the Mount Sinai Health System Institutional Review Board.

Assessment

Demographic, Professional and Organizational Characteristics—Demographic, professional, and organizational characteristics were collected via a self-report quantitative survey on a laptop using QDS Computer-Assisted Personal Interview (CAPI) software. Demographic questions included provider age; sex; ethnicity (Spanish origin, Hispanic or Latino); and race. Professional characteristics included: professional discipline; years of experience treating HIV patients; years of work experience with patients who have problem substance use, and beliefs about universal ART guidelines. Organizational characteristics (of the provider's clinic) included: type of clinic (primary care, specialty care, hospital-based, or other) and estimated proportion of HIV positive patients with alcohol and/or drug problems.

Qualitative Interview—The qualitative interview was conducted using a semi-structured interview guide developed by the researchers, informed by the Consolidated Framework for Implementation Research [46], and modified as new topics arose during early interviews. Interview probes were used to maximize participant responses. The interview guide consisted of a set of 10 base questions (e.g., “Describe your process in working with a new patient with HIV.”) followed by sub-questions (e.g., “What kinds of things are important to assess?”) and prompts (e.g., “How often do you assess for drug or alcohol problems?” or “How do you make referrals to these programs?”), as needed. It was expected that all of the main topics be covered in each interview. Main topics related to substance use included: assessment of substance use and substance use disorders; effect of substance use on provision of ART, including immediate ART initiation; linkage practices for addiction treatment; and program level barriers and facilitators to working with PLWH with substance use disorders. Other HIV care-related topics included: HIV testing; patient barriers and promoters to testing; linkage to care; care coordination; care retention; ART initiation; ART adherence; and responses to sensitive (drug use and sexual risk) conversations.

Interviewers (LW, MW, ST) were trained in qualitative interviewing techniques, participated in role-play trainings, and gained proficiency by conducting an observed or recorded mock interview reviewed in group discussion. The first 1–2 interviews were also reviewed to ensure fidelity to the interview guide. All interviews were digitally recorded and transcribed.

Data Analysis

Demographic, professional, and organizational variables were descriptively analyzed using means, standard deviations, and percentages.

A qualitative interview codebook was developed by the interview team based on a grounded theory approach [47, 48]. The team coded, discussed and achieved coding consensus, on the first four interviews. Decision trails for doing so were documented. Reliability was obtained on the next 5 interviews (20% of total interviews). The final codebook was entered into ATLAS.ti[®] software for data management and systematic coding. Framework analysis, a

systematic method for organizing and sorting coded text by case, themes and sub-themes, was used for data analysis [49, 50]. Direct quotes are included to retain respondents' voice and connection to the raw data.

RESULTS

Demographic, Professional and Organizational Characteristics

Table 1 presents the demographic and professional characteristics of this sample of 25 HIV primary care providers. About half were female (52%); most were non-Hispanic White (52%) or Asian (28%). Two-thirds were physicians (68%). Mean age was 50.0 (SD=7.3). Over half (56%) were based in primary care clinics concentrated in Brooklyn (20%), Manhattan (32%), and the Bronx (36%). Most providers had over 15 years' experience in treating HIV (64%) and in working with problem substance users (68%). Providers estimated that on average about a quarter of their patients had problems with illicit drug (26.2%, SD=17.7%) and/or alcohol use (22%, SD=16.8%). Nearly all providers (88%) agreed or strongly agreed with the universal ART policy recommendations. However, providers endorsed numerous factors that might keep them from initiating ART, including patient ambivalence (72%), housing instability (44%), lack of insurance (44%), and co-occurring substance use disorder (44%).

Qualitative Interview Themes

Data analyses were aimed at exploring four general areas of inquiry: (1) How do providers identify and assess substance use? (2) What factors influence providers' decisions to initiate or withhold ART with substance-using PLWH? (3) What provider characteristics influenced ART initiation practices? and (4) What program characteristics influenced ART initiation practices?

Identification and Assessment of Substance Use—Great variability existed in the ways in which providers reported assessing substance use disorders, but in general there was a lack of consistency and comprehensiveness. Assessment varied from using only outward signs and cues to using non-standardized clinical interviews to always using standardized assessment with every patient. For example, providers reported conducting clinical interviews about substance use in place of standardized assessments:

“Usually what we try to do is assess their level of, or acknowledgement in terms of how much the substance use has affected their lives or, and if they can describe that and how much they use if they themselves feel it's a problem, if they're at a stage where they want to do something about it.” Provider 003, MD, Male, Age Range 46–55.

“So within our EMR, there are templates for the assessment of these issues. And, these do get completed during the course of care, [...]. I find that those templates are not very helpful to me as a clinician.” Provider 002, MD, Male, Age Range 46–55.

Other providers talked about using a standard set of questions in their electronic medical records:

“Right, we have standard questions in EMR. Well, they could be single item, particularly if they say no. If they say yes to substance abuse, then there’s generally a chain of questions. (laughs)” Provider 011, MD, Male, Age Range 46–55.

HIV primary care provider knowledge of problem substance use and substance use disorders also varied widely and was often linked to previous clinical experiences rather than professional training. Misinformation about the symptoms or signs of use, although less common, was reported.

“And I usually know on the physical exam if they’re substance abusers. I don’t get honest answers when I ask someone and that’s a reality.” Provider 009, MD, Female, Age Range 56–65.

Although providers talked about substance use questions as part of the electronic medical record, these questions were not always asked and/or were often perceived as insufficient. Other providers simply preferred their own clinical inquiry of substance use. Similarly, the frequency of substance use assessment varied from every visit, to quarterly, to yearly, to only when the patient appeared to need it. For example, providers would be more compelled to ask about substance use if they perceived physical signs or symptoms.

“There might be some providers that actually go through the AUDIT [Alcohol Use Disorders Identification Test] or something like that, but it’s not built into our record and it’s not consistent.” Provider 0024, MD, Female, Age Range 56–65.

“Yeah, so we have, we have a fairly constricted questionnaire on alcohol use. We certainly ask about it. We could do a better job quantifying it and learning a little bit more about our patients’ alcohol use.” Provider 011, MD, Male, Age Range 46–55.

Discomfort on the part of providers may have led to avoidance of discussing substance use issues, thus contributing to some of the variation in substance use assessment. Provider comfort varied widely from matter of fact (“like any other topic”) to minimal, dismissive, and distanced. Providers reported concerns that their patients would not want to be asked about substance use.

“And I think if they have a problem and they don’t want help, then they probably don’t even tell me about it.” Provider 006, MD/PhD, Male, Age Range 46–55.

“I ask do you use alcohol, do you use drugs? And they give me the look like, you don’t know me, I don’t use. So you tell them, you know, just this is the question, I’m supposed to ask these once a year so we’re fulfilling some criteria.” Provider 008, MD, Male, Age Range 46–55.

One provider noted that she might back off from questioning if a patient was reluctant to discuss or disclose their substance use:

“...you know, the response is not like a consistent mandated response. It’s going to depend on what the patient reports back, you know, are they motivated to make a change? Do they see this as a problem? We would latch right on to that. If they’re minimizing, they’re not expressing a lot of desire to change, then we’re going to kind of back burner it and try to establish a relationship, move forward with the

medical aspects, you know, kind of keep it there. This may be part of the problem.
(laughs) ”Provider 024, MD, Female, Age Range 56–65.

Practical issues of time and feasibility to ask about drugs and alcohol at every appointment was also a commonly stated reason why providers may not have asked substance use questions.

“Yeah they (substance use screening) happen at every annual visit and at every CD4 monitoring visit as a rule. But the model and the best practice really is to address it at every visit. It’s not practical or feasible in reality.” Provider 013, MD, Male, Age Range 35–45.

Providers alluded to the difficulty of knowing who might use alcohol and drugs without directly asking, but that patients were unlikely to disclose without prompting.

Interviewer: “How often do you ask the questions about drug use?”

“Not very often. But you know, then who uses drugs usually? No, actually we don’t know. (laughs) ... Yeah. I don’t ask routinely.” Provider 012, MD, Male, Age Range 56–65.

“...if you did not ask, you would never know because you have to ask. That’s why you have to, you know? Because it isn’t obvious, it’s just not obvious at all, unless they’re just flat drunk when they come in, you know.” Provider 025, NP, Female, Age Range 56–65.

Factors Influencing Providers’ Decisions to Initiate ART

Patient Functionality: Consideration of patient functionality emerged as the primary theme in providers’ decisions about initiating ART with substance-using PLWH. The ability to adhere to medication was a critical factor for whether providers would initiate ART (second only to clear medical evidence that ART was required – i.e., low CD4 count). Providers were interested in whether, based on functioning and organization, a patient could manage his/her treatment regimen. Providers’ central determination for whether or not they would initiate ART among substance using patients was grounded in weighing patient functionality versus disorganization, and routine versus chaotic lifestyle. Functionality was dually defined in: (1) practical terms, such as ability to attend medical visits; and (2) in terms of a level of substance use that could still make ART initiation and adherence feasible and manageable. Interpretation of functionality differed across providers, who considered patient behavior over frequency, quantity, method of substance use (e.g., injection drug use), or drug type.

“So it’s sort of asking how that substance abuse is affecting their life. Like is it making their life chaotic or not? [...] So it’s just seeing, trying to figure out if someone could be adherent to daily medication, asking if they feel they could be adherent.” Provider 007, MD, Male, Age Range 56–55.

“... I mean also the sense of when they do it, how much they use, ... is there a regular, some, you know, semblance of regularity in how they use it? Are they, you know, where are they in terms of want and help? Do they feel it’s a problem? Things like that. And also if they have some sense of normalcy or some pattern,

whether they feel that they can incorporate antivirals into their lives.” Provider 003, MD, Male, Age Range 46–55.

Determining functionality, despite problem substance use, also depended on the intersection of drug and alcohol use with other burdens. A salient concern in deciding whether or not to initiate ART was whether or not patients could prioritize HIV treatment over other pressing issues. In addition to substance use, other patient stressors specifically noted were housing instability and mental health. Providers were especially likely to perceive younger patients as likely to move often and being more difficult to retain in consistent care. Provider assessment of patient stressors also included considering the role of stigma attached to HIV – in deterring patients from seeking treatment, remaining in care, and initiating ART, fearing that friends, family or community members might find out they had HIV. Thus, having a SUD was concerning, but providers viewed SUDs in the larger context of how a patient was able to manage the SUD in the context of other aspects of their life.

“...if you don’t have housing and you don’t have money and you have an addiction, pretty much anything I say regarding medication or your health is not going to be on their radar.” Provider 001, NP, Female, Age Range 25–34.

Leveraging Patterned Drug Use: Following common harm reduction approaches, providers described leveraging patterns of substance use to maximize ART adherence. Because substance use can become routinized, providers talked about integrating ART into those substance use patterns. For example, one provider described strategizing with his patients to identify their injection drug use routines and to use them as cues to take their ARTs:

“If someone uses, like shoots up very regularly, we have them take their medicines before they shoot up and then we say, ‘Well, if you shoot up every day at roughly this period of time, if that’s the only way you’ll remember your medicines or, and during times you are, potentially might be impaired, to use it as a trigger to actually take your medicines before that.’” Provider 003, MD, Male, Age Range 46–55.

At the same time, providers cautioned that using drug use schedules to boost ART adherence is only worthwhile if patients are motivated to implement such strategies. Thus, providers would not only attempt to gauge regularity of substance use, but would also assess level of patient motivation related to incorporating ART adherence into substance use routines.

Providers commonly emphasized differences in ART adherence by type of substance used and its potential to disrupt patients’ lives. They typically made the comparison between drugs like opioids that are most often taken regularly as opposed to alcohol and methamphetamines that are more likely to produce chaotic use periods and binge behavior.

“I would say sometimes some of the more organized people are patients that I’ve had who have been people who are using substances, so it kind of depends on (pause) honestly like what kind of substance they’re using, because some of the drugs are a little bit more binge centered as far as like ‘I’m going to go five days and not leave where I am and not know what day it is and not know what time it is.’ Whereas like some of the other drugs are more like ‘Every day at two, this is what I

do.’ So it actually works out well for medications (laughs).” Provider 001, NP, Female, Age Range 25–34.

“Because you know, some of them are very regimented, especially like heroin users, versus my crystal meth users or my alcoholics who tend to, you know, be very—but I have some crystal meth users who say, ‘I only use on weekends’ or ‘I only use at this party, and otherwise work is very important and I go to work.’” Provider 007, MD, Male, Age Range 46–55.

Demonstrating Motivation to take ART: Patient motivation to take ART was another key factor in whether or not providers would start a patient on ART, regardless of patient substance use. For example, providers noted that if a patient is motivated to initiate ART, then other potential barriers become less important. Physicians were more apt than NPs to consider patient motivation when determining whether or not to initiate ART. Providers conceptualized motivation to start ART in the context of substance use in a variety of ways. These included: patient interest in stopping drug or alcohol use; willingness to seek treatment; patient ability to prioritize health care behavior over drug-taking; and no evidence of HIV medication diversion. Although physicians cited the importance of patients entering into SUD treatment either prior to or in conjunction with ART initiation, none of the NPs mentioned SUD treatment in relation to starting their patients on ART. One provider talked about patients’ entry into SUD treatment prior to ART initiation as a measure of trustworthiness; however, this was not a common sentiment.

“If he is really motivated, then I can start. If he’s not motivated, we have to solve this problem first. Yeah.” Provider 012, MD, Male, Age Range 56–65.

“Whatever preparation we need to do, assuming they were not drug users, has been done, and now they’ve come to that stage where if they were drugs users, I was ready to start them. If they’ve moved through the process seamlessly and smoothly, then yeah, I would start them on antiretroviral treatment.” Provider 002, MD, Male, Age Range 56–55.

A provider noted that physicians are not necessarily good at predicting who will be adherent to ART medications, and reported using substance use as an indicator of potential non-adherence. This provider also highlighted that improved medication regimens since the era of HIV medication cocktails facilitated adherence despite potential barriers like SUDs.

“...so you can have someone [...] who’s got no psychiatric issues and no substance use issues and very highly educated, and not going to take their medications well. And I’ve had hard-core substance users, active injection drug users who can manage. Particularly nowadays, all you have to do is put one pill in your mouth once a day that can do that.” Provider 011, MD, Male, Age Range 46–55.

Patient Substance Use: An underlying theme among providers was that substance use in and of itself was not a “deal breaker” in whether or not they would initiate ART. Along the same lines, providers mentioned practices for managing health behavior, such as scheduling more frequent healthcare visits, to compensate for the possible negative effects of substance use.

“I think someone who admits to be stuck in, you know, in a heavy battle against substance use and has a T cell count of six hundred (pause), if that person told me “I really want to start antiretrovirals,” I wouldn’t deny it, I wouldn’t withhold it from them. I might encourage them to try to get their substance abuse under better control first, but it wouldn’t be, it wouldn’t be a deal breaker for me and, and similarly with psychiatric illness. I’d like to get it better controlled before starting on meds, but it wouldn’t be a deal breaker.” Provider 011, MD, Male, Age Range 46–55.

“You know, I always say to people up front, you know, substance abuse does not carry the death penalty in this state. So you should not die of untreated HIV, diabetes, hypertension because you use. And (long pause) if we can keep you in care enough that you and I are in touch, that you come in periodically, and that you can take your medication ninety percent of the time, (pause) good enough.” Provider 019, NP, Female, Age Range 56–65.

Although substance use in and of itself was not identified as a deterrent to initiating ART, providers still commonly expressed concerns about the effects of substance use, often citing its impact on patients’ ability to follow through with commitments and diverting medications as the real problem. Other substance use related issues included liver functioning and ART tolerance among heavy alcohol users and provider concern over ART resistance in cases where adherence might be challenging. One provider regarded continued use a “betrayal” of trust and several others mentioned issues of trust with regards to substance use. Providers often discussed situations in which they might remove patients from ART as a result of ongoing substance use that was clearly leading to non-adherence.

“Now you might get to a point where I’m prescribing it every month and the viral load remains five hundred thousand, your count remains two, and at that point, I might say, ‘Well, I’m going to stop prescribing this because you’re clearly not taking it.’” Provider 013, MD, Male, Age Range 35–45.

“It has been a deal-breaker. If I – and I have found a patient who restarted his heroin, I saw the new tracks on him, and I said, ‘This is ridiculous, I can’t do this. You broke your promise. Don’t tell me that you can stop any time. He had to prove to me that he was free for two months before I restarted it, or he goes to the [NAME] Hospital for treatment.” Provider 009, MD, Female, Age Range 56–65.

Yet, the medical gravity of patients’ HIV status typically outweighed provider concern over substance use in their decision to initiate ART. Medical gravity included the risk of the patient transmitting HIV to others, as well as the consequences to the patient themselves of not taking ARTs. One example is a provider who mentioned initiating ART if a patient disclosed sex work. Thus, the negative consequences of substance use (or the context surrounding use) were more important factors than the act of using drugs and alcohol themselves. Rather, providers perceived substance use as one of many factors to consider when deciding whether or not to initiate ART.

Provider Characteristics and ART Initiation

Provider flexibility, creativity and thinking outside the box: Tailoring care for each patient appeared critical in providers' work with substance-using PLWH. Providers described creative planning about monitoring adherence, modifying treatment visit schedules, and finding workarounds to bureaucratic barriers, depending on patient challenges. The earlier discussed practice of encouraging patients to pair their medication taking with regular injection times is one example. Other providers, like those below, developed creative ways to support adherence through variations on directly observed treatment.

"...when ours got discontinued (directly observed treatment initiative), I kind of just secretly did it on my own. (laughs) Because it's really important!" Provider 001, NP, Female, Age Range 25–34.

"And I said, 'The way you're getting your meds is you're coming in weekly to meet with the adherence counselors and they will fill the pill bottle up, a pill box, that's it. I am not putting anything in your hands anymore.' And so we started doing that." Provider 004, NP, Female, Age Range 56–65.

Engagement and Rapport: Providers that viewed themselves as having good patient rapport, which included being friendly, non-judgmental, and acting as an additional social support, also seemed willing to work with patients who had SUD. While MDs sometimes described using creative and flexible strategies for supporting patient adherence, all of the NPs and physicians' assistants described using such strategies.

"We have to be so creative to try to help people keep going, you know, and to get them the care that's out there... You know if you had a rat- and mold-infested apartment that you were about to be thrown out of with nowhere else to go with two small children, with your kids have asthma, you have HIV, you have diabetes, you know? How well would you do? You want to like walk in their shoes for a couple of weeks and get back to me on that." Provider 019, NP, Female, Age Range 56–65.

"Like someone who's a hard-core addict or an alcoholic, I'm not going to see them once every three months. (laughs) You know, I'm going to see them every two weeks and it's not necessarily to you know, talk about the HIV." Provider 022, NP, Female, Age Range 46–55.

Program Characteristics and ART Initiation—Providers were able to articulate several program-level components that assisted their patients in overcoming barriers to successful clinical care despite using substances. These programmatic services included outreach strategies like following up after missed appointments, utilizing a program van to pick up patients, making crisis or last minute appointments available for patients who have been out of care, providing flexible hours to accommodate patient schedules, integrating medical and behavioral health care (e.g., team-based or collaborative care approaches), and utilizing behavioral health team members as a bridge to substance use disorder treatment.

However, providers expressed frustration about the lack of and the poor quality of available services. From a more general policy perspective, providers voiced strong support for co-located care coordinators and care coordination programs and the need for bureaucratic streamlining (e.g., eliminating pre-authorizations for certain medications). Providers also uniformly stated that they did not receive systematic feedback on whether a patient linked to addiction treatment referrals. Providers needed to follow up directly with the program or patient if they wanted to know that information.

“I think if you asked me what’s the greatest need in our clinic, it’s having an addiction specialist on site and available, because that’s...I’m not trained to treat that. I’m trained to identify the problem but I’m not trained to treat the problem.”
Provider 013, MD, Male, Age Range 35–45.

“It’s very challenging (linking patients to addiction treatment). There’s not that much, you know, there’s not that much available. A lot is still AA-based. There’s actually a very good alcohol program at [NAME OF PROGRAM] if you can get the patients in. It’s very hard to get patients in.” Provider 019, NP, Female, Age Range 56–65.

DISCUSSION

This New York City-based qualitative study examined the rollout of the policy to offer ART for all people with HIV, specifically in the presence of problem substance use, from the perspective of HIV primary care providers and in the context of HIV treatment. In doing so, it examined how providers discuss and assess substance use. Almost all providers reported their agreement with guidelines for universal ART initiation despite the presence of SUD. Substance use is one of many factors HIV providers consider and, overall, does not preclude or rule out the initiation of ART. Still, identification and management of SUD is challenged by inconsistent assessment, misperceptions about SUD and patients’ willingness to discuss it and lack of accessible SUD treatment resources when identified. In addition, provider concerns about patient ability to adhere to ART sometimes disrupted initiation or continuation of ART in practice. Despite these challenges, many HIV primary care providers used creative and innovative methods to initiate and support ART adherence among PLWH with problem substance use or SUD.

Several themes were salient. First, level of functionality and stability, rather than substance use per se, guided decisions about initiating ART. Providers expressed a willingness to work with patients with SUD and talked specifically about successes in managing HIV and other health issues. Level of functioning (versus “chaos”) was not easily defined. Typically, it was related to patient compliance (able to attend appointments at the required intervals, taking medications regularly) and absence of interference from other major quality of life problems. Less often, providers talked about requiring patients to attend some type of treatment for SUD as a prerequisite to ART initiation or re-initiation. Usually, this was after an unsuccessful attempt to maintain the patient on ART. Use of stimulants and alcohol – associated with potential binges and periods of “dropping out of life” – were of special concern, even more so than opioid use.

At the same time, providers sometimes harbored assumptions about patients who use particular substances. Some made assumptions about whether users of specific substances might or might not be able to adhere based primarily on past clinical experience. They used current patient behavior to support or challenge their assumptions. These observations raised a crucial question about whether or not providers sufficiently recognized the role of polysubstance use, rather than single substance use, among their patients. Some dismissed standardized assessment to make a diagnosis of SUD in favor of diagnosis by intuition or feeling (e.g., can tell by looking at the patient). Altogether, these data made it clear that additional information and training in principles and practices in addiction and its treatment were sorely needed, even among a sample reporting many years of experience working with patients who had SUD.

Second, extent of intersecting burdens from other challenges was another salient concern in initiating ART. Many such burdens were perceived as heightened in substance-using patients including homelessness, mental health problems, unemployment, lack of social support, and general instability. The co-occurrence of multiple problems made ART adherence more challenging. Providing better tools for assessing SUD and functional level are needed. These could include methods for identifying and diagnosing SUD properly (e.g., evidence-based screening tools), as well as skills for exploring readiness, motivation, and capacity to initiate and adhere to ART (e.g., motivational interviewing, brief negotiation intervention). Although finding adequate time with patients continues to be a significant barrier to comprehensive assessment of SUD, training and access to appropriate tools was crucial.

Substance use screening approaches were highly variable, ranging from standardized electronic record questions to informal conversations prompted by “signs” of use. Many providers were skeptical that SUD screening questions could be feasibly integrated into a larger clinical interview. Some providers expressed reservations about the clinical appropriateness of standardized questions, preferring a more informal inquiry that provides greater latitude. Lack of consistent timeframes for questions and limited time left many providers to ask only at annual appointments, if at all. These results suggest the need for practical training on how standardized questions should be used and integrated, practice asking questions in a nonjudgmental way to increase patient (and physician) comfort, and general addiction education. Providers also discussed the lack of sufficient services for patients with SUD as a barrier to physicians’ willingness to discuss alcohol and drug use. Unequipped to deal with the SUD directly and lacking viable treatment options, they felt reluctant to discuss substance use. In turn, sparse discussion of substance use may also have a dampening effect on discussion of HIV transmission risk related to substance use. For example, it is less likely that sex while intoxicated will be assessed. There may also be less opportunity to identify substance and needle sharing partners who may be prime candidates for pre-exposure prophylaxis (PrEP).

While physicians and NPs generally reported similar themes, NPs more often described employing creative and flexible approaches to supporting patient adherence, such as having patients attend more frequent appointments. Physicians, more so than NPs, factored in patient motivation and the need for patients to engage in SUD treatment in deciding whether or not to initiate patients on ARTs. These findings suggest that NPs may be more flexible or

patient-centered in their practice. This flexibility is more in line with CDC guidelines for universal ART [2] that call upon providers to work collaboratively with their patients—regardless of substance use—to develop tailored strategies for ART adherence. However, future research would be needed to specifically assess differences between NPs and physicians in ART practices.

Providers reported frustration with the general lack of program support for addiction treatment services. They often rely on referral to treatment at outside agencies, which can complicate follow-up. Those few providers who did have onsite behavioral health support and resources, including social workers, addiction specialists, case managers, and psychiatrists, spoke very positively about the usefulness of these supports. Providers expressed relief in knowing exactly what could be done should a SUD be identified. Although healthcare guidelines do support integrated behavioral health care into primary care settings, progress has been limited and more research is needed to identify successful and practical implementation strategies. This is likely to include a reexamination of the mission of primary care clinics that would include addiction services.

This qualitative analysis of 25 HIV primary care providers offers new information about how providers manage guidelines for universal ART in the context of substance use and associated challenges. Several limitations should be noted that may reduce generalizability. Although the sample was diverse in terms of healthcare setting and type of position, providers were generally highly experienced HIV practitioners. These findings may not generalize to those with less experience treating HIV or to those working outside the NYC area. Further, although providers were randomly selected from published professional organization rosters, recruitment challenges (e.g., inaccurate contact information, difficulty making direct contact) resulted in a low response rate. Those providers that did respond may have been different than those that did not. Another limitation of the sample is that its size did not permit subgroup comparison (e.g., by sex or other potentially important parameters).

CONCLUSION

The vast majority of providers interviewed in this sample appeared to accept universal ART initiation guidelines; however, how these guidelines were implemented in practice was more complex. Important gaps remain in the delivery of services to recognize, manage, track and treat SUD among PLWH. Greater guidance and training and greater integration of SUD and other behavioral healthcare into HIV primary care, including harm reduction strategies, are critically needed. Providers identified some of these strategies and their perception that they would be helpful to improving ART uptake and viral load suppression in substance users. They also cited enhanced adherence supports, such as adherence counseling and Directly Observed Therapy, as effective and patient-centered means of enhancing viral load suppression among substance users. This study suggests robust agreement with universal ART policy guidelines in this sample of NYC HIV primary care providers and clear targets for intervention and additional resources for PLWH who also have SUD.

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Table 1

Provider characteristics (N=25)

	M	SD
Age (years)	50.0	7.3
	n	%
Sex (female)	13	52
Race/Ethnicity		
Non-Hispanic Black or African American	1	4
Non-Hispanic Asian	7	28
Non-Hispanic White	13	52
Non-Hispanic Multiracial/Race not specified	3	12
Hispanic/Latino	1	4
Professional Discipline		
Nurse Practitioner	7	28
Physician's Assistant	1	4
Physician	17	68
Years of HIV Treatment Experience		
1 – 5	2	8
6 – 10	3	12
11 – 15	4	16
15 or more	16	64
Clinic Location (NYC Borough)		
Bronx	9	36
Brooklyn	5	20
Manhattan	8	32
Queens	2	8
Staten Island	1	4
Clinic Type		
Primary Care	14	56
Specialty Care	5	20
Hospital-based	6	24
Years Working with Patients with Problem Substance Use		
1 – 5	2	8
6 – 10	2	8
11 – 15	4	16
15 or more	17	68
Agree/Strongly Agree with Universal ART Policy Guidelines	22	88
Barriers to Initiating Patients on ART		
Patient Ambivalence	18	72
Housing Instability	11	44

	M	SD
Lack of Insurance/Inadequate Insurance	11	44
Co-occurring Substance Use Disorder	11	44
Co-occurring Mental Health Disorder	8	32
Inconsistent Access or Challenges Accessing Meds	8	32
Limited Social Support	4	16
Economic/Financial Instability	3	12
	M	SD
Estimate of Proportion of HIV patients with:		
Economic/Financial Instability Alcohol Problems	21.9	16.8
Economic/Financial Instability Prescription Drug Problems	14.5	11.8
Economic/Financial Instability Illicit Drug Problems	26.2	17.7
Economic/Financial Instability Injection Drug Problems	6.4	6.9

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