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HIV Treatment Knowledge in the Context of “Treatment as Prevention” (TasP)

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Abstract

According to 2012 universal ART guidelines, as part of “treatment as prevention” (TasP), all people living with HIV (PLWH) should immediately initiate antiretroviral therapy post-diagnosis to facilitate viral suppression. PLWH who are virally suppressed have no risk of sexually transmitting HIV. This study used descriptive analysis of quantitative data (N=99) and thematic analysis of qualitative interviews (n=36) to compare participants recruited from a hospital-based detoxification (detox) unit, largely diagnosed with HIV pre-2012 (n=63) vs. those recruited from public, urban sexual health clinics (SHCs), mainly diagnosed in 2012 or later (n=36). Detox participants were significantly more knowledgeable than SHC participants about HIV treatment, except regarding TaSP. SHC participants’ desire for rapid linkage to care and ART initiation was in line with 2012 universal ART guidelines and TasP messaging regarding viral suppression. More

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Informed Consent: Informed consent was obtained from all individual participants included in the study.

targeted messaging to PLWH pre-2012 could ensure that all PLWH benefit from scientific advances in HIV treatment.

Keywords

HIV/AIDS; antiretroviral treatment; treatment as prevention; health knowledge

INTRODUCTION

As of 2012, federal guidelines recommend that individuals diagnosed with HIV initiate antiretroviral therapy (ART) immediately following a diagnosis of HIV infection regardless of CD4 count or disease status [1]. The New York City Department of Health and Mental Hygiene (NYC DOHMH) endorsed this “universal ART” policy on World AIDS Day, December 1, 2011. The “universal ART” policy is part of the “treatment as prevention” (TasP) strategy: not only does universal ART contribute to improved health outcomes for PLWH through reduced viral load and increased CD4 count [1–3], but it also lowers the likelihood of HIV transmission to HIV negative partners [4–7]. TasP has been touted as a means of reducing HIV-related stigma by reshaping public perceptions of PLWH and by increasing knowledge about HIV [8]. Undetectable = untransmittable (U=U), shorthand for the widespread clinical guideline that people living with HIV who are on ART and have sustained an undetectable viral load for a minimum of six months cannot sexually transmit HIV [9], comprises part of TasP. TasP messaging may also encourage PLWH to initiate ART immediately following an HIV diagnosis, to remain ART-adherent, and to continue in care [10]. Moreover, increased general HIV knowledge [11], as well as knowledge of the effectiveness of ART [12], have been found to motivate ART adherence among PLWH, while higher levels of HIV-related stigma often lead to ART non-adherence and gaps in HIV care [13–15].

For TasP to reduce HIV stigma, facilitate rapid linkage to care and ART initiation, and support ongoing ART adherence, TasP messaging must be effectively and widely disseminated to diverse communities. Some existing research has explored public perceptions, knowledge, and understanding of TasP concepts in the era of universal ART [16–21]. More recent literature has focused on variations in TasP beliefs and knowledge between HIV-positive and HIV-negative individuals [8, 16–18]. For example, a 2015 study in Vancouver, Canada found that nearly 70% of HIV-positive participants were aware of TasP compared to only about 40% of those who were HIV-negative [17]. Other recent studies reported similar findings [16, 20, 21], with HIV-positive participants consistently more knowledgeable about the fact that an undetectable viral load reduces the likelihood of HIV transmission [20, 21] and about the importance of early ART initiation [18]. Some literature has also suggested that having a higher level of education (e.g., master’s degree vs. high school diploma) predicts greater awareness of TasP [18, 20].

Missing from the literature, however, is a comparison of how TasP and other HIV treatment knowledge may differ between long-term survivors of HIV and those diagnosed more recently. Individuals who were diagnosed with HIV many years ago, particularly before highly active ART became available in 1996, initially contended with a lack of effective treatment medications as well as harsh side effects of early ART [22]. As such, it would be important to understand whether long-term survivors of HIV have received and internalized more recent messages of HIV treatment optimism related to TasP. Given the potential for TasP knowledge to foster ART adherence and retention in HIV care [11, 12], all PLWH could benefit from access to and a clear understanding of TasP information.

Purpose

The primary aims of this NYC-based study were to: (1) compare individuals recruited from NYC DOHMH sexual health clinics (SHCs) vs. those recruited from a hospital-based detoxification (detox) unit by their HIV-related knowledge, using quantitative data; and (2) use qualitative data to contextualize quantitative findings.Because most participants recruited from the SHCs had learned of their HIV-positive status within weeks of their baseline interview, we expected these participants to be similar to the HIV-negative individuals in recent studies comparing TasP knowledge by HIV status [16, 17, 20, 21]. In other words, we hypothesized that those recruited from the SHCs would be less knowledgeable about HIV treatment and TasP compared to the participants recruited from detox, who were mainly long-term survivors of HIV. Results will provide information on the diffusion of TasP messaging across a diverse sample of PLWH, particularly addressing gaps in the literature on TasP knowledge among long-term survivors of HIV.

METHODS

Participants

This mixed methods analysis was part of a larger evaluation of universal ART implementation among people with problem substance use in NYC [23]. Initially, only those with newly diagnosed HIV infection were eligible for the study. Given a steep drop in HIV incidence in NYC that overlapped with the years of study recruitment [24, 25], eligibility criteria were loosened to also include those already living with HIV. Due to this shift, the overall sample ultimately comprised two unique recruitment subgroups: participants recruited from the detox unit, nearly three quarters of whom had been diagnosed with HIV at least 15 years prior to study enrollment, and participants from SHCs, who were primarily diagnosed with HIV after the advent of the universal ART policy. This provided an opportunity to compare TasP and other HIV treatment knowledge across the two groups.

The current sample included 99 PLWH recruited between 2014 and 2017; 63 were recruited from detox or from referrals by detox participants (including one recruited via a hospital flyer) and 36 from SHCs. A sub-sample of 36 participants (14 detox; 22 SHC) comprised the qualitative sample. To be eligible for the study, participants had to: (a) report problem substance use, operationalized as any illicit drug use in the past year and/or heavy drinking in the past month (in a single day, more than four drinks for those assigned male at birth; more than three drinks for those assigned female at birth) [26]; b) report an HIV-positive status; c) be able to speak and understand English; and d) live in one of the five boroughs of NYC.

Procedures

Potential participants were recruited from NYC DOHMH SHCs, in a hospital-based detox unit, or through participant referral and flyers. Those interested in the study provided verbal consent and completed a brief screening interview. Eligible participants then attended an in-person appointment where they provided written consent for all study procedures and completed a baseline assessment. Participants subsequently attended four follow-up assessments every six months over the next two years. Qualitative interviews were conducted at the six-month follow-up visit. Each assessment took approximately 90 minutes. The Institutional Review Boards (IRB) of the Icahn School of Medicine at Mount Sinai and the NYC DOHMH approved the study.

Assessment

Demographics and HIV treatment knowledge—The baseline interview included the following demographic questions: gender identity; race/ethnicity; alcohol, cannabis, opioid, and stimulant use disorders (endorsement of at least two of 11 Diagnostic and Statistical Manual – 5th Edition [DSM-5] symptoms in the past 12 months) [27]; year of HIV diagnosis, age, and education in years. HIV outcomes included self-reported linkage to HIV care (had already gone to a doctor or clinic for HIV care at least once) and self-reported ART initiation (ART prescription within the last 30 days). Viral suppression was documented using the NYC DOHMH HIV Surveillance Registry at 6-month follow-up to give enough time for those newly diagnosed with HIV to have achieved viral suppression. HIV treatment knowledge was measured using the HIV/AIDS Treatment Related Knowledge questionnaire adapted from the Treatment Services Review [28]. The HIV/AIDS Treatment Related Knowledge questionnaire included 12 statements that participants were instructed to identify as true or false, or to indicate that they didn’t know. Statements assessed knowledge regarding HIV virus progression and treatment.

Qualitative interview—A sub-sample of participants was interviewed at their 6-month follow-up assessment (n = 36) until interviews no longer produced new themes (i.e., saturation) [29]. We conducted qualitative interviews using a semi-structured interview guide, which for the larger study, we compiled by drawing from the Consolidated Framework for Implementation Research and adapted to include new themes as they emerged during initial interviews. Interview probes served to expand participant responses [30]. For the current analysis, we focused on themes related to the Health Belief Model, which conceptualizes individuals’ perceptions of disease severity, benefits of and barriers to help-seeking, and actions to address health problems [31]. The interview guide comprised 8 core question domains (e.g., *How did you react when you first learned you were HIV positive? Have you tried to see a healthcare provider about your HIV?*), as well as sub-questions and prompts when needed to encourage participants to provide more in-depth responses. All domains were addressed in each interview.

Interviewers received training in qualitative interviewing techniques and conducted mock interviews that were either observed or audio recorded. Mock interviews were then reviewed and discussed. The first two formal interviews were also reviewed to confirm adherence to the interview guide. All interviews were digitally recorded and transcribed.

Data Analysis

Quantitative analysis—Using chi square or Fisher's exact tests, descriptive analyses examined demographic and HIV treatment outcome differences between SHC and detox participants (Table 1). We also used chi square tests to assess differences between SHC and detox participants by the proportion of each of the 12 HIV Treatment Knowledge statements that were identified correctly as true or false (responses of "don't know" were considered to be an incorrect response; Table 2). All hypothesis tests were two-sided using 5% level of significance and performed in SAS® 9.4 [SAS institute, Cary, NC].

Qualitative analysis—For the qualitative analysis, a code book was developed using a grounded theory approach [32, 33]. First, we formulated the hypothesis that participants recruited from the SHCs and the detox unit would differ in terms of HIV treatment initiation and linkage to care, which we defined as initiating medical care with an HIV healthcare provider. With that hypothesis in mind, the salient themes—e.g., HIV treatment optimism and TasP optimism—emerged from the analysis. We developed coding consensus and assessed reliability on the first four interviews (10% of total interviews).We entered the final codebook into ATLAS.ti® software for data management and systematic coding. A framework analysis was used for data analyses, which is a systematic method for organizing and sorting coded text by case, themes, and sub-themes [34, 35]. We also compared qualitative domains and themes between SHC and detox participants to provide additional perspective on the quantitative analysis.

RESULTS

Quantitative results: Participant Characteristics

Table 1 displays demographic characteristics of the full sample (N = 99). The majority of the sample identified as cisgender men ($n = 85$, 85.9%), 12% ($n = 12$, 12.1%) as cisgender women, and 2% ($n = 2$, 2.0%) as transgender women. Participants were mainly non-Hispanic Black/African American ($n = 51$, 50.5%) or Latinx/Hispanic of any race ($n = 35$, 35.4%). On average, participants were 44 years old (mean [M] = 43.6, standard deviation [SD] = 13.2, range = 21–65) and had 13 years of education (M = 13.1, SD = 2.5, range = 6–19). Over 60% ($n = 63$, 63.6%) of the sample were diagnosed with HIV prior to 2012, while nearly 40% ($n = 36$, 36.4%) were diagnosed in 2012 or later. At the baseline visit, nearly 90% of the sample reported having linked to HIV care (89.9%) and over three-fourths (76.8%) had initiated ART. At 6-month follow-up, 62.2% were virally suppressed. Over half the sample had an alcohol use disorder (56.6%) or a stimulant use disorder (60.6%), 34.3% had a cannabis use disorder, and 26.6% had an opioid use disorder.

Compared to SHC participants, detox participants were significantly less likely to be cisgender men (SHC $n = 35$, 97.2% vs. detox $n = 50$, 79.4%, $p = .004$, Fisher's exact test), and significantly more likely to be Black/African American (SHC $n = 11$, 30.6% vs. detox $n = 40$, 63.5%, $p < .001$, Fisher's exact test), to be diagnosed with HIV before 2012 (SHC $n = 3$, 8.3% vs. detox $n = 60$, 95.2%, $p < .001$, Fisher's exact test), to be of an older age (SHC M = 28.1, SD = 6.0 vs. detox M = 52.5, SD = 6.0, $p < .001$, $F = .175$), and to have fewer years of education (SHC M = 14.9, SD = 2.0 vs. detox M = 12.1, SD = 2.1, p < .001, $F = .214$).

Compared to SHC participants, detox participants were also more likely to have linked to HIV care (SHC $n = 26$, 72.2%, vs. detox $n = 63$, 100.0%, $p < .001$, Fisher's exact test) and to have initiated ART (SHC $n = 17$, 47.2%, vs. detox $n = 59$, 93.7%, $p < .001$, $\chi^2 = 27.69$). However, compared to SHC participants, detox participants were significantly less likely to be virally suppressed at 6-month follow-up (SHC $n = 29$, 80.6% vs. detox $n = 33$, 52.4%, $p = .014$, $\chi^2 = 6.06$). Compared to SHC participants, detox participants were also significantly more likely to have an opioid use disorder (SHC $n = 1$, 2.8% vs. detox $n = 25$, 39.7%, $p < .001$, $\chi^2 = 16.11$) or a stimulant use disorder (SHC $n = 13$, 36.1% vs. detox $n = 47$, 74.6%, $p < .001$, $\chi^2 = 14.23$).

Quantitative results: HIV/AIDS Treatment Knowledge

Table 2 shows the percentages of SHC and detox participants who correctly answered 12 true/false questions about HIV/AIDS treatment. SHC and detox participants significantly differed in their knowledge of eight of the 12 statements, with detox participants being significantly *more* knowledgeable for seven statements. This included knowledge about ART suppressing the HIV virus (100% of detox participants answered correctly vs. 83.3% of SHC participants, $p = .002$, Fisher's exact test), the importance of adhering to ART in order to maintain enough medication in the blood (96.8% of detox vs. 75.0% of SHC, $p = .002$, Fisher's exact test), the possibility of viral resistance to ART (90.5% of detox vs. 69.% of SHC, $p = .008$, $\chi^2 = 7.13$), the purpose of measuring CD4 counts (90.5% of detox vs. 75.0% of SHC, $p = .039$, $\chi^2 = 4.27$), the purpose of a viral load test (98.4% of detox vs. 86.1% of SHC, $p = .023$, Fisher's exact test), the impact of an elevated viral load on CD4 counts (81.0% of detox vs. 58.3% of SHC, $p = .015$, $\chi^2 = 5.91$), and the particularly stark contrast in knowledge that ART improves CD4 count (90.5% of detox vs. 52.8% of SHC, $p < .001$, $\chi^2 = 18.26$).

By contrast, SHC participants were significantly more knowledgeable than detox participants on only one of the 12 statements, with 75.0% of SHC participants and 46.0% ($p = .006$, $\chi^2 = 7.83$) of detox participants knowing that a low or undetectable viral load makes one less likely to transmit HIV (i.e., TasP).

Qualitative Analysis: Diagnosis reactions, and linkage to care

Small sample sizes precluded exploration of which factors were associated with differences in TasP knowledge across the two recruitment subgroups. We suspected that differences were driven by the fact that most SHC participants were diagnosed with HIV after 2012, when the universal ART policy went into effect. Although qualitative interviews did not directly explore the impact of TasP knowledge on motivations to initiate ART, we turned to the qualitative data to provide additional context for the quantitative findings. We explored two primary qualitative domains: (1) how reactions to receiving a diagnosis of HIV infection varied among SHC and detox participants; and (2) how those reactions, when combined with HIV knowledge, either impeded or facilitated engagement in HIV treatment among the two groups. Consideration of these domains was grounded in the literature showing that knowledge of TasP may motivate those living with HIV to more rapidly link to HIV care and initiate ART [8], despite the fact that our qualitative data could not directly answer that question.

Initial reactions to a diagnosis of HIV infection—Reactions to receiving an HIV diagnosis were similar across recruitment subgroups despite great diversity in when the diagnosis was received. Common emotional responses included becoming depressed and experiencing guilt, fear, anger, numbness, and disbelief. For example, one SHC participant (cisgender man, age 20–25, white, diagnosed in 2014), when asked about his initial reaction to learning his HIV diagnosis, responded:

> "I was depressed because I just felt like what's happened, how this happened to me, why it's going on, what decisions did I make? And I started reflecting on the people I surrounded myself with and also like the people I was hooking up with at the time, that I just said I should have known better, I should have did better. Why was I doing these bad things?"

Similarly, a detox participant (cisgender man, age 30–34, Latino, diagnosed in 2011) expressed that upon learning his HIV diagnosis, he "started crying, I got really depressed."

Several SHC and detox participants described being stunned when they first learned they were HIV positive. For example, one detox participant (transgender woman, age 50–55, Latina, diagnosed in 1999) stated that she "kind of didn't believe it. It was really shocking and it was like (pause) overwhelming and shocking at the same time." Similarly, an SHC participant (cisgender man, age 40–45, white, diagnosed in 2015) said that he was "in shock…I felt shock and numb, like I couldn't grasp the whole situation and the whole news."

SHC Participants: Leveraging knowledge to link to care—SHC and detox participants' experiences diverged, however, when describing how negative emotional reactions to the diagnosis impacted linkage to care. The majority of SHC participants—most of whom were diagnosed in an era of universal ART guidelines and availability of highly effective HIV medications with minimal side effects—leveraged their feelings of depression, shock, and fear as motivation to seek HIV treatment as quickly as possible. SHC participants were eager to start taking HIV medications, even when they were still processing the news of their diagnosis. Medication initiation may have helped SHC participants cope with the range of negative emotional responses to an HIV diagnosis.

Two SHC participants expressed HIV treatment optimism by explicitly referencing their knowledge that rapid ART initiation is important in lowering viral load and improving HIV outcomes, which is a component of TasP. Although the participants in the following quotes seemed to possess some TasP knowledge, neither participant explicitly referenced the idea of U=U. Still, both quotes suggest that treatment optimism helped to modulate post-diagnosis depression and that messaging about early ART initiation, at least related to lowering viral load, has been effective.

Detox participants: Difficulty accepting an HIV diagnosis and substance use as barriers to linkage to care—In contrast to SHC participants, whose desire for rapid linkage to HIV care and treatment initiation seemed to follow universal ART guidelines and to align with TasP messaging, detox participants expressed barriers to linkage to care that were often reflective of the lack of effective and safe HIV medications at the time they were diagnosed [36]. Detox participants' reticence in linking to care seemed to be emblematic of the hopelessness surrounding an HIV diagnosis before combination ART made HIV a chronic rather than a fatal disease [37]. For example, several detox participants identified that difficulty accepting their diagnosis, sometimes combined with a fear of the severe medication side effects (a reality even after the advent of highly active ART in 1996) [22], posed barriers to rapid linkage to care.

Substance use among detox participants further impeded linkage to care. For example, one participant (cisgender man, 50–55, Black, Diagnosed with HIV in 1998) described using alcohol and drugs to escape having to deal with his HIV status, stating that he "…didn't want to talk to anybody. I didn't want to—I went on drinking binges, drug binges. I didn't want to, I didn't want, I didn't want to hear anything about that."

For some detox participants, the fact that they were not initially experiencing any HIV-related symptoms and felt healthy contributed to difficulty in accepting their HIV status.

One detox participant mentioned that although his distress following his diagnosis did not impact linking to care, his difficulty accepting his HIV status served as a barrier to taking ART. For this participant, HIV medications would have solidified the fact that he was HIV positive.

Detox participants: Motivation to link to care to understand one's health status—Some detox participants were motivated to get into care to monitor their health status and HIV virus progression, even though ART initiation was not a primary motivating, or even necessarily an available option.

Detox participants: Linkage to care with intermittent ART adherence—Although some detox participants linked to care and started ART shortly after learning their HIV positive status, a few described intermittent adherence to ART. Again, detox participants mentioned substance use as a key factor that influenced their HIV care and treatment. One participant, diagnosed in 2011, started an ART cocktail just after being diagnosed but after about five and a half months he relapsed, began using drugs again, and ceased ART. As he worked toward achieving ART adherence again, difficulty accepting his status remained an ongoing barrier.

For another participant who linked to care immediately following his diagnosis, inconsistent adherence was related to lack of effective medications at that time.

DISCUSSION

In this mixed methods study, we examined differences in HIV treatment knowledge between two distinct subgroups, one recruited from the NYC DOHMH SHCs and one from a hospital-based detox unit. whom had been living with HIV for at least 15 years, Our quantitative findings show that detox participants, most of had significantly more HIV treatment knowledge than SHC participants, most of whom were diagnosed with HIV after universal ART guidelines went into effect. The only exception was the statement regarding

TasP. SHC participants were significantly more likely than detox participants to recognize that a lower viral load indicates reduced likelihood of HIV transmission.

This finding differed from our hypothesis that SHC participants would be less knowledgeable about TasP compared to detox participants. Although the extant research does not appear to have compared such knowledge among those with long-term HIV infection vs. those recently diagnosed, recent studies have found that HIV-positive individuals in general have greater TasP knowledge compared to those who are HIV-negative [16, 17, 20, 21]. As previously mentioned, we expected TasP knowledge among our SHC sample to be similar to TasP knowledge among HIV-negative participants in previous studies given that most of the SHC participants had been diagnosed with HIV just prior to enrolling in our study. Research has also found that having a connection to an HIV-related agency predicts increased TasP knowledge [20]. Thus, we would have also expected to see increased TasP knowledge among the mainly long-diagnosed detox sample, who were significantly more likely than the SHC subgroup to have linked to HIV care and treatment at baseline.

We then turned to our qualitative data to provide additional context for the differences between the two participant subgroups, while recognizing that the qualitative data could not fully answer the question of why we observed these differences. Qualitative data revealed that diagnosis-related distress persisted despite biomedical advances in HIV treatment and prevention. In the current study, although both cohorts experienced adverse mental health outcomes upon receipt of HIV diagnosis, only SHC participants cited negative emotions (including depression) as triggering motivation to rapidly link to care without “wasting” time. In fact, recent research suggests a link between higher levels of depression and anxiety and more rapid ART initiation [38]. Although SHC participants’ motivation for rapid linkage may have been a function of when SHC participants were diagnosed (i.e., in the context of the availability of highly effective HIV medications), the SHC cohort’s higher level of education [38], in addition to greater access to TasP knowledge, may been additional contributing factors. As noted in another recent review, having accurate information about ART can spur ART initiation [39].

SHC participants’ desire for rapid linkage to care and ART initiation also seemed to be in line with 2012 universal ART guidelines and more recent TasP messaging, in that some participants’ motivation for rapid ART initiation was grounded in a desire to achieve an undetectable viral load and facilitate optimal health outcomes. Research supports this finding, demonstrating that TasP knowledge can lead to motivation for immediate ART initiation following an HIV diagnosis [10]. Moreover, possessing knowledge and information about HIV in general [11] and ART effectiveness [12], can also support ART initiation among PLWH.

Although SHC participants seemed to have absorbed TasP messaging, at least in terms of the fact that rapidly achieving an undetectable viral load can lead to better health outcomes, it seemed that detox participants had either not been given the same message or had not retained information they may have received. As such, disseminating broad-based knowledge of TasP and making such information comprehensible to all PLWH, regardless of when they were diagnosed, is crucial to enhancing HIV care outcomes.

Still, wide knowledge dissemination is not enough to reach all groups of PLWH; targeted and relevant messaging is also crucial. In addition to differences in qualitative findings related to linkage to HIV care and treatment initiation, our sample of participants were also significantly different in terms of several demographic characteristics, with detox participants more likely to be people of color and to have a lower level of education. Given significant demographic differences, we might have expected to see the same pattern in level of knowledge for each group across all knowledge items; however, results show that detox participants were much more knowledgeable about HIV treatment except regarding TasP. Results thus indirectly show that participants who were white and who had a higher level of education were disproportionately more knowledgeable about TasP, despite the detox group being better informed about HIV treatment in general. As Richman of the Prevention Access Campaign noted in 2017, “People who know this information tend to be privileged, have private insurance, are often white. That is so unjust that information that concerns our social, sexual and reproductive health and lives is being withheld” [40].

Another key difference between the two groups in our sample was severity of substance use, with those recruited from the detox unit having much higher levels of substance use disorders.Detox participants often mentioned substance use as a barrier to HIV care and treatment, which is reflective of the literature showing that substance use disorders are known deterrents to HIV care linkage, retention [41], and ART adherence [42, 43]. The higher likelihood of substance use disorders among the detox sample may have explained their lower levels of viral suppression by 6-month follow-up. Research has shown that HIV providers are sometimes reluctant to initiate ART among their patients with substance misuse and disorders [44–46], a practice that has been particularly common among patients of color [47]. HIV providers may also be less engaged overall with their patients who misuse substances, and thus may be less communicative about advancements in HIV treatment such as TasP. Thus, differences between the SHC and detox participants could have also been attributed to differences in substance use histories and severity between the two groups.

Finally, not only did SHC participants have the advantage of mainly being diagnosed after the rollout of universal ART recommendations, but those recruited in the last year of the study would have also benefitted from the NYC DOHMH JumpstART program that began in 2017. JumpstART provided SHC patients with the opportunity for ART initiation immediately following an HIV diagnosis, with support for linkage to continuing care [48]. Providers may need to check in with their patients who have been living with HIV for a long time, such as detox participants from this study, to ensure that they have received all up-to-date HIV treatment information such as TasP and U=U. Public health campaigns about TasP and U=U should also attempt to target long-term survivors of HIV, as well as people with substance use disorders.

Limitations

This study should be considered in light of several limitations. First, recall bias may have impacted responses among detox participants given that some were describing experiences that occurred well over 10 years prior to the interview. Second, some participants may have reported being motivated to engage in HIV treatment and care due to social desirability bias in the context of an HIV research study. Third, detox participants were significantly more likely an SHC participants to be a racial or ethnic minority, of an older age, and with fewer years of education. Historically, due to decreased economic opportunities, stigma, and racial discrimination, racial and ethnic minorities have lower educational attainment and less access to health care, and in turn, fewer opportunities for linkage and adherence to ART [49, 50]. Such demographic differences in the current sample therefore could have explained differences in TasP-related knowledge but we did not have the power to adjust for those differences. Finally, although the qualitative data provided some background for the TasP knowledge differences across the cohorts, we were unable to directly explore reasons for these differences given that the qualitative interview did not explicitly ask about TasP knowledge.

Implications

The current study demonstrates that improved strategies are needed to widely disseminate TasP and U=U information to people diagnosed with HIV before the 2012 release of universal ART guidelines and the advent of TasP, especially those who are older, are racial and ethnic minorities, who have a lower level of education, and who have challenges with substance use. Peer support groups for PLWH have sometimes been found to facilitate knowledge sharing among group members [51] and thus could potentially help bridge knowledge gaps among people who have been living with HIV for varying lengths of time.

Providers could also assist with these efforts by sharing TasP information with their patients regardless of how long they’ve been living with HIV and regardless of whether they use substances. On November 28, 2017, the NYC DOHMH disseminated frequently asked questions (FAQ) regarding U=U, one of the most recent advances in the era of TasP, to both patients and providers. The provider FAQ included a section on how to support patients in achieving an undetectable viral load, citing U=U as a motivating factor for patients to remain adherent to their ART medications. Although the NYC DOHMH FAQ offered valuable and comprehensive U=U information for providers, it did not specifically acknowledge that patients diagnosed pre- and post-2012 may have different levels of TasP and U=U knowledge, or that there may be different barriers and facilitators to providing information to each of those groups [48].

Future NYC DOHMH information for providers could highlight the potential need for special attention to and updated messaging strategies for patients who have been living with HIV for a long time, as well as patients with substance use disorders. Those diagnosed before recent biomedical advances may face unique challenges in HIV care and may have received less optimistic messages about HIV treatment outcomes when they were originally diagnosed with HIV. Substance use disorders may further intensify obstacles in HIV care. This may have been the case with participants in the current sample who were recruited from the detox unit. Early negative messaging regarding HIV risks and prognoses may have affected their ability to accept the more recent advancements and optimism surrounding HIV treatment outcomes. On May 16, 2018, the NYC DOHMH held a community listening session regarding U=U. Future social marketing campaigns should also be implemented to widely disseminate tailored TasP messages.

The present study suggests that TasP knowledge is critical to support linkage to care and early ART initiation. In an era of highly effective HIV treatment with few side effects and the ability to reduce HIV transmissibility to zero, all PLWH should have equal access not only to treatment itself, but also to treatment knowledge. Increasing knowledge of TasP could foster optimism among both people who have been living with HIV for a long time, as well as those more recently diagnosed.

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Interviewer: “And all these negative emotions, did they affect seeking out health care?

Participant: “Umm, no. No, no…I had it clear I have to get health care if I have this, so I just went straight to it…I didn’t want to waste a second.” -Cisgender man, Age 26–30, white; Diagnosed with HIV in 2014

Interviewer: “So did your initial feelings affect seeking out a health care provider?

Participant: “No. It uh (pause) it pushed me to look for some services of some kind, just take the next steps.” –Cisgender man, Age 40–45, Latino, Diagnosed with HIV in 2014

Interviewer: “Did these feelings affect seeking out a health care provider?

Participant: “Yes, absolutely. The second she said I was, you have to give me the best doctor that you know that’s around, the one who’s most attentive, the one who will put me on medication today” -Cisgender man, Age 26–30, white; Diagnosed with HIV in 2014

Interviewer: “So how did your initial feelings after the diagnosis affect you seeking out a health care provider, if at all?”

Participant: “Oh, it didn’t. It was like, you gotta do it, you gotta do it.”

Interviewer: “So you were just ready.”

Participant: “Oh yeah, and I was like I need to, and I already knew that it’s as early as you can to take the, the drugs, it’s more likely to lower your count until (pause) an undetectable rate and actually develop the disease, so I knew that.” -Cisgender man, Age 30–35, Latino, Diagnosed with HIV in 2015

Interviewer: “So did these initial feelings of intense fear and shock, did that affect you seeking out a health care provider?”

Participant: “(pause) I think what hap—I mean, I think, like anything else you go through, denial and, the first thing that kicks in, so I think that was, I was in denial for a long, long time. And I think that’s what stopped me from taking meds, in addition to the meds being so strong and this, you know, the fear that was instilled in me because of what I would hear.” –Cisgender man, Age 50–55, Latino, Diagnosed with HIV in 1989

Interviewer: “Okay, and how did those initial feelings affect your seeking out health care?”

Participant: “Well…I (pause) ____ I wasn’t sick. It was a thing I was in denial for about a year or so.” -Cisgender woman, Age 50–55, Black, Diagnosed in 1990

Interviewer: “Did you feel motivated to get into health care at all or how long do you think you were in denial for?

Participant: “Uh (pause) quite a while. I mean, I, I, I believed that I had it, but it was like that I didn’t believe that I had because, you know, I felt healthy, I wasn’t sick or anything…You know, my, my CD-4 count was pretty high, you know, for a bunch of years, you know, over five hundred.” -Cisgender man, Age 40–45, Latino, Diagnosed in 1987

Participant: “I felt if I would take medications, that’s like a confirmation I do have it and I just couldn’t deal with it, I couldn’t accept it. I still can’t accept it. I have no idea where it’s from.

Interviewer: “So did your initial feelings of just total shock and sadness and confusion, did these affect your seeking out a health care provider?”

Participant: “No, it made it actually the opposite because uh, of course I went to my clinic. [My doctor] helped me kind of get through it, but I didn’t, I wasn’t taking the medication because I mostly, like I said, I didn’t want to take the medication. I started taking the medication, I lost about forty pounds in a week or two…[it was] just depressing to take medication” -Cisgender man, Age 50–55, Black, Diagnosed with HIV in 1997

Participant: “You know? So the best thing I can do was go and see how, how my vitals was. How bad, you know, how, how long, how long gone it was. It was, it was eating up my system.”

Interviewer: “Right. So your immediate reaction then was to get into health care immediately.

Participant: “Yeah, yeah.” -Cisgender man, Age 56–60, Black, Diagnosed with HIV in 1993

Interviewer: “So you said you first felt disbelief but you did get into care. What motivated you to find a doctor?”

Participant: “I see a lot of my friends pass away.” -Transgender woman, Age 50–55, Latina, Diagnosed with HIV in 1999

"Almost 4 years that I've had [HIV] and now I'm getting consistent with staying on my medications, taking them on time…but the thing is, up to this date, you know, I still feel like I haven't mentally processed that my life has changed dramatically from having this. Like I can probably no longer have kids. I fear informing people sometimes…" -Cisgender man, Age 30–35, Latino, Diagnosed with HIV in 2011

"Oh, right away I, I had to find some places to get comfort, to help me out."

Interviewer: "What do you mean by that?"

"Some medication. In those times, medication was not working…because I was afraid of taking the medication, like five, six years, and I take it on and off, on and off. And my mother passed away because of this thing too.

Interviewer: "So how long did it take you, when you first learned that you were HIV positive, to actually go and see the doctor about it, to get into HIV care? Immediately, or did you—"

"Oh immediately."

Interviewer: "Immediately."

"…I could not wait. (laughs) Yeah, yeah."

Interviewer: "Right. It was just the medication you didn't feel good about."

"(overlapping) Exactly, yeah." -Cisgender man, Age 50–55, Black, Diagnosed with HIV in 1989

Table 1.

Demographic Characteristics & Recruitment Subgroups (N=99)

		Recruitment Subgroups			
	Total Sample *n* (%)/M (SD)	**Detoxification Unit (*n*=63) *n* (%)/M (SD)**	**Sexual Health Clinics (*n*=36) *n* (%)/M (SD)**	***F*/ χ^2**	***P*[a]**
Gender Identity				N/A	.004[b]
Cisgender Men	85 (85.9)	50 (79.4)	35 (97.2)		
Cisgender Women	12 (12.1)	12 (19.1)	0 (0.0)		
Transgender Women	2 (2.0)	1 (1.6)	1 (2.8)		
Race & Ethnicity				N/A	**.001**[b]
Black/African American, Non-Hispanic	51 (50.5)	40 (63.5)	11 (30.6)		
Hispanic/Latinx, Any Race	35 (35.4)	20 (31.8)	15 (41.7)		
White, Non-Hispanic	12 (12.1)	3 (4.8)	9 (25.00)		
Other/Multiracial, Non-Hispanic	1 (1.0)	0 (0.0)	1 (2.8)		
Substance Use Disorders					
Alcohol Use Disorder	56 (56.6)	37 (58.7)	19 (52.8)	.330	.565
Cannabis Use Disorder	34 (34.3)	19 (30.2)	15 (41.7)	1.35	.246
Opioid Use Disorder	26 (26.6)	25 (39.7)	1 (2.8)	16.11	<**.001**
Stimulant Use Disorder	60 (60.6)	47 (74.6)	13 (36.1)	14.23	<**.001**
HIV Diagnosis				N/A	<**.001**[b]
≥ 2012	36 (36.4)	3 (4.8)	33 (91.7)		
< 2012	63 (63.6)	60 (95.2)	3 (8.3)		
HIV Outcomes					
Linked to Care	89 (89.9)	63 (100.0)	26 (72.2)	N/A	<**.001**[b]
Initiated Antiretroviral Therapy	76 (76.8)	59 (93.7)	17 (47.2)	27.69	<**.001**
Virally suppressed at 6-month follow-up	62 (62.62)	33 (52.4)	29 (80.6)	6.06	**.014**
Age	43.6 (13.2)	52.5 (6.0)	28.1 (6.0)	.175	<**.001**
Years of Education	13.1 (2.5)	12.1 (2.1)	14.9 (2.0)	.214	<**.001**

[a] Bold indicates P-values < .05

[b] P-values are based on Fisher's Exact Tests

Table 2.

HIV Treatment Knowledge Scale Responses (N = 99)

		Total Sample (N=99)	**Detox Unit (n=63)**	**Sexual Health Clinics (*n*=36)**		
		***n* (%)**	***n* (%)**	***n* (%)**	χ^2	***P***[a]
1. Antiretroviral medication aims to reduce or suppress the activity of the HIV virus in the body.	True	93 (93.9)	63 (100.0)	30 (83.3)	N/A	**.002**[b]
2. Taking antiretroviral medications on time helps keep the right amount of medicine in one's system	True	88 (88.9)	61 (96.8)	27 (75.0)	N/A	**.002**[b]
3. Resistance can be caused when a drug is not taken on schedule, or when doses are reduced or missed.	True	87 (87.9)	58 (92.1)	29 (80.6)	N/A	.114[b]
4. Resistance to a particular drug means that the drug is not working because the virus is no longer susceptible to it.	True	82 (82.8)	57 (90.5)	25 (69.4)	7.13	**.008**
5. If the HIV virus is resistant to one medication, then it may be resistant to others.	False	21 (21.2)	14 (22.2)	7 (19.4)	.106	.745
6. CD4 counts are used to measure immune system functioning.	True	84 (84.8)	57 (90.5)	27 (75.0)	4.27	**.039**
7. Viral load measures the amount of HIV virus in the blood.	True	93 (93.9)	62 (98.4)	31 (86.1)	N/A	**.023**[b]
8. If an HIV+ person has an undetectable amount or less than detectable level of virus, it means that person is less likely to infect someone else (Treatment as prevention [TaSP])	True	56 (56.6)	29 (46.0)	27 (75.0)	7.83	**.006**
9. Sometimes lab results say that a person's viral load is undetectable or less than detectable level. This means that there is no virus left.	False	82 (82.8)	52 (82.5)	30 (83.3)	.010	.920
10. An elevated viral load over time will lead to a decline in CD4 count.	True	72 (72.7)	51 (81.0)	21 (58.3)	5.91	**.015**
11. Taking antiretroviral therapy exactly as prescribed is likely to reduce viral load.	True	76 (76.8)	49 (77.8)	27 (75.0)	.099	.753
12. Taking antiretroviral therapy exactly as prescribed may increase CD4 count	True	76 (76.8)	57 (90.5)	19 (52.8)	18.26	<**.001**

[a] Bold indicates P-values < .05

[b] P-values are based on Fisher's Exact Tests