

Adhering to antiretroviral therapy: A qualitative analysis of motivations for and obstacles to consistent use of antiretroviral therapy in people living with HIV

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Abstract

Objectives: Based on the 2015 U.S. Centers for Disease Control and Prevention data, 40% of people living with HIV in the United States with an HIV diagnosis and 18.5% of people living with HIV in HIV care in the United States are not virally suppressed. Many HIV care clinics have implemented recommendations to improve the percentage of people living with HIV on antiretroviral therapy. To understand what more could be done, we examine patients' motivations and obstacles to maintaining adherence to antiretroviral therapy.

Methods: We conducted qualitative analysis using a qualitative description framework of in-depth interviews with people living with HIV receiving care at an urban HIV care clinic in the midwestern United States.

Results: We found that while many traditional barriers to care have been addressed by existing programs, there are key differences between those consistent with antiretroviral therapy and those inconsistent with antiretroviral therapy. In particular, self-motivation, diagnosis acceptance, treatment for depression, spiritual beliefs, perceived value of the HIV care team, and prior experience with health care distinguish these two groups. Most significantly, we found that people living with HIV consistent with antiretroviral therapy describe their main motivation as coming from themselves, whereas people living with HIV inconsistent with antiretroviral therapy more often describe their main motivation as coming from the HIV care team.

Conclusion: Our results highlight the importance of the HIV care team's encouragement of maintaining antiretroviral adherence, as well as encouraging treatment for depression.

Keywords

HIV, antiretroviral therapy, adherence, compliance

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Introduction

HIV is a chronic disease that confers virtually normal expected lifespan in persons who achieve and maintain viral suppression.¹ In addition, there is effectively no transmission of disease from people living with HIV (PLWH) who maintain viral suppression.^{1,2} With modern antiretroviral therapies (ARTs), it is believed that virtually all treatment-naïve PLWH can achieve viral suppression through daily adherence to an appropriate combination of ART.³ The proportion of PLWH in the United States *with a diagnosis* that achieved viral suppression in 2015 (most recent data available) is estimated by the U.S. Centers for Disease Control and Prevention (CDC) to be less than 60% nationwide.⁴ Improving this percentage is essential as most HIV transmissions in the United

States are now attributed to untreated HIV rather than undiagnosed HIV.⁴

With the goal of reducing the spread of HIV, in 2014 United Nations Program on HIV and AIDS (UNAIDS) announced its ambitious treatment target of “90–90–90” by

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2020 for PLWH: By 2020, 90% of all PLWH will be diagnosed, 90% of all diagnosed with HIV will be receiving ART, and 90% of PLWH on ART will be virally suppressed.⁵ According to the U.S. CDC's 2016 report, for PLWH *in HIV care* in the United States in 2015 (at least one CD4 or viral load during the year), 81.5% achieved viral suppression.⁴ ART adherence is necessary for attaining viral suppression. Thus, to achieve treatment targets, as well as improve individual health and decrease disease transmission, improving the percentage of PLWH who are adherent to ART is paramount. World-wide, using a common definition of adherence as taking at least 90% of prescribed medication, adherence to prescribed HIV medication is estimated at 62%.⁶

The World Health Organization groups factors affecting adherence to ART into three main categories: health care delivery system-related, medication-related, and individual-related.^{7,8} In an effort to help highlight and address barriers to adherence, a panel from the International Association of Physicians in AIDS Care (IAPAC) published evidence-based guidelines for improving entry and retention in care and ART adherence for PLWH.⁹ These interventions are designed to address individual-related, medication-related, and health system factors. Adherence interventions that received either a level A or B rating from IAPAC for adult PLWH include: obtain routinely self-reported adherence and monitor with pharmacy refill data; prescribe once daily and single tablet regimens if possible when starting or switching regimens; promote and educate on use of specific adherence-related tools; provide one-on-one education on ART and one-on-one adherence support; use multidisciplinary teams to educate patients; address food, housing, and transportation needs; screen, manage, and treat depression/mental illness in combination with adherence counseling. Adherence is also intimately connected to entry and retention in care and barriers affecting care retention.¹⁰⁻²³

Implementation of the IAPAC recommendations has had significant impact on the proportion of PLWH in care and on medication. As indicated in the recommendations, adherence to ART has been made easier by simplified ART regimens and medications with fewer side effects. In the United States, the Ryan White program has allowed participants to overcome cost barriers to medications and care.²⁴ The U.S. CDC has promoted an Internet-accessible campaign in English and Spanish aimed at stopping HIV stigma and promoting HIV testing, prevention, and treatment that targets both the general public and health care providers.²⁵ States and cities within the United States are also implementing their own programs, for example, New York State's 2014 "Ending the AIDS Epidemic" program is designed to decrease HIV prevalence in the state by the end of 2020 by promotion of testing, linkage, retention, treatment, and pre-exposure prophylaxis.²⁶ Yet despite these interventions (or, interventions promoted through 2016), a significant percentage of PLWH are still not virally suppressed. With the exception of

several focal successes—for example, in historical hot-spots of HIV infection such as New York City and San Francisco, rates of new HIV infection have been falling²⁷⁻²⁹—there is evidence that progress in HIV prevention in the United States may have stalled.^{30,31}

Goal

At present we have some idea of the programs that help to retain people in care and the barriers that discourage PLWH who are not retained in care. We are lacking understanding of (1) why PLWH who may face these barriers still choose to enter into care and remain on ART, (2) why others who receive HIV care at programs that have adopted the IAPAC guidelines, struggle with medication adherence. *The primary goal of this current study was to uncover additional intervention targets by understanding what motivates PLWH receiving HIV care to be consistent with their medication, and how this group of PLWH compares to and differs from those who are not consistent with their medication but are still engaged in HIV care.* We were also interested in understanding how well other barriers to care have been addressed and the different experiences participants had in entering care and staying in care.

Methods

Setting

Qualitative interviews exploring motivations and obstacles to entering and staying in HIV care as well as attitudes about medication adherence were completed among patients receiving care at a large safety net hospital-based HIV clinic. The HIV clinic has several programs in place to address many obstacles to care, including all the IAPAC evidence-based recommendations listed above. Of PLWH that had at least a single office visit to the HIV clinic in 2016, 80% achieved viral suppression by the end of 2016.³²

Sample, eligibility, and recruitment

Patients were eligible for the study if they were (1) currently being treated for HIV at the clinic; (2) entered HIV care at least 6 months ago; (3) within the past 30 months (so that participants would be able to adequately recollect their experiences during the time period), either (a) started HIV medication for the first time, or (b) restarted HIV care after a gap of over 1 year, or (c) have a period of over 1 month where they were not taking HIV medication regularly; (4) were born in the United States or U.S. territories; (5) have as their first language either English or Spanish; (6) were at least 18 years old; (7) were physically and mentally able to conduct a reliable, spoken interview (e.g. no diagnosis of intellectual disability, dementia, or deafness).

Participants were recruited by phone call or in person in the HIV clinic between October 10, 2017 and November 17, 2017 after a chart review determined their eligibility. Reasons for not participating included not being interested or willing, lack of time to meet, not responding to pre-arranged phone calls, or not showing up for a pre-arranged interview appointment. Study sample was both a convenience sample and a purposive sample. It was a convenience sample in that participants were patients who came to appointments (or answered their phones) and were willing to take the extra time to participate in a 30-to-60-min confidential interview to share their motivations and obstacles for entering into and staying in HIV care, without compensation. It was a purposive sample in that efforts were made to recruit participants of diverse ages and gender as well as inconsistent patients. We invited all who met criteria per our chart review and who had appointments in the clinic during the days we were available to interview to participate. However, if there were multiple people that might be in clinic at the same time, we prioritized recruitment of those patients who were from less well represented categories in our sample (e.g. inconsistent, female, transgender, Hispanic), and in particular we prioritized inconsistent participants over Consistent participants. Interviews were concluded after reaching apparent data saturation with Consistent patients. Inconsistent patients were less accessible, and thus it is less clear if saturation was reached with them. Details regarding participants who were invited but did not complete the interview, as well as those that did not meet inclusion criteria were not recorded.

Procedures

Interviews occurred either over the phone, or in a private exam room in the clinic with just interviewer and interviewee present. Only four interviews were completed by phone due to technical and logistical difficulties with conducting and recording phone interviews. All interviews were conducted by L.F., who has a PhD and was a medical student at the time of the study. Patients provided verbal informed consent prior to the interview. As part of the informed consent, patients knew the interviewer was a medical student working with A.A., a physician in the HIV clinic, and that the research was being conducted to learn about factors that motivate patients to enter and maintain HIV care. Interviews were conducted using a structured interview guide, which included the following: participant's history of HIV care and medication, motivations for entering care, reasons for stopping medications or care, challenges of living with HIV, sources of support, attitudes about and experiences with care providers and health care in general, health literacy in general and with regards to HIV, and substance use history. Interviews were audio-recorded and each participant's statements were transcribed verbatim from the audio recordings. Demographics and information regarding patient's recent HIV care history was recorded

from the patient's medical record. All study procedures were approved by the hospital Institutional Review Board (IRB), under study protocol IRB 17-00311.

Based on chart review and interview, participants were then classified into one of two groups: "Consistent" (with medication) is the set of participants that have been taking HIV medication *regularly* since they (re-)started care at least 6 months ago, or for the past 12 months if they have been in care for at least that long. "Regularly" was defined as no single break in medication adherence greater than 2 weeks, and with medication being taken most days of each week other than this single gap. Consistent use was documented in the medical record by their HIV provider, confirmed in the interview, and verified by consistently undetectable viral loads within the past year. "Inconsistent" (with medication) is the set of participants that had not been taking medication regularly throughout the past year as documented in the medical record by their HIV provider and confirmed in the interview.

Transcripts were analyzed using a qualitative description framework.³³ They were coded line-by-line using NVivo software package. Codes that overlapped significantly in labeled text were organized into broader themes derived from the data. Text with the same codes were grouped and analyzed by subthemes determined by the text to explore differences and commonalities among the two study groups "Consistent" and "Inconsistent." Demographic information was used to understand other factors that may explain differences among the two study groups. One third of interviews were coded by both investigators to ensure consistency.

Results

Demographics of study sample

Twenty-nine interviews were completed and transcribed. Nineteen participants were consistently on HIV medications for the past year, 10 were Inconsistent. There were 21 males and eight females, including one transgender female. The demographic information for our sample, along with a breakdown by group, is summarized in Table 1. While our sample's demographics are fairly balanced between both the Consistent and Inconsistent groups, the average Consistent group member is older, lives in an area of higher socio-economic status, may be more likely to have completed high school, and has been more recently diagnosed.

Findings

In this section, we discuss our findings theme-by-theme. We start with two themes in which both Consistent and Inconsistent participants had common experiences, and then move on to themes where the two groups had more differences. Commonalities existed in health-systems factors such as linkage to care and HIV-related education. Differences

Table 1. Study demographics.

N	Total	Consistent	Inconsistent
	29	19	10
Sex			
Males	21	14	7
Females	8	5	3
Race			
Black	18	12	6
White	10	7	3
Other	1	0	1
Median age (range 18–58 years)	33	35	30
Ethnicity			
Hispanic	3	2	1
Non-Hispanic	26	17	9
Sexual orientation			
Gay	16	11	5
Straight	9	6	3
Bisexual	2	0	2
Undisclosed	2	2	0
Median household income in the patient's zip code^a			
<US\$30,000	14	8	6
US\$30,000–US\$60,000	15	11	4
Insurance source			
Medicaid	19	12	7
Medicare	2	2	0
Ryan White	3	2	1
Job-associated ^b	4	3	1
None	1	0	1
Time since diagnosis^c			
≤30 months	13	11	2
>30 months	16	8	8
Education			
<12 years	4	0	4
High school graduate	14	12	2
Unknown	11	7	4

^aBased on 2010 Census data.

^bJob-associated=job-associated private or union insurance ± enrollment in a Financial Assistance Program or Copay Coverage Program.

^cAs of date of interview.

were found in many individual factors such as prior experiences, motivations, attitudes, and beliefs, whereas commonalities existed in perceptions of others beliefs. We break this down according to theme in what follows.

Linkage to care

One of the changes in HIV care over the years has been an increased emphasis on screening and on providing social and medical support to ensure prompt linkage to care and retention in care. Thus, the year of diagnosis may have an impact on how quickly PLWH enter and engage with care. Our interview guide included open-ended questions that asked how people learned of their diagnosis and entered (or re-entered care). However, for participants who entered

care initially a while ago, we did not pursue linkage-to-care aspect of the interview in detail. We made this decision due both to the unclear relevance to our study of recent medication adherence, and also to the difficulty participants may have in remembering accurately events of the distant past.

As revealed in interviews and confirmed by the medical record (when possible) most of the participants in both groups of our study had prompt linkage to care. All 14 participants who received their initial diagnosis within the past 30 months engaged in care within 2 months of diagnosis. We had inconsistently thorough or incomplete information for remaining participants. Regardless of the date of diagnosis, there did not seem to be distinguishing aspects among the Consistent and Inconsistent groups.

Acceptance of medication effectiveness. Almost all of the patients we interviewed in both groups accepted the effectiveness of ART. One of the participants with better understanding of the medication expressed their acceptance as follows (Data excerpts are labeled by participant's number, study group, gender identity, and age at or below versus above median 33.)

Cause they suppress the HIV virus, so the body can make its white blood counts to fight off viruses that otherwise it wouldn't be able to fight off infections. (#05, Consistent male >33)

Although others did not have much of an idea of what the medication does, they trusted their doctor or the information they received about ART to conclude that it would keep them healthy,

I just trust that doctors go to school for seven or I don't know how many years, an' I know nothin' about it, so, I mean basics. They know what they're doin' and I believe that. (#29, Consistent male >33)

Prior experience with the health care system. One obstacle to medication adherence may be a lack of familiarity and experience in working with the health care system. For example, this can be reflected in difficulties filling prescriptions, taking medications, or maintaining health insurance. For that reason, we asked participants about their prior experience with the health care system. About half of the people we interviewed did not have consistent health care in the years prior to their HIV diagnosis

I wasn't really in medical treatment before I met [my HIV doctor]. For years . . . I just didn't need it, I didn't think. I was on drugs and didn't care about anything else. (#02, Consistent female ≤33)

I didn't even think about 'em or barely came to a doctor's appointment or anything before I found out I was sick. It was more or less, "I'll see you when I see you." (#23, Inconsistent female >33)

Among PLWH consistent with ART, roughly half had regular health care before their HIV diagnosis, either through a relationship with a primary care provider or due to having another chronic condition prior to HIV diagnosis

I've been in and out since I was a little kid, since of having asthma on top of it. . . Usually, numerous times a year being in a hospital because of an asthma attack. I mean, I've always been inside of hospitals . . . I feel that being in and out of a hospital so much, I've realized being in it so many times and still being here that it's not as bad as everyone makes it to be. (#06, Consistent male ≤ 33)

Among those inconsistent with ART, only two had an ongoing relationship with the health care system prior to diagnosis, one with primary care, another due to a chronic condition,

I came to my appointments. . . with my primary care doctor. . . when I needed to go to my appointments. I didn't feel like I had a relationship with any of my doctors or anything like that before. (#21, Inconsistent male ≤ 33)

Motivations to enter and stay in care. Motivators that were common to both groups were (1) support of family members, and (2) improved physical health on ART. However, PLWH in the Consistent group were most likely to describe their motivation to stay in care and on medication as coming from themselves

I'm very active in my own health, I'm very active in my own finances. I'm very active in stuff. I need to know, I want to know. 'Cause I don't want it to be the ruling factor, let's get it under control, and we'll move on. . . They [friends, family, providers] had no role. It was all my decision to get the test, and get the action. It is my life. (#05, Consistent male > 33)

I wanted to live. And I didn't want to look like other people that get full-blown AIDS and die and nobody cares for them, and all of that. So immediately, I went to get my numbers where they need to be, undetected and all of that. (#27, Consistent male > 33)

Compared to self-motivation, PLWH in the Inconsistent group were more likely to discuss the importance of the support they received from their HIV care provider or social worker as instrumental to their maintenance of care

Because without you guys, I don't even think I would take my medicine. Because it is just so hard, you know, waking up and knowing I gotta pop a big humungous pill. I just be like, oh my god. (#09, Inconsistent male ≤ 33)

I think it's just up to me just to stay consistent with the whole HIV care. . . The doctors are there to help, and its up to me to make the initiative. So they play a huge role too. . . if you guys get patients, just stay on 'em. It helped me so much. I almost cried [just now], omigod. It helped me so much, just stayin' on

top of me. Cause I get so all over the place, or I get spreaded so thin. . . you guys have a great team, it jus' help me so much. (#24, Inconsistent male ≤ 33)

The Consistent group did not mention HIV care providers at all as part of their motivation. Nevertheless, their motivation was often influenced by HIV education, in that they recognized the importance of having information of the diagnosis, the benefits of the medication, and the role of being undetectable in their ability to have healthy children and not infect others. Both Consistent and Inconsistent groups acknowledged the important role of the HIV care team in providing education on HIV and antiretroviral therapy.

Obstacles to care. Compared to the Consistent group, PLWH in the Inconsistent group found lack of personal initiative, depression, and medication side effects to be significant obstacles to care.

Lack of initiative. Whereas PLWH Consistent with medication often viewed themselves as self-motivated, PLWH in the Inconsistent group were more likely to see their lack of personal initiative as an obstacle to care,

I used to miss a lot of my appointments. I was very inconsistent with my health care, with my health. I just had to step my game up, you know, get healthy. (#24, Inconsistent male ≤ 33)

I get 'em filled, but then I would move away from wherever I was at, or leave 'em different places. I wasn't very consistent with anything I was doin' . . . Myself is the only challenge. (#19, Inconsistent male > 33)

Depression. Whereas both groups talk about depression as an obstacle to care, people in the Inconsistent group found that depression keeps them off medications or out of care (four cite depression as a contributing factor to being off ART and two of these for out of care, plus one more cites depression as contributing to missed appointments):

I was going through so much depression. I was thinking to myself, . . . why am I still here, why am I even botherin'. (#23, Inconsistent female > 33)

I went through a depression, so I didn't have the will to get signed up for Ryan White and go through everything that I needed to be doing to get what I needed. (#21, Inconsistent male ≤ 33)

PLWH in the Consistent group recognized the role of depression in reducing motivation and referred to it as something that may have kept them out of care in the past, or as something that needs to be overcome to stay in care: One noticed that she temporarily stopped taking her medication when she had some personal issues, but realized she needed to get back on them despite her situational depression (#26,

Consistent female ≤ 33). Another commented that he had been diagnosed with depression about a year before receiving the HIV diagnosis and had learned to cope with his feelings of depression (along with taking anti-depressant medication), so that when he received the HIV diagnosis, he was able to deal with it. He recognized the importance of dealing with the depression before tackling HIV care:

I think in the beginning, if somebody gets on the wrong path, that needs to be addressed first. Why am I feeling like this sucks, in other words. So, . . . a counselor, or maybe depression medications, . . . But until I don't accept it, it's not gonna work. 'Cause . . . "this is bulls*, I'm not going, I don't deserve this . . ." As long as I have all those feelings, it's gonna be a miserable time, even if you do it. But once I accept it, this is where I need to be, this is what I'm doin' . . . An' I think in the beginning, that's part of the treatment, even though it's not, but I think it's a chain link to get somebody's head right first. (#29, Consistent male >33)

A third Consistent participant commented that while he thought it was okay to feel sad for a few days after receiving the diagnosis, not being able to move on from that could be a problem to taking care of your HIV (#25, Consistent male ≤ 33). A fourth Consistent participant recognized that part of his reasons for being off medication in the past was when he was "going through some deep s*" but that now that he has "things to live for," he is motivated to stay on medication (#10, Consistent male >33). Along the lines of recognizing that depression could be an obstacle and is something that should be dealt with, four of the participants in the Consistent group were meeting regularly with therapists at the time of the interview, while no one in the Inconsistent group was doing so.

Side effects. Both groups recognized side effects as a barrier, but PLWH in the Consistent group were more likely to report no side effects, or only in the beginning, or come up with a change in medication or medication routine to reduce the side effects they experienced. On the contrary, several PLWH in the Inconsistent group complained of side effects including vomiting that prevented them from taking their medication regularly. It was harder for participants in the Inconsistent group experiencing side effects to stay on medications long enough to get over the initial side effects, as they often did not take the medications on consecutive days:

They started me on Stribild. It wasn't helpin' but it was partly my fault, because I would take one every now and then. I didn't want to take "em daily. But then the medicine was makin' me sick too. I was pukin' a lot and still fightin' with depression. I didn't wanna be on those medicines either. (#23, Inconsistent female >33)

The above statement highlights that denial, depression, and side effects combined can be a potent obstacle. The level

to which patients allowed these factors to affect them may depend much on their attitude toward having HIV.

Attitude toward having HIV. PLWH in the Inconsistent group were much more likely to talk about the struggle of denial versus acceptance and some of them admit they are still in denial

It's hard for me to believe that I got the condition. It's really hard for me to accept it. I jus' wanna live life, and normal, and not act like its there. . . . I'm in denial with it. I don' wanna believe it. . . . It [the medication] is for somethin' that I didn't aks for it, that should never happened to me or nobody else, . . . (#28, Inconsistent female >33)

In contrast, PLWH in the Consistent group talk about positive thinking, or acceptance

In a way, it's a good thing that I've gotten it. I've seen the good and the bad out of the situation. I've seen that 'cause now I'm more aware of what I consume in my body, and what I want to do live a healthier lifestyle that I didn't do prior to my diagnosis. I didn't do. Now, everything is kinda switched up in that way. Its kinda good. (#08, Consistent male >33)

A few people in the Consistent group do mention not wanting to think about HIV, just take the medicine, but no one talks about being in denial

I don't necessarily have any coping strategies. I don't necessarily think that I need some, because I lead a regular life and I'm doin' other stuff, so its not like I spend an excessive amount of time dwelling on it. I know its there. I know its something I can't change, so, move on! (#26, Consistent female ≤ 33)

Perception of other's beliefs regarding HIV. It has long been thought that stigma could have a negative effect on treatment adherence. Indeed, several recent systematic reviews have argued that the research on this question points more often toward an association between HIV-related stigma and decreased adherence,^{34,35} possibly through mediators of increased depression and reduction of self-efficacy for pill taking.

We did not ask specifically about stigma associated with PLWH nor participants' perceptions of other's beliefs, but this frequently came up in response to other questions, such as "What challenges have you had in living with HIV?" or to questions about disclosure. We did not perceive large differences between Consistent and Inconsistent participants regarding perception of stigma nor major differences in disclosure behavior—a manifestation of stigma. Members of both groups talked about public misconceptions about HIV infectivity, and implied judgment of the type of person who gets HIV. A consistent message from most PLWH is that they still feel a lack of acceptance from some parts of society

More of an acceptance from society . . . its . . . having to let other people know and deal with the backlash from that is more so what makes people live in stealth as far as being HIV positive goes. (#26, Consistent female ≤33)

I wasn't sure if anyone else would accept me. If I'd ever be able to get remarried, if anyone would love me with this virus, how my kids. . . everything. It's pretty much how everyone will look at you, accept you. It's very hard. It's still a challenge. (#07, Consistent female >33)

I find that people are very malicious and mean and don't always have the best intention. So it kinda makes me not want to tell no one. . . . people still don't know, still think it's just a death sentence, think you can get it from touchin' someone. (#13, Inconsistent male >33)

Only two participants directly linked delay to care or challenges with adherence to stigma, one from each group. The following quote from a Consistent member illustrates how non-disclosure is an active effort, that may itself require self-motivation to maintain

My environment is not conducive for me to keep poppin' pills. We have a very close-knit family . . . My medicine is stored there, inside my personal cosmetic bag. So they're there, but the box those pills come in, one box has just been delivered, . . . and people are lookin' at it like "What's . . . in there? Why is your name on it?" And I have to lie about that. . . . God forbid, something happens to me and somebody decides to open the box up, google the pills, or go in my cosmetic bag and see the pills, or the pills that are out of the box that are in my little container, those are in my luggage, on the side of my luggage. I push all my clothes and pack the luggage a certain way so they don't get exposed. (#27, Consistent male >33)

The idea of concealment as being an active strategy is put forth in a recent qualitative study aimed at understanding how stigma management strategies might disrupt treatment adherence.³⁶ If we link ability to maintain an active strategy with self-efficacy, this could also explain our otherwise puzzling finding that the four participants who did not disclose to anybody other than providers and partners are all in the Consistent group.

Religious beliefs. Religious beliefs was not a topic our interview explored specifically, yet nine PLWH brought it into the discussion in some respect, five in the Consistent group and four in the Inconsistent group. All five from the Consistent group talk about the role of prayer, and the implied message is prayer as a form of asking for assistance:

I pray and I ask Him to help me get through this. (#07, Consistent female >33)

In contrast, no one in the Inconsistent group mentions prayer. Instead they mention God as controlling fate:

"God won't let me go through anything I can't handle." (#13, Inconsistent male >33)

"I had a thought that maybe God was really just gonna make it just disappear." (#23, Inconsistent female >33)

Discussion

In this study, we look at what distinguishes people who are Consistent with their ART versus people who are Inconsistent, in light of the fact that many people in both groups may face similar obstacles in terms of socioeconomic status, depression, and side effects. Among the patients interviewed, we found that many of the recognized barriers to HIV care and medication adherence have likely been addressed successfully by existing linkage programs, well trained and compassionate staff, initial and continuing patient education on HIV and ART, and supportive services including health care coverage assistance. Thus, our study suggests that some previous barriers to increasing the percentage of PLWH achieving viral suppression are effectively targeted by programs that are now in place.

We found that what distinguished patients who are Consistent with their ART from those who are Inconsistent were patient-reported motivations and attitudes. Some of this may be connected to lack of experience with the health care system prior to HIV diagnosis (more common among Inconsistent participants than Consistent) as well as level of education, as these are two of the main demographic differences among our participant groups. While the remainder of our sample's demographics are fairly balanced between both the Consistent and Inconsistent groups, the average Consistent group member is older, lives in an area of higher socio-economic status, and has been more recently diagnosed. Many of these factors have been associated as correlated with higher adherence³⁷ and some may also be correlated with self-motivation.

A main distinction that we found between the Consistent group and the Inconsistent group was their motivations for entering into and staying in care. PLWH in the Consistent group were much more likely to claim that they or their health was their main motivator; whereas PLWH in the Inconsistent group more often talked about the importance of their interaction with their HIV care professionals as motivating them to come to appointments and take their medicine. Along with this, PLWH in the Inconsistent group described as obstacles to treatment incidents that illustrated their own lack of follow-through, and recognized their role in their treatment-failure.

This contrast of self-motivation shows up again in attitudes toward depression and perhaps also side effects. Participants in the Inconsistent group were more likely to find depression to be an obstacle to their consistent medication use. Participants in the Consistent group realized that depression could be an obstacle, but they were more active in recognizing and dealing with their depression, and not

letting it stand in the way of their HIV care for long. Some participants may have struggled with depression and falling out of care in the past but at the time of our study were on track with treatment for both their mental illness and their HIV. Participants in the Inconsistent group were more likely to find side effects to be an obstacle to consistent medication use. It is hard to determine if some people in the Inconsistent group are in that group because they experienced worse side effects, or if their perception of the side effects was influenced by other determinants, for example, a lack of will to follow through with the medication or reduced capacity to find a way to overcome side effects. While some participants in the Consistent group also had side effects, they tried out different medications or medication routines to minimize the side effects and thus make them tolerable.

Similarly, we saw a difference in attitudes toward having HIV. PLWH in the Inconsistent group were more likely to struggle with denial; whereas PLWH in the Consistent group talk about positive thinking, and the importance of accepting it, dealing with it, and moving on. Religious attitudes also differed between the two groups. Consistent participants who brought up religion all talked about the role of prayer in learning to live with HIV. On the contrary, no Inconsistent participant mentioned prayer, and instead Inconsistent members were more likely to either express their belief that God controlled their fate. One interpretation is that Consistent participants sought help in moving on, whereas inconsistent participants expressed powerlessness. Together, these findings about self-motivation, acceptance, and religious attitudes point to the important role of patients' attitudes in the role of successful HIV treatment. Notably, both groups perceived stigma associated with living with HIV, so that this did not differentiate Inconsistent from Consistent behavior.

Prior research has linked medication adherence to self-motivation and diagnosis acceptance and found inverse relationship with fatalistic beliefs. Similar to work by Norman et al.,³⁸ patients we interviewed who were Inconsistent with medications reported ideas consistent with an external or chance locus of control. In addition, we find that self-motivation to adhere and active coping styles have a positive correlation with adherence, as also noted by Finocchiaro-Kessler et al.³⁹ As with Brown et al, we observe optimal adherence linked to greater adherence self-efficacy and personal beliefs of necessary high levels of adherence.⁴⁰ Like Diiorio et al.,⁴¹ we see a link between adherence and both self-efficacy and depression. Interestingly, a 2014 meta-analysis that considers many of the above, plus work that has focused on populations in other countries, finds that the primary predictor/correlate of adherence to be adherence self-efficacy,⁴² which is similar to our own main finding and related to other work on HIV adherence.^{43,44}

Limitations

Our study sample was a both a convenience sample and a purposeful sample. It was a convenience sample in that

participants were patients who came to appointments (or answered their phones) and took extra time to participate in a 30-to-60-min confidential interview to share their motivations and obstacles for entering into and staying in HIV care, without compensation. So, our sample likely reflects a bias toward patients who have sufficient trust and regard in their HIV care providers to agree to take the extra time to contribute to this study. Our sample size is also relatively small, so it also may not be representative of PLWH receiving HIV care for reasons of pure chance.

Implications and further study

Our main goal with this study was to understand what else could be done to improve adherence to ART, so that limited resources can be aimed at reaching or surpassing the UNAIDS "90–90–90" treatment target, and thereby improve the health of PLWH and reduce the spread of HIV. We have identified several differences that distinguish PLWH who are Consistent with ART versus those who are Inconsistent. An important next step is to translate our findings into an assessment tool to better identify patients at risk for inconsistency and design effective interventions targeted to this group earlier in treatment. While assessing depression, motivation, self-efficacy, denial, and spiritual beliefs are not new ideas to helping guide patients with behavior change in general, the combination and emphasis may be something that can modified in initial and follow-up HIV counseling sessions to help PLWH reach medication adherence more often and earlier. Our analysis suggests that in addition to programs already in place, a combination of screening questions and education could help target PLWH at higher risk of inconsistent medication use. Some specific directions this study points to are understanding an ongoing relationship with primary care provider or chronic disease provider as a positive predictor of adherence, assessing self-motivation and self-efficacy for adherence, screening for depression and educating patients on the impact of treatment for depression on adherence, educating about possible side effects and their likely temporary nature if adherent, screening for acceptance versus denial of HIV infection or attitudes about having HIV, and assessing religious beliefs and practices especially with regard to prayer and God locus of control.

Conclusion

Advances in HIV diagnosis and linkage to care have greatly increased the proportion of PLWH who receive care. Improvements in medication regimens and side effects have helped increase ART adherence. Yet despite this, still 42% of PLWH who have received a diagnosis and 20% of PLWH in care are not virally suppressed. In conjunction with support from Medicaid and Ryan White, HIV clinics around the nation have implemented a sequence of recommendations to help improve the percentage of PLWH in care and on medication. We find that many traditional barriers to care have

been addressed by existing programs, but there are still key differences between those Consistent with ART and those Inconsistent with ART. In particular, self-motivation, diagnosis acceptance, involvement in treatment for depression, spiritual beliefs, perceived value of the HIV care team, and prior experience with health care distinguish these two groups. We hope that our findings can be used to target interventions to PLWH entering care who are at increased risk for inconsistent adherence.

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Ethical approval

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Informed consent

Verbal informed consent was obtained from all subjects before the study. We used verbal consent because some of the interviews were conducted by phone and we sought to make the consent process uniform for all participants. This method of obtaining informed consent was approved by our IRB.

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Supplemental material

Supplemental material for this article is available online.

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