Published in final edited form as:

Behav Med. 2020 ; 46(1): 75–85. doi:10.1080/08964289.2019.1570070.

Resilience and beliefs in the effectiveness of current antiretroviral therapies among recently disengaged low-income people of color living with HIV

J. Jaiswal^{1,2,3}, S.N. Singer^{1,4}, H-K Lekas^{5,6}

¹Center for Health, Identity, Behavior and Prevention Studies, New York University

²Department of Social and Behavioral Sciences, College of Global Public Health, New York University

³Center for Interdisciplinary Research on AIDS, Yale University School of Public Health

⁴Graduate School of Applied and Professional Psychology, Rutgers University

⁵Division of Social Solutions and Services Research, Nathan Kline Institute for Psychiatric Research, State of New York Office of Mental Health

⁶Department of Psychiatry, School of Medicine, New York University

Abstract

Consistent antiretroviral adherence is key to viral suppression, but many low-income people of color living with HIV are not optimally adherent due to a wide variety of interrelated social and structural factors. Previous studies have found that HIV medication beliefs are an important facet of adherence. In contrast to the AZT era, currently available antiretroviral therapies are significantly safer and more effective, but research suggests that negative beliefs may persist among racial and ethnic minority people. Twenty-seven semi-structured interviews were conducted with low-income Black and Latinx people living with HIV in New York City that were currently, or had been recently, disengaged from outpatient HIV medical care. This research suggests that socially- and economically-marginalized people living with HIV, many long-term survivors who lived through the AZT era, recognized that current treatments are very effective in making HIV a chronic, manageable illness and a significant improvement compared to the therapies early in the epidemic. Most importantly, the data suggests that people demonstrate great resilience despite their experiences of social and economic exclusion. Both clinical practice and public health interventions can benefit from these findings. HIV care providers should speak with patients about their beliefs related to HIV medication, and public health interventions should specifically address HIV medication-related beliefs in order to enhance adherence. In order to avoid reifying people's marginalization, public health should endeavor to recognize and support people's resilience.

Keywords

ART beliefs; HIV care; ART adherence; HIV medication; resilience

Background and significance

The HIV treatment cascade, also commonly referred to as the HIV care continuum, comprises the sequential steps of HIV medical care, including diagnosis, linkage to care, being retained in care, adhering to treatment and ultimately, viral suppression. As of 2014, there were an estimated 1.1 million people living with HIV in the United States; of these, 85% had been diagnosed, and only 49% had achieved viral suppression¹⁻³. Consistent antiretroviral therapy (ART) adherence is a critical step of the care continuum⁴. Poor adherence can result in numerous negative outcomes, including excess morbidity and mortality, and increased likelihood of transmitting HIV to sexual or drug using partners⁵.

The most recent analyses show that racial and ethnic minority groups fare worse at every phase of the care continuum. In 2014, Black and Latinx people were less likely than White people to be diagnosed, to be engaged in care, and to be virally suppressed. Among some subgroups of sexual minority men, the disparity seems to be increasing; between 2010-2014, while new HIV diagnoses in Black and White sexual minority men remained stable, new HIV diagnoses increased 14% among Latinx sexual minority men⁶. Similarly, groups with lower socioeconomic status living with HIV also tended to have disproportionately higher rates of being undiagnosed, disengaged from care, and not virally suppressed⁷.

There is a wealth of literature that elucidates the contributors to these HIV-related health disparities among both racial and ethnic minority people and low-income people. Socioeconomic factors, including housing instability and homelessness, insurance status, and income, have been explored in depth as drivers of HIV-related health disparities. In a 2013 study that examined disparities in engagement in HIV care and viral suppression among people living with HIV (PLWH) in San Francisco, socioeconomic factors, including lack of insurance and unstable housing, were significantly associated with being disengaged from care and not virally suppressed. Indeed, these socioeconomic factors were more salient in accounting for the disparities than gender or race and ethnicity⁸. Similarly, stigma has been conceptualized as a social determinant of health⁹, and the deleterious effects of HIV stigma has been extensively documented¹⁰⁻¹³. Perceived stigma from providers among both low-income people and racial and ethnic minority PLWH has a significant adverse impact across the HIV care continuum¹⁴⁻¹⁸.

In addition to structural inequality, treatment beliefs – specifically the belief that HIV medications enhance health – have been shown to significantly increase adherence rates¹⁹⁻²¹. Concerns related to HIV treatment have been shown to undermine adherence^{20,22}, as well as mediate fears about medication side effects²¹. Research has also found that people's beliefs about antiretroviral treatment (ART) have become more positive over time. Prior to 1996 and the advent of highly active antiretroviral treatment (HAART), HIV treatment regimens, often referred to as treatments of the “AZT era” or the “pre-HAART era”, entailed

complex pill schedules and high numbers of pills. Moreover, these complex combinations were less tolerable due to severe side effects and therefore, less effective²³.

Currently, PLWH have a choice of several effective treatments, including one-pill-a-day options²⁴. These dramatic improvements have increased the quality and longevity of life for people living with the disease, and have thus greatly improved the long-term management of the illness²⁵. However, concerns about HIV medications persist, perhaps particularly among people of color. For example, Schrimshaw and colleagues (2005)²⁶ explored attitudes toward antiretroviral medication among two samples of women; those who lived in the AZT-era and those who lived in the HAART-era. Women living in the AZT-era overwhelmingly held negative beliefs towards antiretroviral medications, deeming them ineffective and with unmanageable side effects. Women living in the HAART-era, with the exception of African-American women who still held negative beliefs about antiretroviral medications, were more likely to believe that medications were effective with manageable side effects²⁶. More recent literature suggests that negative ART beliefs continue to persist, particularly among people of color²⁷⁻²⁹. These findings suggest that although these days many people hold positive beliefs about ART, racial and ethnic minority people in particular may have persistent negative beliefs and perceptions about the effectiveness and safety of current HIV therapies.

Overall, the literature suggests that a range of factors, both interpersonal and structural, shape the environments in which people live and make decisions around their health. Despite what we know about the facilitators and barriers to linking and remaining engaged in HIV care and becoming virally suppressed, inequalities persist that make it difficult for people to manage their health. Applying a socio-ecological framework allows for a multi-level consideration of the experiences of this population and can provide a context in which to understand their challenges in re-engaging in care, as well as their resilience and desire to become healthier. Specifically, a socio-ecological lens enables us to consider how multiple, interrelated distal and proximal factors shape how people take care of their health. For low-income racial and ethnic minority PLWH, the role of structural inequalities is particularly salient as these inequalities are mutually reinforced by interlocking stigmas³⁰ associated with being HIV positive, poor, unstably housed, and/or substance-using.

The study presented here also seeks to demonstrate how the HIV medication beliefs and experiences of socially marginalized groups, in this case, low-income people of color disengaged or inconsistently engaged in HIV care, reveal their resilience and desire to take care of their health, even in the context of extreme structural inequality.

Methods

Sample study population and recruitment

From July 2015 to May 2016, in-depth interviews were conducted with 27 Black and Latinx PLWH living in the New York City area. The study presented here utilized a purposive sample from a larger parent study examining disengagement from HIV care. This sample is unique because participants were disengaged at the time of the interview, or were precariously or very recently re-engaged after a prolonged period of disengagement. The parent study recruited adult individuals (age 21 and older) who were hospitalized overnight

or longer at the university hospital for their poorly controlled HIV. Disengagement from HIV care was assessed in several ways using criteria based on the literature and clinical gold standards^{31,32}. To be eligible for the study, the individual had to: 1) self-identify as non-Hispanic Black or Latinx (of any race); 2) self-identify as HIV-positive; 3) be confirmed as HIV-positive based on medical record; 4) report having been diagnosed with HIV for at least two years; 5) most recent CD4 cell count under 350. To be deemed disengaged and eligible, the individual also had to: 6a) have not been to an outpatient HIV scheduled visit for the past 6 months, or 6b) have missed at least one scheduled outpatient HIV visit and was not taking HIV medication prior to hospitalization, or 6c) have not attended two or more outpatient HIV scheduled visits in the past 12 months that were separated by three months or longer. Since their HIV diagnosis, participants had attended a wide variety of HIV care settings across the five boroughs of New York City, and thus their interviews represent their experiences from many different clinic settings.

The purpose of the study presented here was to contact parent study participants a year or more after their participation in the parent study to follow up with them about how they were managing their HIV. Thus, at the time of the study described here, participants had been disengaged from HIV care within the previous one to three years, depending on when they were reached by the research team. Overall, the team attempted to contact approximately 100 individuals using contact information that participants provided during the parent study. However, it was very difficult to follow up with most participants given their infrequent engagement with the healthcare system and the high mortality rate of this population. The first author utilized various HIPAA-compliant strategies to maximize the chances of locating these individuals, including contacting case managers and social workers, as well as contacting friends and family using information provided by the participant during the parent study for the specific purpose of following up for research. Though the intention was to follow up within six to nine months after the initial parent interview, it often took 12 to 24 months to locate the participants for a follow-up interview. In addition, the research team worked closely with the university hospital's patient coordinator to monitor new in-patient admissions for participants lost to follow-up. Of the total 33 individuals successfully contacted, 27 agreed to participate in the study presented here. Two individuals declined to participate, citing lack of time. One individual agreed to participate but was found to be not mentally competent enough to provide consent. The remaining three were initially reached via telephone, but their numbers were disconnected before an interview could be scheduled. Participants signed an informed consent document for the study presented, and were compensated \$50 for their participation. The Institutional Review Board of Columbia University approved this study.

Data collection

In-depth qualitative interviews can generate novel insights by enabling participants to express their ideas, experiences and beliefs in an open-ended manner, and in their own words^{33,34}. A semi-structured interview guide was developed to broadly explore participants' experiences with HIV care, including their experiences with medical providers, experiences and beliefs related to ART, and any potential barriers and facilitators they faced in engaging in outpatient HIV care. Prior to the qualitative interview, a five-to-eight minute

interviewer-administered survey collected participants' sociodemographic data. After the survey, the first author, trained in qualitative methods, conducted the in-depth interviews using the interview guide. Interviews lasted between 25 minutes and two hours, with an average of 45 minutes. Interviews that lasted a shorter amount of time were largely due to participant fatigue associated with poor health. Thematic saturation was reached at 25 interviews³⁵, and two additional interviews were completed to confirm saturation (total n=27).

Data analysis

In-depth interviews were audio recorded and transcribed by a professional transcription service. Of the 27 interviews, 20% were randomly selected for quality control and accuracy purposes. To ensure the integrity of the qualitative data, the researcher implemented a multi-step method of identifying, contextualizing, and analyzing the themes. This included developing a coding scheme, applying it to the data, and using it to discern patterns, themes and subcategories. The scheme was a hierarchically organized tool that ranged from the general and abstract to the more specific. After all transcripts were coded, text segments were organized by codes/subcodes and were extracted and closely read in order to begin identifying a higher level of abstraction in regard to themes, and to also discern the relationship among codes. Analyses were closely reviewed by the first and last authors, as well as two researchers external to the project, to address any differences in interpretation and confirm themes. Specifically, the authors employed multiple strategies to establish trustworthiness, including credibility and confirmability, in the analysis³⁶. The research team engaged in memo-ing exercises, peer debriefing and engaged in periodic external audits with researchers who were not involved in the study³⁶. All qualitative data was organized using Atlas.ti. Quantitative data was analyzed using SPSS. To protect confidentiality, participants' names were changed.

Results

Sociodemographic characteristics

Of the 27 participants, 59% were female (n=16), and 41% were male (n=11). Participants ranged in age from 28-55 years old. The majority was non-Hispanic Black (78%, n=21) and 22% were Latinx (n=6). The majority (89%, n=24) reported being unemployed at the time of the interview, and all participants had Medicaid. Most (93%) reported that they lived in public assistance-funded apartments, housing supported by the New York City-funded HIV/AIDS Services Administration (HASA), or in temporary housing (e.g., single room occupancy housing, SROs). More than a quarter of the sample (30%) considered themselves homeless (although homelessness was defined to participants as "not having a place to sleep at night," many participants who were living in SROs also reported that they were homeless. Thus, the percentages add up to more than 100%).

Qualitative findings:

The data revealed two main themes that speak to participants' desire to survive and manage their HIV. First, participants recognized and believed in the effectiveness of current

antiretroviral therapies. As many of the participants were long-term survivors of HIV, it was common for people to contrast the AZT era therapies with current, more effective and safer treatment options. Second, participants articulated their desire to live and survive after experiencing extensive social and economic exclusion, thus demonstrating their resilience.

Theme 1: *The Effectiveness of Current Therapies*

The majority of participants in this study had previously taken ART, either consistently or inconsistently, at some period in their lives; only a few had recently begun taking HIV medication for the first time. Many of the participants were long-term survivors, having lived with HIV for one to two decades, or longer. Notably, all expressed an active commitment to remaining adherent to their ART regimens, or if still disengaged or not on ART, a strong desire to re-start HIV medication. Specifically, all participants shared the belief that ART provided them with the opportunity to live a longer, healthier life, and that without it, they would die. Although a few participants had managed to successfully re-engage in outpatient HIV care after periods of disengagement and/or non-adherence, many were still in the process of re-engaging or re-starting an ART regimen at the time of the study presented here.

The data presented below explore how people, some of whom personally experienced or witnessed AZT-related suffering, were able to clearly differentiate the often toxic and ineffective treatments of the past from the current classes of ART. Thus, many participants contrasted AZT-era medication with newer, more effective and less toxic classes of HIV medication. For example, Luis, a 55-year-old Latinx man, was diagnosed in 1988. At the time of the interview, he was preparing to leave his nursing facility of two years to move into a single room occupancy housing until HASA could help him find an apartment. Luis decided to re-start HIV medication two years prior to the interview, after a decade of not taking HIV medication. He decided to re-start medication when he became extremely ill with multiple bouts of pneumocystis carinii pneumonia. He recounted his frightening experiences with AZT, which led him to delay re-starting a regimen for a decade:

It almost killed me, the AZT. What happened was, after that, I stopped taking the meds. I became afraid of the pills. The counselors, everybody, the case managers, case workers—everybody said, finally, “you gotta take it. Your t cells are real low.” The doctors were telling me, and I’m like, “I’m not taking it no matter what. I’m not taking it. It almost killed me.” ...I became fearful of those pills, man. So eventually, I grew over the fear. I said, let me try it again.... today, people are living much longer with the virus. It’s not—I don’t see it as a death sentence no more. I don’t. The Center[s] for Disease Control said, it’s a chronic illness...I believe that too. It’s a chronic illness. Even though I still feel people are dying, but the extension of life has been prolonged because of the medication...I feel that due to the fact that people are living a lot longer with the virus, that they should take the medications. [Luis]

CeeCee, a 48-year-old Black woman, was diagnosed in 2006. Her viral load was undetectable and she reported having taken ART consistently for one year at the time of the interview. She also reported previously struggling with alcohol and cocaine use and

sometimes selling her HIV medication to pay for cocaine, which contributed to her difficulty staying consistently engaged in care and adhering to treatment. CeeCee explained how earlier classes of HIV medication and issues related to ART resistance frightened her:

It was scary, sad. Then, a lot of my friends died because a lot of the people get resistant. When you're resistant, none of the medicine works. That's the last stages of HIV. Nobody wants to go there. [Laughter] I was really scared. Another thing with my kidneys being bad, some of the medicine weren't working. When they got this regimen that I'm on now, and it works, and it's not botherin' 'em, so I'm runnin' with it. I wanna take it... I don't wanna get resistant, and I don't want my T-cells to go low. [CeeCee]

Tanya, a 40-year-old Black woman, was diagnosed in 1993. For the eight months prior to the interview, she had been sober and had not relapsed due to her participation in a drug treatment program for her crack use. Although she still "occasionally" missed a pill or an appointment, she reported that she was taking her medication regularly, and that stopping her substance use made it possible for her to become engaged in care again. She was blunt in her assessment of the importance of taking ART:

If you wanna live, just take your meds. If you don't wanna live, then—you ain't gonna live if you don't take your meds. You have to take your meds. You have to. [Tanya]

Sandra, a 42-year-old Black woman, diagnosed in 1993, was undetectable and adherent at the time of the interview. She had switched providers due to moving apartments in the past few months, but was able to remain on ART consistently. Prior to re-starting ART two years prior to the interview, her Medicaid had lapsed and she stopped taking her medication. She expressed gratitude that more effective and safe medications were now available:

I don't wanna die, and I know that if I don't take the medications, that complications will build up in my body, and I'll pass away. That much, I do know. I know that medication, it's not gonna stop it, but it'll slow it up... medication, it's helpin' me... I would say, prolongin' my life. I know someday, I am gonna pass away, but it's not today. I'm really, really grateful for that because like I said before, back when people was taking AZT or when the virus first came out, people were droppin' like flies. They didn't know what was goin' on. Just to see 26 years later, I'm still here. [Sandra]

Myra, a 44-year-old Black woman who had been diagnosed in 2012, was undetectable at the time of the interview and was both engaged and adherent. Two years prior to the interview, she had become stably housed after being homeless for ten consecutive years. She attributed her ability to begin ART for the first time and manage her HIV and her health to obtaining stable housing. Like Sandra above, she expressed gratitude that her diagnosis came after the AZT era of medication:

I was told that I'm one of the lucky ones. I got diagnosed...with HIV when the medication became better. Before, 10 years before me, the medication sometimes was worse for patients than having the HIV itself. A lot of patients didn't like the medicine. They would not take it because they would feel better with HIV without.

Now the medication is much better... You have to treat it. You have to take the medicine. I learned there are a lot of patients that are not taking their medications like they're supposed to.... [I've] learned about the medicine. It works. My viral load and my CD4 count is beautiful...they're calling me a star patient over there in [my] clinic. [Myra]

Theme 2: *Resilience and desire to live*

As shown above, this sample expressed strong, positive beliefs about ART. These beliefs were expressed in the context of explaining their desire to become healthier and survive after experiencing the often-interrelated challenges of homelessness and housing instability, mental health and substance use disorders, poverty, lack of social support, stigma, and untreated HIV. As noted earlier, all participants in this sample had recently experienced, or were still experiencing, prolonged disengagement from HIV care. While some participants had successfully engaged in care and were doing quite well (e.g., Myra), most were still struggling to put the scaffolding in place to begin managing their HIV and overall health. For example, Janae, a 42-year-old Black woman, had been consistently taking ART for approximately one month at the time of the interview. She had recently started a new regimen after a period of going off ART due to experiencing severe side effects and feeling that her doctor was ignoring her concerns. Below, she explains her perspective about taking care of one's health:

...you gotta do the best thing to do to make you live for yourself, and stop listenin' to these peoples. Make sure—you gotta take care of your body. If somethin' don't work, you gotta communicate with your doctor. ... If somethin' don't work, I have to stay on that doctor's back and say, "Well, listen, this is not workin' for me. Can you help me? ... I don't wanna die.... No, you gotta take care of yourself until they find you something. That's what I did. I had to keep myself active, keep myself busy. I can't worry about a lot because once you start worryin' you gonna start losin' weight, you gonna start gettin' sick, you gonna start not carin' about yourself at all... You gotta pick up yourself... It might not be all right with you, but you gotta make it all right. [Janae]

Myra, quoted earlier, experienced extensive hardship that reflected the social and economic inequality of these participants. Specifically, she indicated she was homeless for a decade around Pennsylvania Station in New York City. During this time, she had inadequate access to healthcare, engaged in sexual risks in exchange for a place to stay, and used substances. Moving forward, Myra was adamant about improving her health. Recalling the suffering and extreme hardship while on the street, she stated being resolved to keep getting healthier:

HIV medication, psych meds, you have to be consistent with it for it to work. That's what I do. Or, you can take your benefits and go back now and then, spend your money smoking and drinking in the streets. That's how I got sick in the first place. I'm deciding I was so sick that I don't wanna do that. [Living like that] was hard. It was very painful. [Now] I'm doing well... I don't wanna not have money to eat, not have money to dress clean and warm, take the medication every day.... Not doing too much drugs and spending all the money on drugs and then stealing. I

don't wanna go that route... Feeling sick is the worst 'cause now you're too sick to take care of yourself. I'm still healing ...Even though it's still two years later I still got to get to the apartment, to the SRO. I still have to budget properly. I still have to spend money wisely. I still have to buy clean underwear every month and things like that. [Myra]

Jamal, a 36-year-old Black man, was diagnosed in 2010. At the time of the interview, he was disengaged from outpatient HIV care and not on ART. He stated that he “didn't like taking pills”, and shared that he initially stopped taking his ART due to depression about his lack of social support and stable housing as well as his substance use. Although Jamal had experienced severe illness and housing instability, he demonstrated resilience and a hope for the future. When asked why he had decided to re-start ART and antidepressants, Jamal explained:

Jamal: I'm not dead yet, and I don't want to be, even though I've probably shaved seven years off, I'm sure of it from me not takin' care of myself for so long...I'm ready to at least give it a fighting chance one more time and see what I can do to save myself. Only I'm able to do that. Nobody else is gonna do it for me. People can make all the suggestions in the world, but it takes me to go sit down and do it.

Interviewer: When you went off your medication before, what was that due to?

Jamal: ... I stopped caring, and I just wanted to shrivel up and fade away and die. Then, things started going better in my life once I started doing things for myself... [Right now] I may need somebody to call me every day. “Did you take your meds?” “Why didn't you take them? You have your keychain with your pills in it?” “No, I don't.” “You should carry your keychain with your pills in it.” You know? It might work this time. It might actually stick. Until I can get into the habit myself—it just becomes innate. In the morning, you look in your medicine cabinet—that's also a problem. I don't have a medicine cabinet right now. I have a basket with my things in it, and I have to carry them back and forth. That's what I want. In the grand scheme of things, I just wanna be settled. I'm old. I'm tired. I just wanna be settled. I want my own place, my own bathroom, a medicine cabinet. I want a refrigerator where I don't have to label the things inside of it because they're all mine. [269]

Similarly, Terrence, a 39-year-old Black man, was diagnosed in 1989 as a young teenager, but had only sought care in his early 30s, when he was diagnosed with AIDS and began ART for the first time. Terrence's doctor called him the day of the interview to let him know that he was undetectable. Like the other participants in the sample, he had also faced pervasive social and economic structural barriers that undermined his ability to take care of his health. When asked why he made the choice to re-start ART, Terrence explained:

I think it took something within myself to kinda deal with that sickness...I just kinda needed time to kinda grasp, if you will. I was in no particular rush to go back on the meds, in a way. I know I responded well when I was on, when I took 'em as I was supposed to, I responded well... I felt like I had a little time to kinda [and] deal with my other issues, whether that was syphilis or other things that—my housing. The meds just became like a whole 'nother issue, because it was almost like, “Okay.

I gotta jump through hoops at [CBO 1]. Then I don't wanna use 'em no more. I'm gonna go back to [CBO 2]. I hope I don't get that same doctor." It was a lot of uncertainty... [When I started ART again] my confidence in taking the meds again kinda were solidified again. I felt like, "Okay. I can do this now." I got my housing. Whatever I don't got, I can't think about. That's what I used to be wrapped up in before and not looking at what I do have.... I think of all that I've gained and all the positive that happened when I was on my meds... I wanted to get that back. I wanna live ultimately. Yeah, we're all gonna die, but I wanna live. [Terrence]

Like the other participants, Terrence's experiences with structural inequality did not prevent him from showing resilience and hope for the future. Luis, quoted earlier, echoed similar sentiments:

Live. Because you know what? In the end, tomorrow's not promised to nobody, you understand? I can go, and I can go to sleep tonight and not wake up. It doesn't have nothing to do with being HIV positive... The fact that tomorrow's not promised to nobody, then live each day at a time. I gotta remind myself that a lot, too, to take it one day at a time.

Do what you gotta do in order to live your life to the fullest one day at a time. If that means taking your HIV meds, then that means taking your HIV meds and whatever else you need to do in order to take care of your health [Luis]

Similarly, Jada, a 29-year-old Black woman who was born HIV positive, also showed resilience when she shared her experiences with trying to overcome her ART-related challenges. Around the time of the interview, Jada was experiencing severe kidney problems. At the time of the interview, she had been taking ART for three consecutive weeks, after multiple periods of adherence and non-adherence. She stated that she had never been able to stay undetectable long enough to be put on the kidney transplant list. Nevertheless, she planned to overcome her "psychological" barriers to taking pills in order to become consistently adherent and ultimately undetectable. Below, she articulated her resilience and her desire to persevere. When asked why she decided to restart ART three weeks prior to the interview, Jada explained:

I don't wanna die ... Going isn't hard ... I've been in the ICU, and I've been dead... The hard part is when you come back. ... You become a new self and have to figure out how to maneuver and manage your new self to be to the point where you wanna be. ... It's like I've come to my realization that I'm supposed to be here. Why not try to do the things to prolong my stay? ... If you wanna stay, then you know what you need to do. Nobody should have to tell you. ... Nobody will take care of you, like you will... It's like growing up; I wasn't supposed to see this age or that one. It's like, now, I feel like I'm the champion. All those doctors, right? ... They gave me numbers I wasn't supposed to see... 15, 17, 21, 25... Now, I'm 28. I'm goin' to 30... they all slept on me... They marked me with doubt. I didn't mark myself with doubt. I didn't let them win by accepting their doubts... In the end, they all were wrong... Now, I'm tryin' my best to do whatever it is I need to do to at least gain a few more [years]. I'm not gonna say [the doctors are] totally wrong. If I'm still

livin' the same way I was livin' then, chances are, it can happen now... I was strong enough not to let that seep in, and doubt, and weigh me down, and take me out. It helped me get strength to find an out. Now that I'm out, I need to make sure it's up to me to stay out... In a sense, like a flower. It's like a plant. Stay abloom. A new season will come, I won't die out. I'll still be abloom, like that. [Jada]

Taken together, these themes demonstrate how people can be persistent and resilient even in the context of pervasive structural inequality. In particular, these quotes reflect participants' desire to "keep going", become able to take care of themselves, and not give up hope. In this sense, this perseverance and resilience is evident in their positive ART beliefs (with many participants having had to overcome negative experiences with AZT), and their articulation of their desire to not only survive, but live.

Discussion

The population featured here is often thought of as "the weakest link" in the HIV care treatment continuum. They are indeed individuals that are marginalized by racial and socioeconomic inequalities, and are members of social groups that are often stigmatized by society: people living with HIV, people who use substances, sexual and gender minority people, and people contending with homelessness or housing instability. However, thinking about this group as the "weakest link" is problematic and serves to potentially reify people's marginalization.

These findings are important because it draws our attention to the more human side of the morbidity and mortality statistics for this population. Society often views socially and economically marginalized people as less deserving of genuine care and concern due to the nature of their bad "choices", rather than taking into account the role of social and material inequality^{37,38}. Although HIV-related disparities are indeed most pronounced among these subgroups, the data presented here suggests that people, even when facing multiple, interlocking social and structural barriers, believe that ART is an effective treatment for HIV that makes the disease chronic and manageable. Thus, while structural inequality is at the root of the hardships faced by marginalized groups, it is important to also highlight the ways in which people maintain resilience, are deeply thoughtful about their health beliefs and behaviors, and are motivated to improve the management of their health even in the context of pervasive social inequalities.

Many of the participants in this study were long-term survivors of HIV and had witnessed firsthand the suffering and deaths of their peers in the earlier stages of the epidemic, when the available HIV treatment entailed complex regimens and posed serious side effects. However, all participants in the study believed that consistent ART use makes HIV a manageable, chronic disease, and none expressed the view that ART is toxic or that ART is poison. This denotes a shift from an era earlier in the epidemic in which people sometimes described ART as toxic, or even poison meant to eliminate racial and ethnic minority groups, a sentiment that has been well documented among racial and ethnic minority people^{39,40}. This aligns with previous research that has found that treatment beliefs – specifically the

belief that HIV medications promote improved health – have been shown to significantly increase adherence rates¹⁹⁻²¹.

Most importantly, these positive beliefs, considered in the context of participants' plans and hopes for the future, signal great resilience. The concept of resilience is used to describe how people can “bounce back” even after experiencing crises, trauma or stressors⁴¹. Research has documented PLWH to be both vulnerable and resilient⁴², and resilience among people living with HIV has been well documented⁴³⁻⁴⁶. Indeed, many of this sample's participants were long-term survivors of epidemic, and previous research has found that resilience is a critical aspect of aging with HIV⁵²⁻⁵⁶. Resilience is also increasingly being used in the lesbian, gay, bisexual, transgender and queer (LGBTQ) literature as well to call attention to the strengths and resilient nature of people that often experience high levels of stress and marginalization and to provide a framework for understanding the health challenges facing these populations⁴⁷⁻⁵¹. Our findings contribute to these existing literatures on resilience by offering a window into understanding how people who are struggling with engaging in HIV care think about their own health and HIV management.

Recommendations

These findings demonstrate that it is possible to cultivate positive ART beliefs even after having traumatic experiences with HIV medication, negative experiences with healthcare providers, and more broadly, experiencing severe social and economic inequalities. More broadly, we argue that the resilience of socially marginalized groups may be under-recognized and thus needs to be directly and meaningfully incorporated into programming and interventions that work with this population. Importantly, these findings need to inform interventions for public health practitioners and clinicians as well as patients. First, beliefs around HIV medication must be addressed by providers in order to maximize the effectiveness of adherence support programs and other initiatives to improve adherence. Second, and more importantly, public health practitioners and clinicians must see beyond patient deficits that are both real and perceived and develop resilience approaches to care.

Previous research suggests that public health interventions need to specifically address HIV medication-related beliefs and concerns in order to improve ART adherence⁵⁷. This recommendation is particularly important for low-income people of color living with HIV, as previous research has found that negative beliefs about ART may persist among racial and ethnic minority people²⁷⁻²⁹. However, Kalichman and colleagues recently explored HIV medication-related beliefs as a predictor of adherence to ART in a sample of people facing multiple forms of poverty. They found that HIV medication-related beliefs were predictors of treatment adherence over and above other structural factors, and recommended adherence interventions designed for this population⁵⁸.

At the provider-patient level, HIV care providers should explicitly ask patients about their HIV medication-related beliefs. It is important that providers create a space in which patients can speak directly about their feelings and beliefs about HIV medication, which in turn can create opportunities for providers to engage patients in a discussion of the advancements in HIV treatment in the post-AZT, HAART era. Specific efforts to ask about beliefs can facilitate addressing misconceptions about the effectiveness of current ART

therapies, and strengthen patients' confidence in currently available therapies. This sample also expressed a strong desire for patient-centered care, particularly in the context of changing one's ART regimen⁵⁹. Positive experiences with HIV providers can decrease fear of HIV medication and medication-related side effects and increase motivation to begin, re-start, or consistently adhere to ART. Indeed, the literature has shown that patient-centered care and meaningful communication between patients and HIV care providers improves engagement^{59,60}. Thus, providers can support the process of changing beliefs or building new beliefs for patients who were either on AZT themselves, or witnessed friends and loved ones who suffered while taking AZT. Most importantly, these recommendations must be enacted in a context where public health practitioners and clinicians identify the resilience of their patients and make concerted efforts to enhance and support this resilient attitude⁶¹. Further research is needed to better understand how a resilience framework can specifically help re-engage populations that are inconsistently or under-engaged.

Limitations

This study is not without limitations. This study took place in New York City, where there is greater public health messaging and social and material support provided to low-income PLWH than in most other parts of the country. Thus, it may be that this sample represents individuals who have received extensive HIV-related education and support. Further research is needed to better understand the nature of ART-related beliefs and resilience of other low-income PLWH living in less urban and potentially more underserved parts of the country. Furthermore, although ART beliefs and resilience were strong emergent themes in the data, the qualitative interview guide was not specifically designed to explore how people experience resilience. Further research is needed to better understand the nuance and complexity of how resilience may affect people's ability to consistently engage in HIV care. Finally, while social desirability bias was not measured, the research team was extensively trained on how to elicit sensitive or potentially stigmatizing information.

Conclusion

In this sample, some participants had successfully become re-engaged in care and consistently adherent to their ART regimens after periods of disengagement and/or non-adherence, while most were still contending with challenges related to consistently engaging with services and adhering to treatment. However, all participants in this sample endorsed the belief that consistent ART use makes HIV a chronic, manageable illness. The data presented here, in conjunction with the broader extant literature on HIV medication beliefs, suggests that it is possible to cultivate positive beliefs about the effectiveness of more recent classes of HIV medication, even if one had experienced the fears and side effects associated with the AZT era treatment. Beyond the salience of ART beliefs, the data highlights the notion that people can experience systematic structural, social and economic inequalities and demonstrate great resilience and desire to become healthier and live meaningful lives. Public health programs and interventions seeking to improve ART adherence must integrate information and dialogue about HIV-related beliefs, particularly beliefs about HIV medications, and more pointedly, identify and cultivate the resilience of people living with HIV.

Funding acknowledgements:

The work was supported by the following NIH grants: 3R01MH095849-01S1, IMSD R25GM062454, and REIDS R25MH087217.

References

- Centers for Disease Control and Prevention. HIV Continuum of Care, U.S., 2014, Overall and by Age, Race/Ethnicity, Transmission Route and Sex. 2017; <https://www.cdc.gov/nchstp/newsroom/2017/HIV-Continuum-of-Care.html>. Accessed September 22, 2018.
- HIV.gov. HIV Care Continuum. 2018; <https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum>. Accessed September 22, 2018.
- Centers for Disease Control and Prevention. Understanding the HIV Care Continuum. 2018; <https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf>. Accessed September 22, 2018.
- Thompson MA, Mugavero MJ, Amico KR, et al. Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. *Annals of internal medicine*. 2012;156(11):817. [PubMed: 22393036]
- Giordano TP, Gifford AL, White AC Jr., et al. Retention in care: a challenge to survival with HIV infection In: *Clin Infect Dis*. Vol 44 United States 2007:1493–1499. [PubMed: 17479948]
- Centers for Disease Control and Prevention. HIV Among Hispanics/Latinos. 2018; <https://www.cdc.gov/hiv/group/raciaethnic/hispaniclatinos/index.html>. Accessed September 22, 2018.
- American Psychological Association. HIV/AIDS and Socioeconomic Status. 2018; <http://www.apa.org/pi/ses/resources/publications/hiv-aids.aspx>. Accessed September 22, 2018.
- Muthulingam D, Chin J, Hsu L, Scheer S, Schwarcz S. Disparities in engagement in care and viral suppression among persons with HIV. *J Acquir Immune Defic Syndr*. 2013;63(1):112–119. [PubMed: 23392459]
- Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;103(5):813–821. [PubMed: 23488505]
- Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003;57(1):13–24. [PubMed: 12753813]
- Grov C, Golub SA, Parsons JT, Brennan M, Karpiak SE. Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS Care*. 2010;22(5):630–639. [PubMed: 20401765]
- Golub SA, Gamarel KE. The impact of anticipated HIV stigma on delays in HIV testing behaviors: findings from a community-based sample of men who have sex with men and transgender women in New York City. *AIDS Patient Care STDS*. 2013;27(11):621–627. [PubMed: 24138486]
- Turan B, Budhwani H, Fazeli PL, et al. How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. *AIDS Behav*. 2017;21(1):283–291. [PubMed: 27272742]
- Katz IT, Ryu AE, Onuegbu AG, et al. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc*. 2013;16(3 Suppl 2):18640. [PubMed: 24242258]
- Kinsler JJ, Wong MD, Sayles JN, Davis C, Cunningham WE. The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care STDS*. 2007;21(8):584–592. [PubMed: 17711383]
- Sweeney SM, Venable PA. The Association of HIV-Related Stigma to HIV Medication Adherence: A Systematic Review and Synthesis of the Literature. *AIDS Behav*. 2016;20(1):29–50. [PubMed: 26303196]
- Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works? *J Int AIDS Soc*. 2009;12:15. [PubMed: 19660113]

18. Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med*. 2009;24(10):1101–1108. [PubMed: 19653047]
19. Surratt HL, O'Grady CL, Levi-Minzi MA, Kurtz SP. Medication adherence challenges among HIV positive substance abusers: the role of food and housing insecurity. *AIDS Care*. 2015;27(3):307–314. [PubMed: 25314042]
20. Kalichman SC, Price D, Eaton LA, et al. Diminishing Perceived Threat of AIDS and Increasing Sexual Risks of HIV Among Men Who Have Sex with Men, 1997–2015. *Arch Sex Behav*. 2017;46(4):895–902. [PubMed: 28168543]
21. Alison Phillips L, Leventhal H, Leventhal EA. Assessing theoretical predictors of long-term medication adherence: patients' treatment-related beliefs, experiential feedback and habit development. *Psychol Health*. 2013;28(10):1135–1151. [PubMed: 23627524]
22. Gonzalez JS, Penedo FJ, Llabre MM, et al. Physical symptoms, beliefs about medications, negative mood, and long-term HIV medication adherence. *Ann Behav Med*. 2007;34(1):46–55. [PubMed: 17688396]
23. Richman DD, Fischl MA, Grieco MH, et al. The toxicity of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex. A double-blind, placebo-controlled trial. *N Engl J Med*. 1987;317(4):192–197. [PubMed: 3299090]
24. Airolidi M, Zaccarelli M, Bisi L, et al. One-pill once-a-day HAART: a simplification strategy that improves adherence and quality of life of HIV-infected subjects. *Patient Prefer Adherence*. 2010;4:115–125. [PubMed: 20517472]
25. Montaner JS, Hogg R, Wood E, et al. The case for expanding access to highly active antiretroviral therapy to curb the growth of the HIV epidemic. *Lancet*. 2006;368(9534):531–536. [PubMed: 16890841]
26. Schrimshaw EW, Siegel K, Lekas HM. Changes in attitudes toward antiviral medication: a comparison of women living with HIV/AIDS in the pre-HAART and HAART Eras. *AIDS Behav*. 2005;9(3):267–279. [PubMed: 16088368]
27. Cooper V, Moyle GJ, Fisher M, et al. Beliefs about antiretroviral therapy, treatment adherence and quality of life in a 48-week randomised study of continuation of zidovudine/lamivudine or switch to tenofovir DF/emtricitabine, each with efavirenz. *AIDS Care*. 2011;23(6):705–713. [PubMed: 21476152]
28. Thrasher AD, Earp JA, Golin CE, Zimmer CR. Discrimination, distrust, and racial/ethnic disparities in antiretroviral therapy adherence among a national sample of HIV-infected patients. *J Acquir Immune Defic Syndr*. 2008;49(1):84–93. [PubMed: 18667919]
29. French T, Tesoriero J, Agins B. Changes in stress, substance use and medication beliefs are associated with changes in adherence to HIV antiretroviral therapy. *AIDS Behav*. 2011;15(7):1416–1428. [PubMed: 20640593]
30. Earnshaw VA, Bogart LM, Dovidio JF, Williams DR. Stigma and racial/ethnic HIV disparities: moving toward resilience. *Am Psychol*. 2013;68(4):225–236. [PubMed: 23688090]
31. Mugavero MJ, Davila JA, Nevin CR, Giordano TP. From access to engagement: measuring retention in outpatient HIV clinical care. *AIDS Patient Care STDS*. 2010;24(10):607–613. [PubMed: 20858055]
32. Mugavero MJ, Westfall AO, Zinski A, et al. Measuring Retention in HIV Care: The Elusive Gold Standard. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2012.
33. Patton MQ. *Qualitative research*. Wiley Online Library; 2005.
34. Strauss A, Corbin J. *Basics of qualitative research: Procedures and techniques for developing grounded theory*. In: Thousand Oaks, CA: Sage; 1998.
35. Creswell JW. *Quality Inquiry and Research Design: Choosing among Five Traditions*. Thousand Oaks, CA: Sage; 1998.
36. Lincoln YS, Guba EG. *Naturalistic inquiry*. Vol 75: Sage; 1985.
37. Cozzarelli C, Wilkinson AV, Tagler MJ, Josi. Attitudes toward the poor and attributions for poverty. 2001;57(2):207–227.
38. Handler JF, Hasenfeld Y. *Blame welfare, ignore poverty and inequality*. Cambridge University Press; 2006.

39. Bogart LM, Wagner G, Galvan FH, Banks D. Conspiracy beliefs about HIV are related to antiretroviral treatment nonadherence among African American men with HIV. *Journal of acquired immune deficiency syndromes (1999)*. 2010;53(5):648. [PubMed: 19952767]
40. Bogart LM, Wagner GJ, Green HD, et al. Medical mistrust among social network members may contribute to antiretroviral treatment nonadherence in African Americans living with HIV. *Soc Sci Med*. 2016;164:133–140. [PubMed: 27046475]
41. Boss PJGMtAJOG, Bereavement. Resilience and health. 2006;9(3):52.
42. De Santis J Exploring the concepts of vulnerability and resilience in the context of HIV infection. *Res Theory Nurs Pract*. 2008;22(4):273–287. [PubMed: 19093664]
43. Emlet CA, Tozay S, Raveis VH. “I’m not going to die from the AIDS”: resilience in aging with HIV disease. *Gerontologist*. 2011;51(1):101–111. [PubMed: 20650948]
44. Dale S, Cohen M, Weber K, Cruise R, Kelso G, Brody L. Abuse and resilience in relation to HAART medication adherence and HIV viral load among women with HIV in the United States. *AIDS Patient Care STDS*. 2014;28(3):136–143. [PubMed: 24568654]
45. Fang X, Vincent W, Calabrese SK, et al. Resilience, stress, and life quality in older adults living with HIV/AIDS. *Aging Ment Health*. 2015;19(11):1015–1021. [PubMed: 25633086]
46. De Santis JP, Florom-Smith A, Vermeesch A, Barroso S, DeLeon DA. Motivation, management, and mastery: a theory of resilience in the context of HIV infection. *J Am Psychiatr Nurses Assoc*. 2013;19(1):36–46. [PubMed: 23392433]
47. Herrick AL, Lim SH, Wei C, et al. Resilience as an untapped resource in behavioral intervention design for gay men. *AIDS Behav*. 2011;15 Suppl 1:S25–29. [PubMed: 21344306]
48. Halkitis PN. *The AIDS generation: Stories of survival and resilience*. Oxford University Press; 2013.
49. Halkitis PN, Singer SN. Chemsex and mental health as part of syndemic in gay and bisexual men. *Int J Drug Policy*. 2018;55:180–182. [PubMed: 29661572]
50. Singh AAJSR. Transgender youth of color and resilience: Negotiating oppression and finding support. 2013;68(11–12):690–702.
51. Colpitts E, Gahagan J. The utility of resilience as a conceptual framework for understanding and measuring LGBTQ health. *Int J Equity Health*. 2016;15:60. [PubMed: 27048319]
52. Garcia-Dia MJ, DiNapoli JM, Garcia-Ona L, Jakubowski R, O’Flaherty D. Concept analysis: resilience. *Arch Psychiatr Nurs*. 2013;27(6):264–270. [PubMed: 24238005]
53. Parkhurst JO. HIV prevention, structural change and social values: the need for an explicit normative approach. *J Int AIDS Soc*. 2012;15 Suppl 1:1–10.
54. Fumaz CR, Ayestaran A, Perez-Alvarez N, et al. Resilience, ageing, and quality of life in long-term diagnosed HIV-infected patients. *AIDS Care*. 2015;27(11):1396–1403. [PubMed: 26679268]
55. Hussen SA, Andes K, Gilliard D, Chakraborty R, Del Rio C, Malebranche DJ. Transition to adulthood and antiretroviral adherence among HIV-positive young Black men who have sex with men. *Am J Public Health*. 2015;105(4):725–731. [PubMed: 24922167]
56. Emlet CA, Shiu C, Kim HJ, Fredriksen-Goldsen K. Bouncing Back: Resilience and Mastery Among HIV-Positive Older Gay and Bisexual Men. *Gerontologist*. 2017;57(suppl 1):S40–S49. [PubMed: 28087794]
57. Langebeek N, Gisolf EH, Reiss P, et al. Predictors and correlates of adherence to combination antiretroviral therapy (ART) for chronic HIV infection: a meta-analysis. *BMC medicine*. 2014;12(1):142. [PubMed: 25145556]
58. Kalichman S, Kalichman MO, Cherry C. Medication beliefs and structural barriers to treatment adherence among people living with HIV infection. *Psychol Health*. 2016;31(4):383–395. [PubMed: 26534788]
59. Jaiswal J, Griffin-Tomas M, Singer SN, Lekas HM. Desire for patient-centered HIV care among inconsistently engaged racial and ethnic minority people living with HIV. *Journal of the Association of Nurses in AIDS Care*. 2018.
60. Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *Journal of acquired immune deficiency syndromes (1999)*. 2013;63(3):362. [PubMed: 23591637]

61. McAllister M, McKinnon J. The importance of teaching and learning resilience in the health disciplines: a critical review of the literature. *Nurse Educ Today*. 2009;29(4):371–379. [PubMed: 19056153]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1:**Participant Socio-Demographics**

Participants' characteristics		N
Gender	Female	16 (59%)
	Male	11 (41%)
Race & Ethnicity	Black Non-Hispanic	21 (78%)
	Hispanic / Latinx	6 (22%)
Current Housing Situation *	HASA or public assistance (apt or room)	18 (67%)
	SRO	7 (26%)
	No financial assistance	2 (7%)
	Nursing home or hospice	3 (11%)
	Homeless	8 (30%)
Health Insurance	Medicaid	25 (93%)
	Medicaid + Medicare	2 (7%)

* Note: Adds up to more than 100% because some participants considered themselves homeless in addition to the housing category they selected (often temporary housing, such as SRO)