

A qualitative study of urban people of color living with human immunodeficiency virus: challenges related to retention in care, antiretroviral therapy acceptance, and “conspiracy beliefs”

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## ABSTRACT

A qualitative study of urban people of color living with human immunodeficiency virus: challenges related to retention in care, antiretroviral therapy acceptance, and HIV-related “conspiracy beliefs”

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*Background:* Despite advances in HIV medication, many people living with HIV (PLWH) do not link to care upon diagnosis, do not remain engaged if linked, and do not achieve viral suppression through consistent ART adherence. Not achieving viral suppression is associated with low CD4-cell counts, preventable hospitalizations, frequent emergency room usage, risk of developing a drug resistance, and excess morbidity and mortality. Despite extensive literature that explores barriers to care, these disparities remain, particularly among racial, ethnic and sexual minority groups. Mistrust of health care systems and/or providers is thought to provide a partial explanation for why racial and ethnic minority groups are less likely to access outpatient HIV care. One form of health-related mistrust, referred to as “conspiracy beliefs” in the literature and in popular culture, is particularly associated with racial and ethnic minority people. HIV-related “conspiracy beliefs” can include the ideas that the government created HIV to target specific minority groups, that antiretroviral medication is used to experiment on vulnerable groups, or that a cure is being withheld or delayed by pharmaceutical companies and/or the government. Although many studies have assessed the prevalence of such beliefs, little is known about the possible relationship between endorsing these ideas and engagement from HIV

care/ART adherence among PLWH. Moreover, the extant literature has provided equivocal findings that point to the need for further research on the relationship between these beliefs and managing one's HIV.

*Methods:* Over the course of one year, 27 semi-structured, in-depth interviews were conducted with low income PLWH of color living in the NYC area that are currently, or were recently, disengaged from outpatient HIV medical care. Additionally, a brief questionnaire was administered to obtain demographic and engagement/medication adherence data to describe the sample of participants.

*Findings:* This analysis revealed the variation, texture and diversity related to people's beliefs about the origin and treatment of HIV. Beliefs about the pharmaceutical industry and the government highlighted both the racism and classism experienced by low income who belong to racial and ethnic minority groups. Notably, HIV care providers did not appear to be perceived as part of the government-pharmaceutical power complex. This suggests that while many people may endorse these types of ideas, endorsement does not necessarily directly impact engagement in care. However, endorsing positive beliefs about the efficacy of ART, and the belief that HIV can be a chronic disease if treated consistently, helped participants remain adherent or desire to re-commit to taking it consistently. Participants also appreciated, and desired, providers that engaged in patient-centered medicine.

*Recommendations:*

It may be that public health does not necessarily need to endeavor to dislodge origin or pharmaceutical/cure-related beliefs; rather, interventions can focus on building trust between health care providers and populations that have been experienced both historically and ongoing marginalization. Participants' emphasis on wanting to manage their ART-related challenges *with*

their providers suggests that HIV providers have an instrumental role in not only lowering viral loads and achieving viral suppression, but also helping their patients feel agentic and able to manage their HIV. Implementing patient-centered medicine will also engender trust, thereby helping patients internalize the belief that consistent engagement and ART adherence makes HIV a chronic, manageable illness.

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## **Dedication**

This dissertation is dedicated to Walter Irwin Nelson.



## **The limitations of the Tuskegee study as a master attribution to medical mistrust: HIV as the prototypical illness for examining HIV-related beliefs**

### **Abstract**

Mistrust of health care systems and/or providers is thought to provide a partial explanation for why African Americans are less likely to access health care. The literature suggests that the Tuskegee Syphilis Study is largely responsible for this persistent mistrust. A particular type of mistrust, most commonly referred to as HIV-related “conspiracy beliefs” in the literature and popular culture, is also primarily attributed to African American populations.

These HIV-related beliefs have been explored in relation to birth control use, HIV testing, and participation in HIV-related biomedical research. More recently, the emphasis on treatment as prevention (TasP) for all people living with HIV has shifted the HIV-related “conspiracy belief” research to studies of engagement and ART adherence. However, the literature on HIV-related “conspiracy beliefs” and engagement and adherence is limited, and has provided equivocal findings that point to the need for further research on the relationship between these beliefs and going to clinic and/or adhering to ART.

Further research should discontinue the use of the phrase “conspiracy beliefs” in favor of more precise terms that describe people’s beliefs in a less judgmental and discrediting way. For example, referring to these ideas as origin- or treatment-related beliefs describes the nature of the ideas, and leaves rhetorical space for thinking about possible reasons why people endorse them. Related, the almost singular focus on the Tuskegee study as the source for ongoing medical mistrust among African Americans (and other minority populations) requires a critical appraisal, if we are to better understand how medical mistrust manifests itself in relation to health beliefs and behaviors.

### *Conceptualizations of the Term “Conspiracy Beliefs”*

Mistrust of health care systems and/or providers is thought to provide a partial explanation for why African Americans are less likely to access health care [1-3]. Most of the literature on medical mistrust pertains to interpersonal trust between physicians and patients [4-6], although some studies explore trust in healthcare systems, hospitals and health insurers [7-8]. Medical mistrust may also be illness-specific (e.g., HIV or vaccine-related suspicion, or mistrust of new reproductive methods) or pertain in general to mistrust of and reluctance to participate in biomedical research. Moreover, the literature suggests mistrust is not merely the opposite of trust; rather, mistrust is more negative than the absence of trust and it refers to the belief that the entity that is the object of mistrust, is acting against one’s best interest and well-being [9,10].

Among racial and ethnic minority groups in particular, the medical mistrust literature also encompasses research on “conspiracy beliefs.” “Conspiracy” theories and beliefs are found throughout society, and pertain to a wide range of social phenomena, including HIV. A conspiracy theory, by definition, is a set of beliefs or theory of a “proposed plot by powerful people working together in secret to accomplish some (usually sinister) goal” [11,12]. Conspiracy theories most typically highlight perceived or actual power differentials between higher status and lower status groups. Interestingly, they “are not by definition false; indeed, many real conspiracies have come to light over the years” [12]. For example, the US federal government recently admitted the existence of Area 51 in Nevada, confirming a decades-long conspiracy theory that was previously vehemently denied by the military. Although the government only admitted to a portion of the conspiracy theory-- the existence of the area, and not the allegations regarding

extraterrestrial beings -- the confirmation of Area 51 was still a victory and serves as a validation for many other “conspiracy” theories [13]. Moreover, “conspiracy beliefs”, “even when wrong, are notoriously resistant to falsification...with new layers of conspiracy being added to rationalize each new piece of disconfirming evidence.” [12] Thus, the nature of “conspiracy beliefs” make it difficult to persuasively present evidence to refute or prove them, especially in light of how such theories are sometimes eventually found to be true or at least partially accurate.

Despite their nebulous nature, “conspiracy beliefs” have a very real public health impact. For instance, while polio has been considered nearly eradicated worldwide, it is emerging again in Pakistan and Somalia. At the heart of this resurgence are “conspiracy beliefs”; that is, in Pakistan and other Muslim countries, public health efforts to vaccinate against the disease have been impeded by widespread rumors that the vaccine sterilizes girls, or contains pork products or even the virus that causes AIDS [13]. In the case of polio, opposition to the vaccine is not specifically related to HIV, but there seems to be a constellation of beliefs that link the polio vaccine to acquiring other diseases, including HIV. This suggests how people, faced with structural, health-related barriers such as poverty, disease and other forms of disenfranchisement (e.g., conflict, economic marginalization) may link pre-existing health-related fears (e.g., sterilization of the poor, HIV as a form of genocide for the poor or racial/ethnic or religious minorities) to newly introduced health policies or interventions.

Locating the phenomenon in a racialized context, Waters (1997) notes “conspiracy theories held by African Americans that seek to explain ethnic inequality are intrinsically interesting as a subset of conspiracy theories because they may indicate areas

of tremendous uncertainty in interethnic relations. In addition, they may shape behavior by providing parameters for political and social action in racial conflicts. In short, conspiracy theories express deep-running ethnic tensions while they influence the directions of interethnic interaction.” [14] In this sense, Waters’ analysis suggests that “conspiracy beliefs” held by African Americans may represent manifestations of the various ways in which society is shaped by rigid, interlocking structures of racism, sexism and classism.

Similarly, Mackenzie posits that “conspiracy beliefs” should be viewed as “counter-narratives” to understand how people’s experiences may be both embodied, and reflective of a particular cultural understanding. Further, she argues counter-narratives “create a rhetorical space for challenges to power through the articulation of oppositional ideas about dominant scientific knowledge.” [15] Therefore, health-related “conspiracy beliefs” can be seen as collective stories generated by socioeconomically and symbolically marginalized groups that attempt to discredit, if not resist, the dominant biomedical discourse.

Similarly Heller (2015) argues that HIV-related “conspiracy beliefs” are not in fact ignorance, but rather can be understood as: 1) the "result of historical experiences that have engendered distrust, 2) a result of continuing distrust, and 3) an indication of social anxieties associated with the HIV/AIDS epidemic, drug use (as a source of HIV infection and as an arm of the genocide attempt), and African American's place in American society" [16]. In this sense, such beliefs are a “measure of trust” between African American communities and the health care system. In contrast to other studies that have suggested education as a means of dispelling “conspiracy beliefs”, Heller notes

that increased knowledge will “work only if people trust the sources of official information”, which are often government agencies such as CDC, or local city and state health departments [16]. Although the public health literature conceptualizes “conspiracy beliefs” as a type of mistrust, the literature largely lacks the nuanced view that Heller proposes and instead overly relies on the Tuskegee syphilis study narrative to explain the phenomenon.

*The Tuskegee Experience as a Master Attribution of “Conspiracy Beliefs”*

The widespread focus on “conspiracy beliefs” as a cultural characteristic of the African-American population in the United States is largely explained by the literature’s emphasis on the Tuskegee study as a catalyst for such ideas and beliefs. Health research has for the most part taken the position that the origins of “conspiracy beliefs” are deeply rooted in the historical-institutional racism that characterized the era of slavery, and was later reflected in the infamous Tuskegee study [17,18]. The study, conducted by the Public Health Service and largely considered one of the most egregious abuses of research participants in public health history, conducted syphilis experiments on socially marginalized Black men from 1932 to 1972, and withheld penicillin to assess the long term effects of syphilis on the body when left untreated [19]. In both the fields of public health and popular culture, including the media, the study is frequently cited as a key contributor to medical distrust among racial/ethnic minority populations [18,20,25]. The emphasis, however, is on the Tuskegee study. The almost singular focus on this particular study as the source for ongoing medical mistrust and “conspiracy beliefs” among African Americans requires a critical appraisal, if we are to better understand how medical

mistrust manifests itself in relation to health beliefs and behaviors and how to address its deleterious effects on health care seeking and engagement in care [20].

The enduring focus on the Tuskegee study perhaps obscures more recent examples of research misconduct or instances of racism in research and medicine, which range from unethical practices in pharmaceutical trials to coercive sterilization of Native American and Puerto Rican women [22-24]. It is possible that the continued emphasis on Tuskegee, as a symbol of past racism in medical research, prevents a more nuanced understanding of how ongoing racism, compounded by historical racism, affects trust and mistrust among populations of color in the United States. I assert that the gravity of the Tuskegee abuse prohibits public health from discerning new ways in which experiences of racism affect the trust or lack thereof people of color have towards the rapidly changing field of biomedicine and new emerging diseases, such as HIV, Ebola, or antibiotic resistant infections. Labeling the collective beliefs and stories that reflect this lack of trust or mistrust of people of color towards the field of biomedicine “conspiracy beliefs” discredits them, and this is why in this literature review I elected to place this phrase in quotation marks.

Many historians and public health researchers have critically analyzed various aspects of this infamous study [20, 25-27]. There is disagreement about the extent of the impact of the Tuskegee study on the African American population’s distrust of the health care system. Some studies have offered the Tuskegee study as a primary cause underlying health-related mistrust, but some empirical investigations have tested this association and concluded that the study has less of a clear explanatory power. For example, a telephone survey of 277 Black participants and 101 white participants in

Baltimore, MD revealed that although there were no significant racial differences regarding Tuskegee knowledge, Black participants expressed higher levels of mistrust toward medical care than their white counterparts [19]. This difference in health-related mistrust became evident when participants who were previously unaware of the Tuskegee study were made aware, and were subsequently asked if they believed a similar event could occur today. Among white participants previously unaware of the study, 63.6% reported that they believed a similar study could happen today, versus 37.5% that had previous knowledge. Thus, for white participants, becoming aware of Tuskegee significantly increased the belief that similar abuses could occur today. However, for Black participants previously unaware of the study, 76.9% indicated that similar abuses can occur today whereas this belief was expressed by 87% of those that had demonstrated previous knowledge of the study. Several inferences can be drawn from these findings. First, becoming aware of the Tuskegee study increased white participants' belief in biomedical abuses to a far greater extent compared to whites who were already aware of this abuse. This suggests that the white participants who had contended with the Tuskegee abuse seem to perceive a historical distance between the past and the present and are optimistic that such abuses are less likely to occur in the present. However, this did not seem to be the experience of the Black participants since the overwhelming majority of those who knew of Tuskegee indicated that it was very possible that similar abuses can occur in the present. These participants, unlike their white counterparts, did not draw a sharp distinction between the past and the present and thus indirectly expressed a distrust of the current systems and policies to prevent biomedical abuses. Moreover, regardless of whether they knew or were informed about Tuskegee during the

study, a very high percent of Black participant endorsed the belief that biomedical abuses are possible even today. These differences suggest that Tuskegee becomes integrated in the collective consciousness of Black communities in different ways compared to whites, and that the health-related mistrust among African Americans is shaped not only by historical events, but also by lowered expectations of health care quality based on ongoing experiences of racism and social exclusion.

A 2009 study by Katz and colleagues found that specific knowledge of the Tuskegee study (TSS) was low among a sample of African Americans, Puerto Ricans, and non-Hispanic whites [28]. The telephone survey was administered to 1,162 adults in Baltimore, MD, San Juan, PR, and New York City. The authors found that 89% or more of African American, Puerto Rican, and white participants were not able to “name or definitely identify” the Tuskegee study when presented with study attributes. Of the three racial/ethnic groups, African Americans were the most likely to identify the Tuskegee study without being given a probe (11.5% of African Americans, versus 6.3% of Puerto Ricans, and 1.9% whites). When participants were given a probe, 37.1% of African Americans “clearly identified” the study, 26.9% whites, and 8.6% for Puerto Ricans. The authors conclude that it is unlikely that specific knowledge of the Tuskegee study has “any current widespread influence” on minority people’s willingness to participate in biomedical research and they advise health disparity researchers to refrain from assuming that community leaders’ knowledge matches that of community members. They note, “these data clearly show then that most people do not have recall memory about, much less routinely think about, the TSS when asked about incidents of medical research abuses.” Although this study suggested that the Tuskegee study is in fact not a factor in



explaining medical mistrust, it is important to note that specific knowledge of the Tuskegee study- such as details of the study regarding location, dates, or particular violations is not necessarily needed for an individual or community to mistrust the health care system, avoid participation in clinical research, or endorse “conspiracy beliefs.” An alternative interpretation of the data could suggest that people may be generally aware of instances of medical abuses, particularly in the context of racism, without widespread knowledge of particular details.

Mays et al. (2012) conducted a telephone survey in Los Angeles to assess the relationship between Tuskegee-specific knowledge levels among 510 African Americans and 253 Latinos and HIV-related “conspiracy theories” [29]. Consistent with previous literature on the prevalence of such beliefs among African Americans and Latinos, this study also found that African Americans were significantly more likely to endorse “conspiracy theories” than their Latino counterparts. Lower income levels and lower HIV knowledge were also predictors of endorsement. Although 72% of African Americans and 94% of Latinos reported that they had never heard of the study, the former group reported more Tuskegee-specific awareness. The authors conclude that while Tuskegee awareness was a significant predictor of endorsing HIV-related “conspiracy theories”, there are other factors that likely contribute to low biomedical research participation rates among African Americans, including low levels of knowledge about HIV, and fears of exploitation during clinical trials. They concluded that the syphilis study alone is an inadequate explanation for medical mistrust and “conspiracy beliefs” among African Americans [29]. The findings of the above studies are important because they substantiate that the Tuskegee study alone is at best a partial explanation for African

Americans' health-related mistrust.

*HIV-related "Conspiracy Beliefs" in the Public Health Literature: the Epidemic of HIV and its Relationship to "Conspiracy Beliefs"*

HIV-related "conspiracy beliefs" center around the notion that the U.S. federal government has been involved in creating and/or maintaining HIV/AIDS as a form of genocide against African Americans and/or other minority populations, such as racial and ethnic minority groups [30,31], and possibly men who have sex with men (MSM) and drug users. Similarly, these theories also refer to beliefs that antiretroviral therapies (ART) are used to experiment upon, and/or kill those with HIV-infection who take them, or that a cure is available but is being secretly withheld by the government and/or pharmaceutical companies in order to further marginalize or exterminate "minority" groups and profit from the sales of antiretroviral medication, respectively [30,31].

Although "conspiracy beliefs" exist in other areas of health and society, HIV exceptionalism likely contributes to the longevity and durability of HIV-related ideas [32,33]. The relatively recent emergence of the disease, and the initial uncertainty regarding its modes of transmission, solidified its association with marginalized groups engaged in lifestyles stigmatized as alien if not perverse [34]. Initially, HIV was associated with gay men, and later, post-GRID, racial and ethnic minorities, substance users and sex workers. The persistent discourse concerning the African origin of HIV has also likely shaped the nature of "conspiracy beliefs." Its enduring disproportionate effect on racial, ethnic, class and sexual minority populations in particular-both in the United State and abroad- has thus made HIV a uniquely stigmatizing illness that is undeniably

linked to pervasive social inequalities [35,36]. Moreover, the intense stigmatization of HIV-infected individuals that were already stigmatized and discredited because of their lifestyle (e.g., MSM or substance users) has the potential to further marginalize and exclude them from social, economic and symbolic resources. This systemic, ongoing alienation constitutes fertile ground for the preservation of HIV-related “conspiracy beliefs.” Therefore, despite advances in biomedicine with regard to HIV, these beliefs remain a part of the illness representation and public health remains interested in examining their association with the epidemiology of the disease. This HIV treatment success explains the public health focus on linking and retaining in care and treating with ART all PLWH; treatment as prevention (TasP) has become the most recent message for ending the epidemic. Therefore, “conspiracy beliefs”, most recently, are being examined in relation to engagement in care, as discussed in the next section.

### ***Engagement in HIV Care and ART Adherence***

Recommendations regarding the HIV care continuum currently focus on treatment as prevention (TasP) [37,38]. The shift from defining HIV prevention as HIV testing has shifted very deliberately to the role of consistent ART adherence as a primary strategy to achieve viral suppression, thus not only reducing the risk of transmission of HIV to others, but also decreasing morbidity and mortality [39,40]. Thus, the trend in HIV prevention has drastically shifted the focus from solely or primarily linking individuals to HIV testing, to linking, engaging, and retaining PLWH in consistent outpatient HIV care thus ensuring ART adherence. This treatment cascade includes federal guidelines for offering and encouraging ART to all patients, regardless of viral

load and CD4 count, as well as PrEP (pre-exposure prophylaxis) to those who are uninfected but engage in high-risk behaviors [37]. Reflecting this trend, research on HIV-related “conspiracy beliefs” has followed suit and has attempted to account for the role of such ideas in the engagement and adherence-related behaviors of people who are socially marginalized. HIV-related “conspiracy beliefs” are associated with primarily low-income people of color, particularly African Americans [43-45]. Thus, it makes sense that research trying to explain the impact of these beliefs has focused on these same populations, given that socially and economically marginalized groups are more likely to be linked later, poorly retained, and struggle with consistent ART adherence [46-48].

HIV-related “conspiracy beliefs” have been widely documented in the public health literature as affecting a variety of health practices and outcomes, including those related to HIV testing [49,50], birth control and condom use [51,52], HIV vaccines [53,54], and participation in HIV-related clinical research [55,56] as they expose fears about reproductive rights violations and genocide [15]. More recently, some work has been done on the relationship between such beliefs and engagement in HIV care and/or ART adherence. However, there is substantially less literature exploring this relationship, and the findings of the limited literature that does exist are mixed in regard to whether or not endorsing such beliefs negatively affects engagement and/or adherence [57-60].

In a 2008 cross-sectional investigation, Clark et al. [57] examined the prevalence of “conspiracy beliefs” among 113 patients engaged in care at four public facilities in Houston, Texas. Using five items that addressed the origin of HIV, and a cure and vaccine for HIV, they found that 63% of the participants endorsed one or more “conspiracy beliefs”, and that African American individuals were significantly more

likely than white and other/multiple race patients to hold such beliefs (however, non-Black participants also endorsed such ideas). Those endorsing the beliefs had higher CD4 counts at diagnosis, and higher current counts. Moreover, the presence of “conspiracy beliefs” among HIV-positive patients was not associated with a delay in diagnosis or ART adherence. However, they did not specifically look at each racial/ethnic group separately, and noted that the study’s recruitment focused on patients engaged in care, and thus did not necessarily represent people living with HIV/AIDS (PLWHA) with more extreme or deeply held “conspiracy beliefs” that do not interact with the healthcare system around their HIV illness. This suggests that further research is needed to better understand how “conspiracy beliefs” may affect how people who are out of care think about HIV and manage their illness, including whether these beliefs prevent them from engaging with care, or influence non-adherence. In particular, Clark and colleagues suggest the prevalence of “conspiracy beliefs” may increase over time, perhaps due to increased interactions with other PLWH, experiences with medication side effects, or HIV-related stigma, both felt and enacted. The authors conclude that trust/mistrust in one’s provider may not be correlated with trust/or mistrust in the government, and that further research is needed to examine if provider trust is more important in terms of influencing health-related behaviors. They recommend that since patients are able to distinguish between their beliefs about the origin and treatment of HIV and their need for medical care, health care providers should endeavor to build more trusting relationships. Importantly, they did not find that educational level was a predictor for “conspiracy beliefs”, thus suggesting that education/awareness-oriented interventions are not the most effective way to counteract the potential negative effects of these ideas.

A 2010 study by Bogart and colleagues on HIV-related “conspiracy beliefs” and adherence found that such beliefs were associated with ART non-adherence among African American men engaged in HIV care in Los Angeles, CA [58]. The baseline included 214 men, and 177 returned for follow up. “Conspiracy beliefs” were operationalized using two distinct sub-scales: 1) genocide-related beliefs, and 2) treatment-related beliefs. Genocide-related beliefs items included, “HIV is a manmade virus”, “AIDS was produced in a government laboratory”, and “AIDS was created by the government to control the Black population.” Treatment-related items included, “People who take the new medications for HIV are human guinea pigs for the government”, and “The medicine that doctors prescribe to treat HIV is poison.”

In bivariate tests, both sub-scales were associated with non-adherence; however, in a multivariate logistic regression, only treatment-related “conspiracy beliefs” were related to a lower probability of optimal adherence at the one-month follow-up. These findings suggest that different HIV-related “conspiracy beliefs” may have distinct dimensions that must be examined individually for identifying their association with different health practices (e.g., attending visits vs. adhering to treatment) and dispositions (e.g., AIDS was created by the government in the laboratory vs. ART is poison). The authors recommend interventions to “address culturally specific roots of non-adherence to overcome medical mistrust”, such as using peer treatment advocates who “understand cultural barriers” to adherence, and encouraging providers to be open to dialogue about patient’s ART-related concerns. Importantly, they note that these kinds of beliefs cannot simply be dismissed as “rare or extreme”, given the high prevalence among Black populations. They call for additional research to explore the social networks of African

American communities to identify sources of both “accurate and inaccurate” HIV information (Bogart and colleagues provide this research in 2016, see below). Like the Clark et al. study (2008), this study also exclusively sampled individuals engaged in care, thus suggesting again that research is needed to explore how “conspiracy beliefs” may affect how disengaged people, who we can hypothesize might be more disenfranchised, think about and utilize care. Additionally, while the Bogart et al. study innovatively explored two distinct dimensions within the broad category of HIV-related “conspiracy beliefs”, thus providing a more nuanced understanding of the different ways in which certain types of beliefs can affect particular aspects of health behavior, the items conflated the role of the government in the epidemic and the role of providers in prescribing toxic medication. Future research on this topic should explore people’s beliefs about the government and health care providers as separate entities in order to allow participants to make these potential connections.

A 2012 study by Beer and colleagues explored the relationship between accessing HIV medical care and what they termed health-related beliefs [59]. This qualitative investigation conducted focus groups in five US cities, nearly all of whom were African American, male and had not received HIV care in the previous six months. The authors found that, among other barriers to care (such as negative experiences with providers), distrust of health care was a key factor in influencing people’s HIV engagement in care decisions. Although some participants had also reported trust issues related to past negative experiences with providers, participants also shared “generalized feelings of distrust of health-care related entities, which contributed to suspicions about recommended medications.” This suspicion encompassed government health care, the

pharmaceutical industry, and the “medical community as a whole”, which not only included pharmaceutical-related ideas, but also beliefs about the genocidal origin of HIV. This study also cites the Tuskegee study as an explanation for the health-related mistrust of people of color. The authors recommend cultivating good patient-provider communication to help reduce mistrust.

In a recent systematic review of the literature pertaining to the associations between HIV-related “conspiracy beliefs” and HIV care, including treatment adherence, Gaston and colleagues (2013) concluded that three main factors affect engagement in care: 1) racism and discrimination within the health care system; 2) “conspiracy beliefs”; and 3) the quality of the patient-provider relationship [17]. Notably, the authors suggested that “conspiracy beliefs” possibly point to the “intergenerational transmission of medical mistrust.” This notion warrants further research, as it implicitly draws attention to the importance of ongoing racism, rather than discrete historical events, and of the role of providers in patients’ lives, including as a potentially countervailing force to “conspiracy beliefs” and discrimination in the medical system. The authors suggest that having a high quality relationship with one’s provider can “serve as a protective factor”, and thus offer several recommendations directed at providers. These included encouraging providers to openly reflect on their own personal beliefs, perceptions and biases (and how they may affect treatment decisions), listen to patient narratives, enable patients to share in treatment decisions, and to expand their social networks to include more diverse people [17]. In doing so, providers can exercise reflexivity, and foster a transparent patient-provider relationship where patients are comfortable sharing their ideas and beliefs without feeling judged or discriminated against.



Although the vast majority of the studies on HIV-related “conspiracy beliefs” examine the phenomenon among adult African Americans, Gillman and colleagues (2013) assessed the impact of “conspiracy beliefs” on linkage to care and retention in care among young MSM of color (ages 13-24) [59]. Recruited from a health center, participants were provided with services over a six-month follow up period. As in previous work on HIV-related “conspiracy beliefs”, the authors assessed beliefs about government involvement in spread of HIV and the possibility that pharmaceutical companies or the government were withholding a cure that already existed. Fifty seven percent endorsed at least one “conspiracy belief”, and “conspiracy beliefs” were associated with negative medication attitudes. However, “conspiracy beliefs” were not correlated with CD4 count at time of diagnosis (suggestive of time from infection to testing), linkage to care or retention in care. Echoing the literature on provider trust, the study also found that trust in physicians was associated with positive medication attitudes. Ultimately, the authors concluded that “conspiracy beliefs” do not predict poor linkage and retention in care among this particular population, but noted that they did not assess medication adherence, and that participants received linkage, case management and clinical services, which may have offset any negative effects. They recommended additional research to elucidate the relationship between provider trust, trust in the health care system, attitudes toward medication, and adherence, particularly among MSM youth living with HIV.

In a recently published study, Bogart and colleagues (2016) explored HIV-related “conspiracy beliefs” in the context of people’s social networks i.e., those closest to them, such as friends and family, as well as acquaintances [60]. “Conspiracy beliefs” were

operationalized with the same genocidal- and treatment-related subscales used in Bogart et al 2010, described above. The authors assessed two main items among a sample of 175 African Americans: 1) whether HIV-related “conspiracy beliefs” in social networks are associated with non-adherence of ART (using electronically monitored bottle caps), and 2) the characteristics of individuals in their social networks who discuss these ideas (e.g., socio-demographic background, such as race and ethnicity and HIV status). HIV-related mistrust was operationalized as whether any social network member had ever discussed “conspiracy beliefs” with the participant. The authors focused on social networks due to previous research suggesting that social network members are in a position to encourage or discourage healthful behaviors via communication of norms and modeling behavior. These assessments were performed at baseline, 6 months, and 12 months post-baseline. The authors found that 63% of participants endorsed at least one “conspiracy belief”, and 55% had heard at least one social network member endorse such beliefs. Endorsement of “conspiracy beliefs” by members of their social networks was significantly associated with participants’ ART non-adherence. They also found that the expression of such beliefs was more likely among social network members who were also HIV positive, who were aware of the participant’s HIV status, and with whom the participant frequently interacted. Notably, the authors argued that previous studies that demonstrated null findings regarding the relationship between HIV-related “conspiracy beliefs” and ART adherence included groups other than or in addition to African Americans, and this make-up of the sample may have been obscured or attenuated the relationship between African Americans endorsing these beliefs and non-adherence. The authors broadly suggest that structural-level interventions are necessary to address “the roots of mistrust, including the

wider historical and present context of structural discrimination in health care and other societal institutions.” Specifically, they offer provider-focused recommendations, such as making providers aware of “the historical context of discrimination” that may be influencing the health behaviors of African Americans, as well as the prevalence of mistrust in patients’ social networks. For example, in “cultural competency trainings”, providers could “be educated about the historical context in which African American patients are approaching healthcare and medical research”, and receive training in motivational interviewing to “proactively stem such beliefs in a non-confrontational, empathetic fashion” [60].

## **Discussion**

Although studies on the relationship between “conspiracy beliefs” and health, particularly HIV, have been deliberate in their critical examinations of historical abuses, the term “conspiracy belief” oversimplifies the complexity of the status quo social and health inequalities that are deeply rooted in not only historical, but also ongoing social injustice. This oversimplification is particularly evident in the excessive emphasis on the Tuskegee narrative as a dominant explanation for such mistrust. Moreover, relying on this explanation implies that other populations of color do not have these beliefs, and/or have not experienced other kinds of medical research abuse, or more broadly, persistent social and economic exclusion.

Previous literature on HIV-related “conspiracy beliefs” and engagement and adherence has provided equivocal findings that point to the need for further research on the relationship between these beliefs and going to clinic and/or adhering to ART.

By reframing “conspiracy beliefs”, and exploring the reasons underlying their existence (as well as the possible purposes they may serve for the individual and group), we may be better able to address the role of “conspiracy beliefs” in affecting health behaviors and outcomes. Thus, moving away from the phrase “conspiracy beliefs” could help re-frame how we understand not only historical, but also ongoing structural inequality as a fundamental cause of social and health inequalities.

First, the word “conspiracy” connotes irrational and paranoid, or even dangerous. Popular culture links this word to a range of social phenomena, from aliens and Area 51, to ideas and theories about the events of September 11, 2001 [61]. Using this phrase to refer to how people think about and experience social inequality is ultimately alienating and discrediting. For example, this uncritical phrase enables the researcher or health care provider to describe certain ideas, beliefs and experiences in ways that discredit them, and excludes the persons or groups that may express them and thus be able to provide a grounded description or definition. If researchers and providers dismiss or characterize patients’ beliefs as paranoid instead of stemming from their sociocultural experiences, they may engage with them in a particular way that is perhaps patronizing instead of patient centered.

Moreover, this phrase has been used in public health to define and problematically point to notions of “culture,” rather than structure, thus reinforcing the problematic notion that racial and ethnic minority groups possess an inherently deficient set of values, norms and beliefs that ultimately contributes to their health disparities. Therefore, a monolithic focus of culture divorced by structural conditions that generate it and maintain it results in a type of “blaming the victim” approach to health beliefs and

behavior. When these ideas are described as “cultural barriers,” the message is both dangerous and misleading, similar to how cultural competence is broadly critiqued for suggesting a tangible set of knowledge - reified in a cultural “checklist” of sorts, where providers are taught to memorize supposed cultural attributes and stereotypical traits of different racial and ethnic groups [62,63]. The concept of “structural competency” that calls for clinicians to understand and integrate into their practice the structural and institutional factors that influence the lives and disposition toward their health of their socially marginalized patients is a step in the right direction and, certainly, moves the field beyond the dangerous concept of cultural competency [68,69].

Here, it is important to push the boundaries of these dominant public health understandings of “conspiracy beliefs” to try to achieve a significantly more complex examination of past and ongoing racism, with a particularly focus on how historical injustice continues to affect interpersonal, institutional and structural phenomena. Although public health has explicitly aimed to reduce the prevalence of HIV-related “conspiracy beliefs”, it is important to consider that such ideas may constitute a form of resistance (direct challenge, deflection, avoidance) to past and ongoing injustice and trauma [15]. Thus, holding such beliefs, and even more so expressing them, may serve in some ways as a protective factor against pervasive racism, discrimination and perhaps stigma in the health care system and more broadly, a society hierarchically structured based on status.

Undoubtedly, not engaging in HIV care is associated with adverse health consequences and therefore is not adaptive in terms of preserving and promoting one’s health. Nevertheless, these beliefs may be an example of a countervailing mechanism

(i.e., a behavior that may be protective in some ways and detrimental to health in other ways) [64]. For people living with HIV that tend to be socioeconomically powerless and that occupy the lower ranks of a social hierarchy that is inherently marginalizing, embracing these “counter-narratives” may be a form of asserting symbolic power [15]. This perspective opens up the space to examine whether endorsing such beliefs fulfills a need to feel that one has some control over one’s life and illness, if only through having control over the narrative they make about their illness. That is, fashioning a story about one’s illness that discredits the dominant biomedical story is a way of exercising symbolic power and this might have psychological advantages, despite producing negative physical consequences. In this sense, holding “conspiracy beliefs” may also be an example of exercising agency and/or resisting dominant power structures, even though this exercise of agency may, at least in part, have some negative impacts on one’s wellbeing, family and community. Thus, the literature’s recommendations to “educate” people in order to dislodge these beliefs serve to highlight the lack of a full understanding of how these ideas may play a role in people’s lives.

### ***Recommendations***

Interrogating and refining the concept of “conspiracy beliefs” as conceptualized in public health allows us to practice reflexivity about the ways in which discourse and the production of knowledge are mutually constitutive and situated in a specific professional, cultural, political and historical context [65]. The phrase “conspiracy beliefs” risks obscuring, discrediting or even erasing the nuances of people’s lived experiences; by applying this phrase to such a wide and diverse ranges of beliefs, we risk missing

opportunities to better understand the thought processes and experiences of the populations with whom we work and serve. Although social determinants models can contribute to helping researchers and public health practitioners understand the impact of population-level material inequality on health outcomes [66], a more critical approach is needed that considers how people, as individuals, but also as members of groups, experience and interpret social and economic exclusion and injustice. This approach necessitates discontinuing the use of the phrase “conspiracy beliefs” in favor of more precise terms that describe people’s beliefs in a less judgmental and discrediting way. For example, referring to these ideas as origin- or treatment-related beliefs describes the nature of the beliefs, and leaves rhetorical space for thinking about possible reasons why people endorse them.

Moreover, a qualitative examination that invites persons with HIV to describe their ideas and beliefs about the illness and its treatment without limiting their accounts to pre-determined or pre-defined explanations of its origin or beliefs about ART can refine the conceptualization of these kinds of ideas and their relationship to becoming involved with the healthcare system. A qualitative design could also explore in-depth socio-economic aspects of these beliefs, as the literature predominantly focuses on race. Related, including in studies other persons of color, and not limiting samples to African Americans, also has the potential to enrich our understanding of this phenomenon and facilitate our moving beyond simplistic associations of health-related “conspiracy beliefs” with the Tuskegee study. Given the intersectional nature of people’s lived experiences, and the multiple layers of stigma experienced by PLWH, it would also be helpful to include other groups that experience stigmatization, such as gay men, people

who are transgender, and people who have substance use disorders.

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## **Targets and conspirators: “poor minorities” and the government-pharmaceutical complex**

### **Abstract**

*Background:* HIV-related “conspiracy beliefs” can include the ideas that the government created HIV to target specific minority groups, that antiretroviral medication is used to experiment on vulnerable groups, or that a cure is being withheld or delayed by pharmaceutical companies. In the United States, this phenomenon, usually framed as a type of medical mistrust, is largely attributed to populations of color, particularly African Americans. The public health literature strongly suggests that HIV-related “conspiracy beliefs” primarily stems from historical medical abuses targeting people of color, particularly the infamous Tuskegee Syphilis Study. Although many studies have assessed the prevalence of such beliefs, little is known about the possible relationship between endorsing these ideas and disengagement from HIV care among persons living with HIV/AIDS (PLWH).

*Methods:* Over the course of one year, 27 semi-structured, in-depth interviews were conducted with low income PLWH of color living in the NYC area that are currently, or were recently, disengaged from outpatient HIV medical care. Additionally, a brief questionnaire was administered to obtain demographic and engagement/medication adherence data to describe the sample of participants.

*Findings:* This analysis revealed the variation, texture and diversity related to people’s beliefs about the origin and treatment of HIV. In particular, beliefs about the pharmaceutical industry and the government highlighted both the racism and classism experienced by low income who belong to racial and ethnic minority groups. Notably, HIV care providers did not appear to be perceived as part of the government-pharmaceutical power complex. This study suggests that while many people may endorse these types of ideas, endorsement does not necessarily directly impact engagement in care.

*Recommendations:*

It may be that public health does not necessarily need to endeavor to dislodge origin or pharmaceutical/cure-related beliefs; rather, interventions can focus on building trust between health care providers and populations that have been experienced both historically and ongoing marginalization. Further research is needed to better understand how the constellation of barriers to care, including health institution- and provider-related mistrust, work together to impede engagement, and to facilitate retention.

## **Background and significance**

HIV-related “conspiracy beliefs” center around the notion that the U.S. federal government has been involved in creating and/or maintaining HIV/AIDS as a form of genocide against African Americans and/or other minority and marginalized populations, such as racial and ethnic minority groups, and possibly men who have sex with men (MSM) and drug users [1]. These ideas also refer to beliefs that anti-retroviral therapy (ART) is used to experiment upon, and/or kill those who take it, or that a cure is available but is being secretly withheld by the government and/or pharmaceutical companies to profit from the sales of ART medication [1,2].

Broadly, “conspiracy beliefs” are found throughout society, and pertain to a wide range of social phenomena. A conspiracy theory, by definition, is the idea of a “proposed plot by powerful people working together in secret to accomplish some (usually sinister) goal.” [3,4] Conspiracy theories most typically highlight perceived or actual power differentials between higher status and lower status groups. Moreover, such ideas “are not by definition false; indeed, many real conspiracies have come to light over the years.” [4] These traits of such beliefs contribute to their durable nature, and provide a partial explanation for why these kinds of beliefs persist over time.

In the United States, the phenomenon of “conspiracy beliefs”, usually framed as a type of medical mistrust, is largely attributed to populations of color, particularly African Americans, and most frequently men. Although there is some US-based research on “conspiracy beliefs” among groups other than African Americans, such as Native Americans and Latinos [5,6], the vast majority of research focuses on Black Americans. A 2006 study found particular socio-demographic factors associated with “conspiracy

beliefs”, including male gender, black identity and lower income [7], in addition to other studies that have also found such beliefs to be prevalent among African American men, and those with lower educational attainment [8,9].

A sociological analysis of HIV-related “conspiracy beliefs” also provides a partial understanding for the persistence of these ideas among racial and ethnic minorities in particular. Waters’ (1997) work on “conspiracy beliefs” suggests that such beliefs held by African Americans may represent manifestations of the various ways in which society is shaped by rigid, interlocking structures of racism, sexism and classism. She notes, “conspiracy theories held by African Americans that seek to explain ethnic inequalities are intrinsically interesting as a subset of conspiracy theories because they may indicate areas of tremendous uncertainty in interethnic relations. In addition, they may shape behavior by providing parameters for political and social action in racial conflicts. In short, conspiracy theories express deep-running ethnic tensions while they influence the directions of interethnic interaction.” [10] Similarly, Mackenzie posits that these ideas should be viewed as “counter-narratives” to understand how people’s experiences may be both embodied, and reflective of a particular cultural understanding. Further, she argues counter-narratives “create a rhetorical space for challenges to power through the articulation of oppositional ideas about dominant scientific knowledge.” [11].

## **Methods**

### *Sample study population and recruitment*

This paper examines the accounts provided by HIV-positive individuals of color - both Black and Latino- that had been recently, or were still, disengaged from care,

regarding the origin of HIV and anti-retroviral treatment. Participants were recruited from a larger sample utilized in a previous study (entitled Bedside to Community, “B2C”) examining disengagement from outpatient HIV care among hospitalized HIV positive patients. To be eligible for the B2C study participants had to: 1) be age 21 or older; 2) self-identify as non-Hispanic Black or Hispanic (of any race); 3) self-identify as HIV-positive; 4) be confirmed as HIV-positive based on medical records; 5) report having been diagnosed with HIV for at least two years; 6) be currently hospitalized in the CUMC Adult AIDS unit; 7) have their most recent CD4 cell count under 350 based on medical record; and 8) report that they have not seen any HIV outpatient clinician for at least 6 months (please see the appendix for a more detailed description of B2C eligibility criteria, including a revised operationalization of disengagement).

At the end of their B2C interview, individuals were asked for permission to contact them in the future to possibly participate in a follow up study, and if in agreement, asked to provide one or ideally two to three different contacts (self, family, friend, etc.) to facilitate follow up communication. This information was recorded in the Permission to Contact form. Individuals who agreed to be contacted about subsequent studies, constituted the sampling frame for the study described here.

From July 2015 to May 2016, interviews were conducted with a subset of the B2C sample, that is, a purposive sample of twenty-seven (N=27) PLWH who, at the time of the interview, were currently disengaged from outpatient HIV care, or had been disengaged within the previous one to three years.

The majority of potential participants were contacted via telephone using contact information they provided in the Permission to Contact form. Of the total 33 individuals



successfully contacted (either via telephone or in person at bedside when hospitalized at CUMC), 27 agreed to participate in the study presented in this paper. Two individuals declined participation, citing lack of time. One participant agreed to participate but was found to be not mentally competent enough to provide consent, and the remaining three were reached via telephone, but then lost again when their numbers appeared to change or go out of service before an interview could be scheduled.

### *Data collection*

In-depth qualitative interviews can generate novel insights by allowing study participants to express in an open-ended manner and in their own words and from their own perspectives their HIV-related beliefs. Another advantage of qualitative interviews is that they facilitate the identification of topics that although unanticipated by the researcher, emerge as salient in the participants' accounts [12,13]. They also can facilitate the identification of associations among topics for participants. Given the sensitive nature of the topic of "conspiracy theories", these features of qualitative interviewing honor the participants' ways of thinking and expressing themselves.

A semi-structured interview guide was developed to examine barriers to engagement in outpatient HIV care, as well as to explore ideas and beliefs about and reactions to "conspiracy beliefs"; it is noteworthy that this phrase was not used in the guide. In many cases, the topic of these beliefs arose spontaneously during the interview and was raised by participants themselves. Participants were also asked about their ideas regarding the possible origin of HIV, and the possibility of a cure. These questions were designed to elicit discussion around the commonly referred to set of beliefs identified and explored in the public health literature as "conspiracy theories" regarding the nature of

HIV and its treatment. Interview topics also included questions about experiences with recent hospitalizations, housing circumstances, experiences with outpatient HIV care (including engagement and ART adherence), other barriers to stable living conditions and/or engagement in care and thoughts and beliefs about HIV/AIDS (please refer to the appendix for examples of interview guide questions). Interviews ranged from 25 minutes to two hours, with an average of 45 minutes. The briefer interviews were the result of participants becoming fatigued due to very poor health; hence, those hospitalized at the time of the interview tended to have shorter interviews. Prior to the in-depth qualitative interview, an interviewer-administered questionnaire (IAQ) was also completed. This five to eight minutes brief survey gathered demographic and health status information (e.g., current housing situation, employment/public assistance status, recent hospitalizations, or ART use status). Importantly, the IAQ did not assess so-called “conspiracy beliefs” in order to allow these ideas to emerge spontaneously and organically in the in-depth interview. Although there are mistrust and “conspiracy belief” scales [14-16], we were interested in allowing participants to articulate their ideas in their own words and therefore elected not to administer these scales in the IAQ.

In this study, engagement and ART adherence were assessed first in an interviewer-administered questionnaire (IAQ), and afterward discussed in-depth in semi-structured interviews. The IAQ and the qualitative interview operationalized engagement/disengagement and adherence/non-adherence differently. The IAQ assessed engagement and adherence with items that asked participants about any outpatient HIV care they had received in the prior 12 and six months, including scheduled but missed appointments, as well as the spacing between each clinic visit. ART utilization and

adherence was assessed with items asking participants if they were currently taking ART at the time of the interview, if the ART was taken as directed, and intentions to begin, or to continue taking, ART in the next six months. Qualitatively, participants could be classified as consistently engaged, inconsistently engaged, or disengaged. The “consistently engaged and adherent” category indicated uninterrupted engagement and adherence over a period of at least the past 6 months. “Inconsistently engaged” was a broader, descriptive category that included the following: (1) participants had only very recently re-established care, for example, a few weeks prior to the interview, but not long enough to establish a pattern of behavior; (2) participants were taking their ART consistently, but had frequently missed their HIV scheduled appointments in the past 6 months; (3) participants were attending their HIV scheduled appointments regularly in the past 6 month, but had not been able to consistently take their ART as directed. The category of “disengaged” indicated participants that were not attending clinic and not taking their ART consistently (i.e., on schedule and as directed). Most participants were classified as “inconsistently engaged” (n =9), 7 were disengaged, and 11 were consistently engaged based on the qualitative assessment.

### *Data analysis*

All interviews were audio recorded for professional transcription. Approximately 20% of the transcriptions were randomly selected for quality control/accuracy that was conducted by the author. Qualitative analysis necessitates the development of a rigorous and organized method of managing and analyzing a rich set of textual data while keeping the data in context. This method must also ensure that the analysis plan does not

compromise the data's conceptual richness and complexity. The author implemented multi-step method of conducting an analysis to systematically identify and contextualize the themes present in the data. 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. At the top of this hierarchy, the author identified the analytic foci (coded as headings), next the core codes (that refer to specific aspects or dimensions of the headings), and last, sub-codes (that refer to specific aspects or dimensions of the core codes). An example of a core code is "pharmaceutical-related beliefs," as defined by participants, and examples of related to this code subcodes are: "believes a cure is being withheld by the pharmaceutical industry" or "the pharmaceutical industry is big business." After all transcripts were coded, text segments organized by codes/subcodes were extracted and closely read in order to begin identifying higher level of abstraction in regard to themes, and to also discern the relationship among codes. For instance, the codes and subcodes applied to segments of text where participants discussed the role of the government in the AIDS epidemic and the role of the pharmaceuticals and how they both benefitted from maintaining the epidemic revealed the similarities between these two power entities. This realization led to the inference that both government and the pharmaceutical industry constituted "conspirators." Similarly, the codes and subcodes applied to segment of text where participants discussed that the patients who are low SES and people of color do not or will not have access to the cure for HIV elicited their understanding of who are the "target of conspiracy." The next analytic step was to define the process of exploitation that associated the conspirators and to the targets of

conspiracy. The software Atlas.ti was used to organize the qualitative data. Data from the Interviewer-administered questionnaire data were analyzed using SPSS and used to generate a description of the sample of participants.

## **Results**

### *Quantitative findings*

Of the 27 participants, 59% were female (n=16), 41% male (n=11), 78% Non-Hispanic Black (n=21) and 22% Latino (n=6). Participant age ranged from 28-55. Asked about their housing circumstances over the past year, 74% of the sample reported living in an apartment, SRO or room supported by public assistance and/or HASA (n=20).

One hundred percent of the participants had Medicaid; two participants had both Medicaid and Medicare. Most (89%) reported being unemployed at the time of the interview (n=24), one person was employed part-time, and two were employed full time. Participants could select more than one answer to describe their main reasons for being unemployed and therefore, the percentages below add up to more than 100. Specifically, 74% reported that they were unable to have a full time job due to not feeling well enough (n=20); 37% were not sure if they will stay well enough to keep a job (n=10); 33% were fearful of losing medical benefits or other benefits if they worked (n=9); and 8% reported having to care for someone else (e.g., ill family member, or children) (n=2).

Using a 12-month interval, we found that 78% had visited a doctor or clinic for HIV care at least once (n=21), and 70% (n=19) reported having been to two or more scheduled medical visits at an HIV outpatient clinic and these visits were separated by at least three months. In the prior *six* months, 74% had attended a scheduled visits and were

examined by an HIV care provider (n=20); of these, 77% reported having missed at least one scheduled appointment (n=17); finally, 81% (n=22) reported being currently on HIV medication at the time of the interview.

**Table 1**

Participants' characteristics		N
Gender	Female	16 (59%)
	Male	11 (41%)
Race / Ethnicity	Black Non-Hispanic	21 (78%)
	Hispanic /Latino	6 (22%)
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%)
Employment status	Homeless	8 (30%)
	Unemployed	24 (89%)
	Employed full or part time	3 (11%)
Health Insurance	Medicaid	25 (93%)
	Medicaid + Medicare	2 (7%)
ER use past 6 months	Yes	19 (70%)
	No	8 (30%)
Attended HIV care past 12 months	Yes	21 (78%)
	No	6 (22%)
Attended HIV care past 6 months	Yes	20 (74%)
	No	7 (26%)
Attended $\geq 2$ HIV visits past 12 months	Yes	19 (70%)
	No	8 (30%)
Currently taking ART	Yes	22 (81%)
	No	5 (19%)

Adds up to <100% because some participants considered themselves homeless in addition to the housing category they selected (often an SRO or other form of temporary housing)

### **Theme 1: Beliefs related to the origin of HIV/AIDS**

Consistent with the literature on the types of common beliefs held by minority individuals regarding the origin of HIV, many participants in this study also believed that HIV was deliberately created by a powerful entity (i.e., usually the US government or

other countries' governments). Some participants believed that HIV was created with the sole intention of eliminating certain segments of the population, particularly racial and ethnic minorities, but also drug users and gay men. Others, however, strongly rejected such ideas, although they acknowledged the racism and powerlessness of racial minority groups and how these forms of social exclusion supported the ideas we tend to call "conspiracy beliefs."

***HIV is a "manmade" virus intended to be genocidal***

The idea that HIV was deliberately created to kill minority people, particularly racial and ethnic minority groups and also substance users and gay people, was prevalent among the participants. For example, Aliyah, a 28-year old Black woman, was born with HIV and was inconsistently attending HIV outpatient care at the time of the interview, but had been consistently adherent to her HIV medication (one pill a day for the last year). Over the six months prior to the interview, she was hospitalized six times for what she described as "potassium-related" issues. She had been recently transitioned from the pediatric HIV clinic to the adult clinic, and perceived this change as a coerced transition that she did not wish to make. Below, she explained why she believed HIV was developed to specifically "kill off Black people":

*Basically I truly believe that HIV was manmade. It was made in a laboratory. I think how it first got out was with those free shots that they was giving everybody, like free flu shots, free measles shots, free this shots. Yeah, that's what I truly believe, but I try to keep stuff like that to myself cuz it upsets people... It was basically designed to kill off Black people. There was too many of us and that's what they wanted to do...when it first came out I did like a whole bunch of research. When it first came out a whole bunch of people just were like dying like right after they got it and they try to basically blame it—like the government trying to blame it on—what was it, like a monkey or gorilla or something like that? They said that. Then they tried to blame it on the gays cuz there*

*was a whole bunch of stuff going on in the 80s. I basically just felt like that's what they wanted to do, just take out a whole bunch of Black people cuz that's what I saw. When you look up HIV that's what you basically see. You see people in Africa and stuff like that...I've seen all the numbers. [It's] not [that] mostly Black people have it, but there's a lot of us that do have it ...That's why I felt like it was created just to take us out...I mean anything is possible with the government because they say they have to... they have to tell us everything, but most of the time we don't know what's going on. That's why I really think that it was just—it was created just to take as many poor Black people out of the—off of the earth... Then they didn't account for some of the White people who do like Black people and then mingling with the white folks and now they got it too. [Aliyah]*

Keira, a 41 year old Black woman, was hospitalized for PCP pneumonia at the time of the interview. Keira was diagnosed in 1997, and reported having begun ART again approximately a year prior to the interview. She believed that HIV was deliberately created by the government and that minority people were used as “guinea pigs.” Below, she reveals the targets, and alludes to the conspirators. When asked by the interviewer about her thoughts on the origin of HIV, Keira responded:

*It's made. I think it's man-made, yes. Hey, it is what it is. It got out there, how'd it got out there? Who knows? All it is, is that we know it's out here... Something just tells me it was a man-made virus. It got out there, but I think it—I mean, something tells me it is. I really can't say why; I just have that feeling. Fine. They fucked up. They fucked up, something that went through the crack.... Even if, like I say, guinea pigs. They take the minority to test the virus. [Keira]*

Luis, a 55-year old Latino male, 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 HIV/AIDS Social Administration (HASA) could help him find an apartment. Luis had a long history of incarceration, and had spent a total of 23 years in prison. He strongly believed that HIV was deliberately created to target minority people. Below, he explained his beliefs about the relationship between the conspirator (government) and the target (people of color):



*I honestly feel that HIV was created in a lab. Viruses could be contained in a dish. We know that. Come on... Like I said, I believe in science and medicine and all that, right? When the virus first came out, it started attacking only certain types of segments of the population, right? Homosexuals, people that were [drug] users, right? Minorities in a way, right? Blacks, you know what I'm saying? Due to those facts, I felt that it was manmade, and a lot of people to this day still feel that... I think scientists got together with the government and made this to attack a segment of the population... Let me tell you about—I think back in the '50s, was it, where they took a segment of Black men and they injected 'em with syphilis, right?... They [the government] didn't tell 'em, right? To find out later on what the effects of it, the same way. If the government was able to do that, man, what else do you think they gonna do?... I guess [they do it] for control, the population. Let's be honest. You know that the Spanish population is gonna be the majority, right? In this country, right? If it's not already, right? That's one reason they want to control the population, right, of different races, especially Caucasian races, right? Basically, how they say they were the ones that basically made America, which is not true. We know that. We know that. This country was made by different people. How was the trains put together? The Asians, Chinese... They were treated like nothing, like a nobody, right? [Luis]*

Luis was one of the very few participants that specifically alluded to the Tuskegee study.

Although several others raised the issues of experimentation, Luis's explicit reference further reveals his deep suspicions of the government, particularly in regard to its historical treatment of minority people.

Pablo, a 44 year old Latino man, was diagnosed in 2001 during a visit to a methadone clinic. Pablo was still on methadone at the time of the interview, and had reported using heroin two days prior. He had experienced multiple periods of incarceration, spanning three decades, and believed he and other inmates were deliberately experimented upon in prison via an influenza or pneumonia vaccine that appeared to cause an outbreak of extremely painful boils (“When you're in jail, you're like a laboratory rat... This is true. Everyone knows that. They want to treat you with different things to see what the reaction and everything like that.”). Pablo believed that there was a racist motivation

underlying the origin of HIV. Below, Pablo explained why he believed the government created HIV to target certain groups:

*I believe [the government created HIV] for the homo, and addict, and Black community...I believe to control the population and take out other people—homos and things like that. I believe that. Everybody got different opinions. Mine, I believe that happens. [Pablo]*

**Rejection of origin-related beliefs: The dissenters**

Although many participants expressed origin-related beliefs, a subset of the sample did not. These dissenters, presented below, are ignored by the literature, as such beliefs are considered to be highly prevalent among racial and ethnic minority people. The following data emerged from interviews with participants who did not support such ideas and some who strongly rejected them.

Dee, a 49 year old Black woman, was diagnosed in 1988. Dee was engaged in HIV care at the time of the interview, but was not consistently adherent to her HIV medications. She attributed this to having been severely traumatized by the death of her HIV-positive 21 year old son five years earlier. He had experienced horrific side effects from AZT as a preteen, and decided to stop taking his medication. Although Dee acknowledged that the newer classes of ART were safer and more effective, she was terrified of side effects due to watching her son struggle with them and eventually pass away. She rejected any notion that HIV was deliberately created to target a particular group, although she had heard this idea in regard to Black and gay people:

*Well, listen, I've heard it was put here for the Black man and stuff like that, right? Then they came up with cancer, so then the White people got cancer, so that's what they get for development AIDS, right, HIV? But I don't believe that. I don't believe that crap. I mean, I have it. What're we gonna do about it? What can we say? I believe maybe at one point*

*that it was a gay disease. You know what I'm sayin'?' But you got all the people [in] Africa who has it. [Dee]*

Sandra, a 43 year old Black woman, was undetectable, engaged in outpatient HIV care and was consistently taking ART at the time of the interview. Having lived with HIV for over 25 years, she had experienced periods of disengagement from care and attributed her most recent period of disengagement to a lapse in her health insurance coverage. Like Dee, she also felt strongly that HIV was not created with the intent of targeting minority people:

*I know that it's not a man-made disease. I feel it in my heart that it's not. One can't be that cruel and just let somethin' out that like for the whole—for it to be exposed to the whole world. It's not only young people gettin' it. I seen a coupla older people, and their husband's cheatin' on them, and now they got it. I seen Black. I've seen White. I've seen Hispanic. I've seen Mexicans. I seen all type a people gettin' it, so it's not just a Africa thing. It's a worldwide thing now. It's like it's spreading, and it's spreading so rapidly that before you knew it, it was here in the United States of America. [Sandra]*

Jada, a 29 year old Black woman who was born HIV positive, had been experiencing severe kidney problems around the time of the interview. 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, although she planned to overcome her “psychological” barriers to taking pills in order to become consistently adherent and ultimately undetectable. When asked about her ideas about where HIV may have come from, Jada responded:

*Oh gosh. I'd like to stay out of that conversation. [Laughter] I really do...It just makes me laugh. People and what they think and believe, it's not what they think, or what they thought, or believe. It's what they've heard... the most preposterous stuff. That's what makes me laugh. I don't think nobody knows. [Jada]*

CeeCee, a 48 year old Black woman, was diagnosed in 2006. She was undetectable and reported having been on ART consistently for one year at the time of the interview. She reported having struggled with alcohol and cocaine use. This contributed to her difficulty staying consistently engaged in care, as she reported that she had sometimes sold her HIV medication to pay for cocaine. CeeCee similarly rejected origin-related ideas, stating “a virus is a virus”:

*I think if somethin' comes out, it comes out for everybody. Just maybe more Black people caught it or whatever, but I don't think it was targeted for just Black people. That's a bunch of crap...I don't care who you are. If there's a virus, it's gonna hit whoever got it. It don't have a color on it. It don't say hit the Black people first. A virus is a virus. It's gonna hit—and the reason why it must've hit a lot of Blacks is because if it came from Africa. Maybe they were more Black people, and more Black people are having sex at that time than the white people. [CeeCee]*

Jimmy, a 39 year Black man, was diagnosed in 2012. Recently married to his longtime partner, Jimmy began taking ART after his latest discharge from the hospital three years ago. At that time and while hospitalized, he had expressed that it had been difficult for him to consistently take his HIV medication because each pill was a reminder of his diagnosis. After nearly years of remaining adherent to his ART, Jimmy explained how he now thinks of ART as a “blessing.” He also rejected genocidal ideas regarding the origin of HIV, and considered such ideas as being used to fuel “race problems” by “white supremacists.” When asked about the context in which he has heard about these ideas, Jimmy responded:

*... I have heard it used to fuel race problems...I have seen propaganda from some white supremacist groups that are like HIV and AIDS is from Africa. It's an African disease. It is a black disease. AIDS is a black disease. It's from Black people, for Black people. Black people have spread this disease. ...I haven't gone any further than that because I'm just like really? I haven't invested any energy into that... I think a lot of these white supremacist groups always find different reasons to figure out ways to bolster themselves to be better than other people. Obviously, race is a hot topic, especially for African Americans in this*

*country right now. It always has been, but it's particularly hot at the moment. I guess it's never really stopped being hot. [Jimmy]*

Although many participants endorsed some variation of the idea that HIV was deliberately created to harm minority people, some also clearly dissented in regard to the endorsement of origin-related ideas. However, even those who did not embrace the belief that HIV was created to eliminate minority people, acknowledged racism and the powerlessness of racial minority groups and how these forms of social exclusion supported the ideas we tend to call “conspiracy beliefs.”

## **Theme 2: Beliefs related to a cure for HIV**

Both those participants who endorsed the idea that HIV was manmade by government or scientists, and those who did not endorse this idea believed in variations of the notion that there was already a cure for HIV, but it was being withheld by the pharmaceutical industry and/or government. This was the most commonly shared belief among the sample. There were many variations of cure-related beliefs, and the vast majority of participants endorsed at least one type of cure or pharmaceutical-related belief, and frequently, more than one.

The following interconnected subthemes emerged: 1) a cure is in fact available but withheld from poor and minority people; 2) rich get better treatment, if not a cure, because they can pay for it; and 3) keeping people sick is good for big business. Some explicitly believed a cure already existed, and was being deliberately withheld, while others believed scientists were still working on a cure, but when it is finally developed, it will be withheld from poor minority people. Thus, these ideas revealed participants' perceptions of minority individuals as targets of exploitation, and the pharmaceutical industry and/or government as the conspirators if not co-conspirators. The exploration of cure-related ideas that follows

reveals an additional dimension, or perhaps actor, in this scenario: wealthy people that were considered as being in sharp contrast to the “poor”, which most of the participants identified with on some level. In the absence of a cure, some participants expressed their suspicion that rich people living with HIV had access to superior medication. This theme highlighted another socioeconomic facet: the perception of the conspirators as a vaguely defined, powerful entity engaging in “big business.” Underlying these beliefs was a pervasive sense of socioeconomic exclusion and powerlessness.

### ***The cure is being withheld***

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 reported occasional methamphetamine use and a history of depression that he stated was also interfering with his ability to try to re-engage. Jamal was deeply suspicious of the government and the pharmaceutical industry. It is noteworthy that in the quote below, the participant, not the interviewer, introduced the phrase “conspiracy theorist”:

*I believe there’s a cure out there because Germany released something a couple years ago where—something with stem cells, and they got rid of the HIV in that one man. We heard about that couple years ago. We haven’t heard anything else. Magic Johnson—he’s had it for fifty, sixty years now, and he’s healthy as a horse. If I had millions of dollars, I’d be healthy as a horse too. There has to be a cure. There has to be if Magic Johnson is still alive, kicking. You’d never know he had HIV. Just sayin’, the guy in Germany—you can get rid of it... We haven’t heard about it because they don’t want us to hear anything else about it. Our media is very skewed into one or two lanes. Yeah, we only hear what they want us to hear. Right now, that’s not what they want us to hear, so we won’t hear anything else about it... They can still control us. Oh, I do sound like a conspiracy theorist. We can still be controlled. We’re still at their beck and call. [Jamal]*

When asked her thoughts about the possibility of a cure already being available, Keira who was introduced earlier responded with initial ambivalence, and then expressed her suspicion

that in fact a cure likely already existed, but was being withheld to maximize the profits of the pharmaceutical companies that are producing ART. She stated that she was disinclined to examine this issue, and was “not checking out” this idea because she was not a “scientist”, suggesting a sense of powerlessness as a consumer of HIV medication that has no choice but to adhere to the treatment if she wants to live:

*It may be, it may be out there, but I'm not the one—I'm not in no position to say there is, and I'm not checking it out because I'm not a scientist. None of that...Scientists, it's all about them finding—okay, finding the cure for the virus. Then again, if scientists is making a pill, that pill is money. For them to keep making pills and making this, they need money. They probably will find it. They probably do have the cure, but they just don't wanna take it out. Because if they get cured, that gamble right there has taken care of the virus, holding the virus, is not gonna be there if they find a cure, so there's—the money is not gonna be there. Because how they get paid? How do they get to funding for this, to do the research? To keep looking, and all that? It's through the pills that they give us. [Keira]*

Aliyah, the 28-year old woman introduced earlier, also expressed suspicion that a cure may already exist, but that it would not be available to “us” that is, to her or other low income Black people:

*Once [my mother] told me and me and her sat down and basically talked, cuz we talked about things that I've heard like, “Oh, I heard that there was a cure. Hopefully we could get our hands on it.” My mother basically just told me—my mother's never kept anything like on the hush-hush with me. Like she was always straightforward. She basically told me that you're gonna have this for the rest of your life and there might be a cure out there, but we're not gonna benefit from that...We won't be able to get it...They just haven't found it yet or they just don't want to give it to us. [Aliyah]*

***If there is not a cure, then at least there is better medication than the one I am getting***

Some participants also believed that Magic Johnson, as evidenced by his apparent good health that they inferred by his healthy physical appearance and longevity, had access to better HIV medication because of his wealth. For example, Sandra, a 42 year old Black

woman, expressed confidence that a cure for HIV would one day be found. Diagnosed in 1990, she was undetectable and adherent at the time of the interview after years of struggling with accepting her illness. Further, her sister had passed away from AIDS-related complications, and Sandra had witnessed her family stigmatize and mistreat her sister, and this led her to avoid disclosing her own status and amplified her denial. Sandra questioned whether or not Magic Johnson was perhaps able to access superior HIV medication due to his wealth:

*Magic Johnson is doin' damn good, and I wonder what he is takin' cuz he can't be takin' the same medication I'm takin'. [laughs] Magic Johnson does not look like he has the virus at all. When I say, "At all," at all, he does not look like he has the virus. They say people with money get certain treatments...I think he's takin' somethin' super. I don't know what he's takin', but he doesn't look like he—he didn't lose any weight. I don't know. I don't know what it is. He does not look—if I didn't know that he had HIV—if I didn't hear it on TV, I wouldn'ta known that he had HIV. He just looks the same. His skin complexion—everything. It looks the same. I don't know. Maybe he caught it in time. Who knows? [Sandra]*

Sandra did not specify who are “they”, that is, the people that disseminate the belief of the availability of superior medications for the wealthy. However, her statement that there are health advantages enjoyed only by the rich patients like Magic Johnson clearly reveals her belief that higher socioeconomic status provides access to what is otherwise unattainable for those who are not wealthy. While she did not endorse the idea that a cure already existed, she did believe that her lower socioeconomic status precluded her from superior medication available to the wealthy.

Manuel, a 52 year old Latino man was diagnosed in 1996. He was engaged in care and adherent to his ART at the time of the interview, though he reported occasionally missing appointments or doses due to his many stressful family obligations. However, he said he



would reschedule missed appointments and felt overall that he was doing well. After two hospitalizations in the previous seven months for chest pain, he recently received two stents in his heart, and stated that he was “doing great now.” Below, Manuel described finding out about pharmaceutical research being done in Puerto Rico that possibly suggested to him that a cure for HIV was being developed. Although he was uncertain about the idea that a cure already existed or would soon be available, he did suggest that “better treatment” is perhaps available to wealthy people, such as Magic Johnson, though he did not “know how this (with money your get better treatment) work[s]”:

*They say they got the cure for HIV...The other day I heard that they had the cure on the TV. I heard it. Well, I don't know what they were talking about but they say—they were doing a lot of tests for a lot of people, even in Puerto Rico. Puerto Rico, they got a big, big—on Macao, they got a big pharmaceutical. They be testing a lot of people like some kind of injection. I don't know. And they be test 'em and they be not finding the HIV in his blood. I know, because I know—I do a little bit research with friends. Even look at this guy, Magic Johnson. Magic Johnson have HIV. And look at that man. He's like this. Why? I don't know what kind of treatment he's getting. Maybe because he got the money to get a better treatment, but I don't know how this work...[Manuel]*

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 took her medication regularly and that stopping her drug use made it possible for her to become engaged in care again. Tanya believed a cure likely existed and that Magic Johnson was able to access it due to his wealth, or at the very least has been able to pay for superior ART that is not accessible to low income people. Tanya did not specify whether the conspirators were the pharmaceutical industry and/or the government as

most participants did; rather, it seemed that there was an amorphous “they” that deliberately withheld the cure from “poor people”:

*Yeah, there's a cure, but they don't wanna give it to us. Us poor people, they don't wanna give it to...They got it for the rich people. They're not givin' it to us. They gotta make us work for—by the time they have a cure for us poor people, we'll be dead already.. Magic Johnson got a cure. He paid for it, but it's a cure out there..He got his cure done...Magic Johnson paid to get the higher meds... He said it on TV!...Do you watch Oprah? When Oprah was on, remember when he came out and said he was HIV-positive the first time? He found a cure for him. He paid for it. Now, he still HIV-positive, but it's a better med for him, a more expensive one. Same us Black people can't afford... They're keepin' it away from the people that need it...The poor people! If you don't have the money—the efficient funds to get it, you're not getting' it. [Tanya]*

### ***Exploitation by Big Business***

The subtheme of big business was closely related to the belief that the pharmaceutical industry and the government, as conspirators, were in collusion and were deliberately withholding the cure for HIV. For Aliyah, who is quoted below, “big business” referred to the pharmaceutical industry and signified to her that greed related to the profitability of ART determined the industry’s activities and therefore, would likely prevent the release of a cure. In this sense, she perceived the government/ pharmaceutical companies as selling effective, necessary medication that enables someone with HIV to survive so as to remain an active consumer. Her quote below, alludes to the government and pharmaceutical industry’s exploitative practices:

*HIV's a big business, you know what I mean?... Just like the government, the pharmaceutical people. It's business. Any time any type of disease come up, somebody's gonna make that vaccine so they can make money off of it. ... The fact that it costs—it wouldn't do the government any good to cure us. It's better to keep us infected because why they—even if the pill was a million dollars, you know what I mean? All you'll get is a million dollars for one pill and then we're cured instead of getting billions of dollars basically from every infected*

*person. We have to keep taking this medicine. We have to stay alive. It's just big business. [Aliyah]*

Jamal also expressed a deep suspicion of the relationship between the pharmaceutical industry and the government, including Medicaid:

*I betcha the pharmaceutical companies have a lot to do with it because HIV medication is so expensive. Yeah, I betcha they're in cahoots with Medicaid 'cuz—I bet, dollars to donuts, at least 67 percent of HIV cases in the city, everybody's in Medicaid. They're getting' some type of kickback. They would lose money, or pharmaceutical companies would fold if they just said, "Oh, ta da, there's a cure. Aha." Yes, just go in and give 'em a stem cell of a baby, and you'd be all set. Yeah. There's some palm-greasing going around, like, "Keep this cure for a couple years while we stack our coffers or while we come up with some other something to accidentally release onto someone." I'm sure, one day, there'll be a cure, but probably not any time soon, just because the [government] wanna keep us paying pharmaceutical companies. ...It's a cycle. It's cyclical. This person pays this person... but I think once they realized that we're gonna pay all this money, and all these non-profits are gonna raise these money—you go down here, and they march for AIDS, and they make millions of dollars, and then they put it back into the pharmaceutical companies so they can give these people these pills. [Jamal]*

For Luis, “medicine”- encompassing pharmaceutical companies, pharmacies and hospitals- was “big business.” Notably, however, he did not include individual providers in this band of co-conspirators:

*Economics. You know how much HIV medication costs? Billions of dollars, right? Just to make it and research it, right, to get it, right, FDA-approved, right, and get it out there, right? There's some money to be made with these pills. They don't want people to get—to get cured, right, because then...Medicine is one of the biggest industries in—we know that. Not in the country, but in the world. I mean, just walk down this block here...Pharmacies and hospitals...HIV is big business. Big money. The pills, everything. The treatment, everything is big money. [Luis]*

Below, Pablo included doctors and pharmacies in the profit-oriented “family” that comprised pharmaceutical companies, the government, pharmacies, and doctors. Pablo’s inclusion of doctors in his understanding of the government-pharmaceutical scheme was unique and not expressed by any of the other participants. In a comment quoted earlier, Pablo expressed his

belief that HIV was created with genocidal intent. He stated that he and other men were experimented on by health care providers while in prison, which may account for his inclusion of doctors in this exploitative “family.” Below, he described why he believed a cure already exists for HIV:

*They got it. I believe in my heart and everything that they got the cure, but the money is more important for [the government]. I believe that...because right now, they got a company with the medication...You know how many billion and billion and billion a year they bring through that medication?... I believe that it's a big family—the company that make the medication, right? Going with the government, the company that made the medication, doctor, pharmacy, they come together. They like one family. They business. They're terrible, these businesses. Nobody can tell me no business, you can see that. You can be blind to not see that it's business. [Pablo]*

The previous two themes, origin beliefs and cure beliefs, revealed the texture and variety of these ideas, as well as the conspirators and targets in these scenarios. Many participants endorsed the idea that a cure exists but is being deliberately withheld by the pharmaceutical industry and/or the government. Participants perceived poor people, particularly those of color, as being excluded from any potential benefits of an existing or soon-to-exist cure, in contrast to wealthy people that have the means to access the cure, or at least superior ART that ensures longer survival and better overall health. Moreover, the widespread perception of the conspirators as a vast, powerful entity that targets poor, primarily minority people, was evident in participants' characterization of these conspirators as “big business”, which comprised primarily the government and pharmaceutical industry, and also, although less often, pharmacies, hospitals and doctors as well.

### **Theme 3: The overlooked dismissive disposition or reaction to “conspiracy beliefs”**

A third theme that emerged from the data was an expression of avoidance and dismissiveness toward the types of beliefs and ideas explored so far in this paper. Some

participants' dismissive and/or avoidant disposition suggested uncertainty about whether these ideas were true or not, or indifference, while others appeared to prefer not to even wish to contend with these ideas. Some of these participants' narratives revealed that they preferred to avoid discussing, thinking about or expending energy on the possible origins of HIV, or the possibility that a cure already existed but was being withheld. This avoidant stance was associated with discussions of the issues participants did in fact want to focus on, namely managing their HIV, their overall health, and dealing with other pressing challenges in their lives. It appeared that for some participants, even the mentioning of the ideas that the literature calls "conspiracy beliefs" led them to "block [it] out", or to explain why they were irrelevant to the management of their daily lives. In this sense, thinking about or dwelling on the possible origins, or the idea that they may be missing out on a cure, was perceived as unproductive, or even perhaps psychologically destabilizing and/or distressing. Thus, in expressing that thinking about, or even discussing, such ideas was in their opinion a waste of time, participants revealed what did in fact matter to them- taking care of their health, and by extension, prevent others from getting infected. In this sense, these kinds of beliefs "didn't matter" because HIV is an irreversible disease that can be a chronic condition if taken care of properly.

For Jay, quoted below, these kinds of ideas constituted "negative stuff", which he tried to "block out.. Jay, a 31 year old Black man diagnosed in 2009, was disengaged from outpatient HIV care and not on ART at the time of the interview. He was interviewed at his bedside while hospitalized for fatigue, shortness of breath, and, in his words, "probably a little pneumonia." At the time of the interview, Jay had been hospitalized for similar reasons twice in the preceding two months. In both the B2C interview and the interview from the study

presented here, Jay stated that he “hated talking about” his status, remarking, “I just can’t be cool with it.” He appeared disinterested or perhaps even avoidant when asked about ideas related to the origin or treatment of HIV:

*...when I hear [these ideas], I just block everything out. I don't hear nothing you're talking about. I stay to myself and I'm gonna always be to myself... That's about it. I don't speak to people really. You can talk, I'm not listening to you. I mind my business... I don't pay attention to the negative stuff. [Jay]*

When asked about the possibility that such ideas may be true, Jay responded that he did believe experimentation occurs, but could not invest time and energy thinking about it:

*I mean, I do, but I don't. I think they experiment with a lot of stuff and things happen, and the stuff just starts forming. I can't be thinking about all that. I got other stuff to think about... [Jay]*

For Jay, “stay[ing]” to himself, and not engaging in distracting conversations about “conspiracy beliefs”, was one way that he was able to “mind [his own] business” and not “pay attention to the negative stuff.” Jay did not believe in any particular “conspiracy beliefs”, and seemed to be purposefully dismissive or even avoidant of them.

Tina, a 53 year old Black woman, was diagnosed in 1995. She was engaged and undetectable at the time of the interview, after many years struggling with forgetting to take her ART, and missing appointments due to “runnin’ the streets” and “being in denial.” In her words, “I don’t know why. I had it so long, but I was just in denial, but I take ‘em [ART] now.” Below, she explained how she focused on taking her medication rather than pondering the idea that a cure does exist:

*I hear, but I don't listen to everything I hear. 'Cause if it was really out there, I think somebody would've brought it out, said somethin', and put it out in the like—I don't know. I don't know. I don't even think about that. I just take my pills. [Tina]*

Tina had heard such ideas being discussed, but was not interested in participating in such discussions, or investing time and energy in pondering whether such ideas were true or not. She vaguely hoped that if a cure did exist, it would become known, but even that hope was not one that she thought deeply about. Her statement, “I don't even think about that. I just take my pills”, reveals how her thoughts and ideas about the possibility of a cure did not impact her daily life, nor her desire and ability to consistently remain on her ART.

Maria, a 34 year Latina woman, was diagnosed in her early twenties. She was undetectable for the first time in her life, and living in a nursing home at the time of the interview. She attributed her previous disengagement to her alcohol abuse, but at the time of the interview had been sober for approximately a year and a half, and this enabled her to manage her multiple health issues, including HIV and recently being diagnosed with narcolepsy. Below, Maria emphasized the importance of managing and preventing HIV over thinking about the possible origin of HIV, and described these types of ideas as “stereotypical”:

*I never inquired more about it, because I really don't care. [Laughter] I just care about being healthy and living...Honestly, if you ask me, I really don't care where it come from. I have it and I need to get rid of it. You know what I'm saying? [Laughter] It's not my judgment of who made it or who passed it around or just those stereotypical things. I really don't care. The only thing I care about is to help stop it, to help reduce it, and to help people just take care of it... It really doesn't matter where it was made at. What matters is that, what are you gonna do about it? [Maria]*

Myra, a 44 year old Black woman, was diagnosed in 2006 and had never engaged in care until approximately two years prior to the interview, when she became stably housed after a period of homelessness that spanned a decade. She reported that she was her doctor's “star

patient”, and was doing very well taking care of her health. Myra was not particularly interested in thinking about or discussing any origin or cure-related beliefs, as she was focused on managing her health:

*It really doesn't matter to me actually...I wouldn't know. It doesn't make a difference. Once you have it you have to treat it. If you don't, you just basically die and you could affect others and others that don't know that they have it. You're forcing them to not treat theirself.* [Myra]

Janae, a 42 year old Black woman, was diagnosed in 2003. She had been consistently taking ART for approximately a month at the time of the interview, as she had recently started a new regimen after a period of going off ART due to severe side effects. When asked if she was familiar with ideas about the human-made origin of HIV or the idea that a cure exists, she responded:

*That's hearsay. I don't pay attention to it. I just turn the TV, 'cause you ain't gonna get my hopes up high... you just gotta keep yourself healthy and keep yourself protected. [on cure rumor]... ..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.' ...I don't worry about people. I worry about myself. I can't worry about what this person have or worried about lookin' up researches. I don't do that. I got other issues. I got other problems.* [Janae, 229, AA female 42]

Juan, a 49 year old Latino man, was diagnosed in 1984. He had moved back to NYC approximately a week before the interview, after living in a rural part of a southern state for eight years. During those eight years, Juan had not received any type of medical care for his HIV. He had been hospitalized for a week prior to the interview due to an HIV-related stomach infection, as soon as he arrived to NYC. He stated that he chose to move back to New York in order to begin receiving care and taking ART, and had an HIV care appointment scheduled the day of the interview. Juan was also dismissive and somewhat



frustrated with the topic, which perhaps suggested that such ideas could be destabilizing to his already precarious situation:

*I don't know where [HIV] came from. I just know I got it. Nothing—where am I gonna find out who? It's not gonna help me any. It's just gonna stress my mind out. I don't need that... Why would you wanna know where how it came from? Could it cure you? Can it get you—can it give you the life—the day and the hours and minutes and seconds that pass by them years ago? Can it get you better? Can't do nothing for you, man. Whoever invented it or how the hell it came about doesn't concern me, as long as I stay alive. [Juan]*

Jamal expressed a deeper level of suspicion than most of the other participants previously quoted, but similarly conveyed his belief that what was most important was taking care of his HIV by taking his ART. In discussing his perceptions of the pharmaceutical industry, he suggested that he understood the profit-driven cycle, but believed ART was an effective treatment for HIV:

*As long as I'm getting the pills that I need, I think I'll be fine...I'm supposed to go and get the pills, and Medicaid gets their voucher, and then they send—yeah. I would fulfill my role in the cycle. Everybody needs to get paid would get paid, except for me. [My role is] to go and get the pills and take them. Actually, my role could just be to go get the pills. I don't have to take them. As long as I go get them, I can go and throw 'em all in the river, and at that point they wouldn't care because I got my pills. I went to the pharmacy. CVS got paid. Callen-Lorde got paid. Abbott got paid...I don't feel like they're placebo pills or things like that. I don't think that, when I go in and get my T cell count, that they're just makin' these numbers up, and the more they don't see me, the worse the numbers get. I don't think that. I do think that there's value and benefits to taking your meds. [Jamal]*

## **Discussion**

The data revealed two main findings: 1) the variation and texture related to people's beliefs about HIV, including ideas related to the origin of HIV, its treatment, the possibility of a cure, and the role of the government and pharmaceutical industry in the epidemic; and 2) endorsing these kinds of beliefs does not necessarily directly impact engagement in care or ART adherence. Participants' beliefs about the government and pharmaceutical industry

highlighted the intersectional nature of social exclusion, particularly the racism and classism facing low income PLWH who belong to racial and ethnic minority groups. Notably, HIV care providers did not appear to be perceived as part of the government-pharmaceutical power complex, suggesting that while many people may endorse these types of ideas, endorsement does not necessarily directly impact engagement in HIV care.

Participants' accounts, that is, their articulations of their beliefs in their own words, highlighted dimensions that can inform our understanding of so-called HIV-related "conspiracy beliefs." First, illuminating variation and texture of various beliefs; second, revealing a strong socioeconomic component, which intersects with the racial inequality experienced by participants; and third, the ideas about the nature of the targets and conspirators discussed by participants that pertained to their perceptions of the government and the pharmaceutical industry.

In the above quotes, participants' experiences and understandings of powerlessness were revealed as having both targets and conspirators. Coming from people largely living on the margins of society- that is to say, socially and economically excluded- these narratives identified an incredibly powerful government-pharmaceutical complex that colludes and schemes to target "poor minorities." In many cases, the terms "the pharmaceutical industry" and "the government" were used interchangeably by participants suggesting a broad, structural mistrust of medication-producing corporations, backed by, or intimately connected to, the government. Sometimes the word "scientists" was used to refer to researchers that work for pharmaceutical companies and/or the government, which highlights how

participants were often aware that many kinds of researchers and scientists receive government funding.

Many participants endorsed origin-related beliefs and believed strongly that the government was responsible for deliberately creating and releasing HIV to specifically target low income racial and ethnic minority people, and possibly substance users and gay men. However, it is also important to document the perspectives of those who do not endorse such ideas. Even when participants disagreed with, or dissented from these ideas, there was a widespread recognition that racial inequality contributed to the prevalence of these beliefs. Previous literature has focused almost exclusively on the ways in which these kinds of ideas are associated with minority groups [17,18], but this study appears to be the first to explore the diversity and texture of viewpoints from the same socio-demographic population.

Pharmaceutical, or cure-related, beliefs were the most common so-called “conspiracy beliefs” shared by participants. The expression of these ideas largely converged on the thought that the medication treatment for HIV is “big business” that makes “billions of dollars” for the pharmaceutical industry and the government. For example, many participants also cited the enduring good health of Magic Johnson as evidence that a cure was indeed already available, but only accessible by the wealthy. This belief was reinforced for many by the knowledge that HIV medications are extremely expensive, and this awareness, in turn, reinforced their understanding that the selling of HIV medications is vastly lucrative for pharmaceutical companies. The perceived profit margin was further reason to conclude that releasing a cure for HIV would go directly against the interests of the pharmaceutical industry and the government. This conflation points to how participants perceived pharmaceutical companies to be co-conspirators with the government, and vice versa.

Moreover, it is important to note that participants' knowledge of research funding politics, as noted above, as well as their knowledge of the extremely high cost of ART, are centered around widely-accepted facts about the pharmaceutical industry. In particular, it is well known that HIV treatment is extremely expensive, and cost-prohibitive for millions of people around the world [24]. Thus, so-called "conspiracy beliefs" seem less paranoid when examined in the context of research and development politics, capitalism, a pervasive lack of access to expensive treatment globally, and the intertwined forces of racism and classism.

Although most participants expressed deep suspicion of the government and the pharmaceutical companies, the data did not suggest that participants generally felt that individual health care providers are similarly powerful. This possibly suggests that participants did not perceive their providers to be motivated by greed or to benefit financially from prescribing ART. Although some participants mentioned pharmacies and, even less frequently, hospitals as part of the government-pharmaceutical power complex, these inclusions signaled that these entities were perceived as directly benefiting from the sale of ART. HIV care providers did not appear to be perceived as or considered co-conspirators with the government and pharmaceutical industry, although it was unclear whether or not participants believed that HIV providers were aware of the government-pharmaceutical collusion. Although some previous research has found that minority populations may be distrustful of health care systems [19,20], these findings are suggesting that people can harbor mistrust, even extreme suspicion, toward health and medical structures, but are able and desire to foster collaborative relationships with their respective HIV providers.

It is important to note that all participants in the study believed that ART allows people to live longer, healthier lives. Therefore, strong beliefs about the nefarious activities of the

pharmaceutical industry and government did not detract from people's acknowledgement and belief that the medications produced by the industry are indeed life-saving (even if they believed that drug companies are not motivated by compassion and are in fact motivated by profits). Rather, the very fact that ART is so incredibly effective in prolonging people's lives and improving the quality of their lives, and that this treatment success in turn also extends the consumption of ARTs was one reason why participants believed that a cure was being withheld. Treatment success, in other words, produced and reproduced a robust market of consumers. In this sense, the efficacy of ART was itself evidence that: first, pharmaceutical research has advanced enough to have produced a cure by now, and second, the accepted efficacy of ART and vast improvement over drugs available in the AZT era has enabled pharmaceutical companies to sell extremely expensive medications that are required to treat what can be a long-term, chronic illness -- an unintended consequence of the treatment advances in HIV.

Although most participants endorsed some variety of origin or pharmaceutical-related belief (most commonly the latter), some expressed uncertainty or dismissiveness toward origin- and pharmaceutical-related beliefs due to a concern that delving into such ideas could derail participants from managing their HIV and their health. Expending time and emotional energy pondering "conspiracy belief"-type ideas was perceived as unproductive and even detrimental to efforts to focus on their health and other life challenges. In this sense, participants viewed time and energy as finite resources. Thus, some participants considered thinking about "conspiracy belief"-type ideas and managing their HIV, general health, and life challenges as an "either or" situation. This is a departure from the majority of public health literature, which suggests endorsing such beliefs is negatively associated with

engagement and adherence [21,22]. These findings provide an opportunity to reframe how we conceptualize the role of origin and pharmaceutical/cure-related ideas in the lives of socially and economically marginalized people.

### **Limitations and challenges**

This study utilized a purposive sampling technique to enroll 27 participants who were living with HIV, and had been recently, or were currently, disengaged from outpatient HIV care at the time of the interview. Although the sample size was modest, the interviewer achieved thematic saturation with the completion of 27 in-depth interviews. Moreover, the sample was diverse in terms of engagement status, that is, included participants that were at various stages in their re-engagement process, thus suggesting that this sample reflected the experiences of the larger population of low income people of color contending with challenges related to engagement in HIV care and consistent ART adherence.

Another challenge that emerged in this study was the different operationalizations of engagement and adherence in regard to the quantitative data and the qualitative data. The IAQ's response choices for the items that were used to evaluate engagement were limited to fixed categories that appeared to have inadvertently resulted in a social desirability bias during the survey portion of the interview. The combination of the desirability bias and the instrument design-related limitations related to recall over six-12 months appeared to have resulted in a higher percentage of participants reporting they regularly attend clinic and consistently take their ART than was actually the case, as discerned during the qualitative portions of the interview. Thus, some participants' quantitative data did not cleanly match the information they shared during the semi-structured portion of the interview. However, it is probable that the social desirability bias was offset during the in-depth interview during

which a greater sense of trust and rapport was built over the course of the qualitative portion of the interview. Moreover, qualitative probing allowed for participants to provide nuanced responses to questions regarding their disengagement and re-engagement experiences.

Finally, although the topic of “conspiracy beliefs” is often regarded as a social taboo or controversial, thus possibly increasing the likelihood of desirability bias, the interviewer took special effort to avoid making pre-judgments about participants’ beliefs. In order to provide an open, non-judgmental environment, the interviewer-administered questionnaire did not inquire about these kinds of beliefs, which allowed the topic to emerge as organically and neutrally as possible during the course of the conversational portion of the interview. Participants tended to raise the topic themselves, but in absence of that, the interviewer used neutral language to ask about beliefs regarding the efficacy of ART, the possibility of a cure, the role of the government, if any, in the epidemic, and the nature of the possible origin of the virus. These strategies, in addition to the extensive training the interviewer received on how to elicit sensitive information, helped reduce the chance of social desirability bias, and encouraged participants to speak candidly and openly about their belief system and their experiences with HIV care.

### **Recommendations for further research and practice**

This data provides an opportunity to reframe how we think about “conspiracy beliefs.” Here, Garfinkel’s concept of “cultural dopes”-- society members that mindlessly reproduce social norms -- is useful for drawing attention to a more nuanced understanding of the meaning of origin and pharmaceutical-related beliefs among low income people of color [23]. These narratives provide an account of life on the margins of society: the perspectives

of people who are often made powerless by intersecting structures of racial and socioeconomic inequality. Rather than being cultural dopes- specifically *minority* cultural dopes that endorse stereotypical, paranoid ideas associated with racial and ethnic minority groups- participants were largely reflective, critical and thoughtful about their own lived experiences. Thus, these findings present an opportunity to reframe the notion of “conspiracy beliefs” and more precisely contextualize them as not only reflections of the consequences of deeply rooted patterns of social exclusion based on race and class, but also of diminished expectations of health care quality based on past and ongoing experiences of structural and interpersonal racism and discrimination [24].

Although widely used in the public health literature, the term “conspiracy beliefs” is problematic and does little to enhance our understanding of why people endorse such ideas, or the role that they may play in people’s everyday lives. Replacing the phrase “conspiracy beliefs” with more precise terms that describe people’s beliefs in a less judgmental and discrediting way -such as origin of illness-related beliefs and pharmaceutical or cure-related beliefs- has the potential to create more space to be critical in our efforts to understand this phenomenon, and thus design more effective interventions to improve engagement, adherence and retention.

Importantly, the data suggest that people can endorse these types of beliefs, and successfully engage or re-engage in care and become adherent to ART. Previous studies on the relationship between HIV-related “conspiracy beliefs” and engagement and adherence have produced mixed results, but most suggest that holding such beliefs negatively impacts care [25]. However, most of these studies were quantitative in nature and examined the beliefs of PLWH who were engaged in care. This study is unique in its qualitative



exploration of such ideas among a sample of participants that were largely inconsistently engaged and adherent at the time of their interviews. While some of them had successfully become re-engaged and consistently adherent after periods of disengagement, most of the participants were still attempting to become more consistently engaged and/or adherent. Notably, all participants in the sample had been disengaged from outpatient HIV care within at least one to three years prior to their interviews. Thus, this study was able to explore these beliefs among a group of people that were either currently struggling with consistent engagement and ART adherence, or had recently managed to re-engage or re-start ART.

Moreover, these findings suggest that public health does not need to endeavor to dislodge origin- or pharmaceutical/cure-related beliefs; in fact, the data suggests that it may not be possible to change these beliefs, as they are inextricably linked to people's experience of racism and classism. Interventions should instead focus on building trust between health care providers and populations that have been experienced both historically and ongoing socially and economic marginalization. It is meaningful and encouraging that HIV care providers did not appear to be perceived as part of the government-pharmaceutical power complex; although the beliefs explored here provide perspectives on social and economic exclusion and powerlessness, the data suggests that endorsing such ideas are not necessarily incompatible with engaging in care, re-establishing care, or the genuine desire to take one's ART consistently. In an era of public health messaging that encourages the use of PrEP for higher risk groups, and ART for all people living with HIV, it is imperative to understand the meaning and significance of HIV-related beliefs among communities that are socially and economically marginalized.

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## **Managing ART-related obstacles and the desire for therapeutic alliance with providers (experiences re-establishing care and/or re-starting ART)**

### **Abstract**

*Background:* Despite advances in HIV medication, many PLWH do not link to care upon diagnosis, do not remain engaged if linked, and do not achieve viral suppression through consistent ART adherence. Not achieving viral suppression is associated with low CD4-cell counts, preventable hospitalizations, frequent emergency room usage, risk of developing a drug resistance, and excess morbidity and mortality. Despite extensive literature that explores barriers to care, these disparities remain, particularly among racial, ethnic and sexual minority groups.

*Methods:* Over the course of one year, 27 semi-structured, in-depth interviews were conducted with low income PLWH of color living in the NYC area that are currently, or were recently, disengaged from outpatient HIV medical care. Additionally, a brief questionnaire was administered to obtain demographic and engagement/medication adherence data to describe the sample of participants.

*Findings:* Facing challenges related to taking ART consistently, and strategizing to overcome them, were facilitating factors for participants that had successfully re-established care, or were trying to re-engage in care. Endorsing positive beliefs about the efficacy of ART, and the belief that HIV can be a chronic disease if treated consistently also helped participants remain adherent or desire to re-commit to taking it consistently. Finally, the data revealed that participants appreciated, and desired, providers that engaged in patient-centered medicine. Having HIV providers that made them feel genuinely heard and cared for, particularly in regard to decision-making about ART issues, contributed to participants feeling agentic and more likely to remain in care and adherent.

*Recommendations:* Participants' emphasis on wanting to manage their ART-related challenges *with* their providers suggests that HIV providers have an instrumental role in not only lowering viral loads and achieving viral suppression, but also helping their patients feel agentic and able to manage their HIV. Implementing patient-centered medicine will also engender trust, thereby helping patients internalize the belief that consistent ART adherence makes HIV a chronic, manageable illness.

## **Background and significance**

HIV is now considered a chronic and manageable illness as a result of the advent of highly effective antiretroviral medication [1,2]. Consistent ART adherence is a critical part of the HIV care continuum (also called the HIV treatment cascade), which comprises the stages from first being diagnosed with HIV, becoming linked to care, and then remaining engaged and adherent, ideally culminating in viral suppression [3,4]. However, US-based studies have found that of those diagnosed with HIV, nearly a quarter (23%) do not link to care, and of those linked to care, 49% are not successfully retained in care [5]. Only 28% of people living with HIV (PLWH) are virally suppressed [6]. According to the CDC, “The largest lost opportunity to achieve a suppressed viral load in the U.S. occurs among individuals who have failed linkage to or retention in HIV medical care.” [7] Many PLWH, and especially those who belong to racial, ethnic and sexual minority groups, are not receiving ongoing HIV medical care [8-10]. Patients who are disengaged from outpatient care tend to initiate antiretroviral therapy later than clinically recommended. They also often have poor adherence to treatment regimens, which typically results in a number of problematic outcomes, including high viral loads, low CD4-cell counts, preventable hospitalizations, frequent ER usage, excess morbidity and mortality, and an increased likelihood of developing a drug resistance [11-13]. Moreover, poorly controlled HIV contributes to the transmission of the virus to sexual and drug using partners [11-13].

A wide range of barriers to HIV care has been well-explored in the literature. These include, but are not limited to, housing instability, mental health issues, substance use, ART side effects, and unsatisfactory patient-provider relationships [14-16].

However, much of the research on engagement and adherence, particularly barriers to care, has been quantitative in nature [17,18], though some recent studies approached this issue qualitatively [19]. Given how critical ART adherence is to achieving viral suppression, it is important to qualitatively explore how people think about engaging in care and adhering to ART, and to allow them to use their own words to describe how they feel about taking antiretroviral medication and the relationships they have with their providers. A qualitative perspective can add to our understanding of these complex phenomena and help contextualize some of the previous findings and make rhetorical space for patients to articulate, in their own words, their struggles with engagement in outpatient HIV care and ART adherence. Thus, additional research is still necessary to explore other possible mechanisms that may contribute to disengagement, as well as the factors that help facilitate re-establishing care.

## **Methods**

### *Sample study population*

Participants for the study presented here were recruited from a larger sample utilized in a previous NIH-funded study (entitled Bedside to Community, and abbreviated as “B2C”). B2C examined disengagement from outpatient HIV care among hospitalized patients with HIV. To be eligible for the B2C study participants had to: 1) be age 21 or older; 2) self-identify as non-Hispanic Black or Hispanic (of any race); 3) self-identify as HIV-positive; 4) be confirmed as HIV-positive based on medical records; 5) report having been diagnosed with HIV for at least two years; 6) be currently hospitalized in the CUMC Adult AIDS unit; 7) have their most recent CD4 cell count under 350 based on

medical record; and 8) report that they have not seen any HIV outpatient clinician for at least 6 months (please see the appendix for a more detailed description of B2C eligibility criteria, including a revised operationalization of disengagement -criterion 8).

### *Recruitment*

From July 2015 to May 2016, in-depth interviews with a purposive sample of twenty-seven (N=27) PLWH who, at the time of the interview, were currently disengaged from outpatient HIV care, or had been recently disengaged within the previous one to three years. At the end of their B2C interview, individuals were asked for permission to contact them in the future to possibly participate in the study presented here, and if in agreement, asked to provide two to three different contacts (self, family, friend, etc.) to facilitate contacting them at a later date.

The majority of potential participants were contacted via telephone using contact information they provided in the Permission to Contact form during their participation in the B2C study. Five participants were contacted in person when they were hospitalized at Presbyterian Hospital. Of the total 33 individuals successfully contacted (either via telephone or in person at bedside when hospitalized), 27 agreed to participate in the study presented in this paper. Two individuals declined participation, citing lack of time. One participant agreed to participate but was found to be not mentally competent and thus unable to provide consent, and the remaining three were reached via telephone, but then lost again when their numbers appeared to change or go out of service before an interview could be completed.

### *Data collection*

In-depth qualitative interviews can generate novel insights by enabling participants to express their life experiences and perspectives in their own words. Another advantage of semi-structured interviews is that they facilitate the emergence of topics that although unanticipated by the researcher, are salient in the participants' narratives [20,21]. Given the potentially sensitive nature of the topic of one's health and health-related beliefs, both these features of qualitative interviewing honor the participants' ways of thinking and articulating their lived experiences.

A semi-structured interview guide was developed to examine barriers and challenges related to engagement in outpatient HIV care and adherence to ART medication. Interview guide topics included questions about experiences with recent hospitalizations, housing circumstances, experiences with outpatient HIV care, ART adherence and experiences taking ART, other barriers to stable living conditions and/or engagement in care, and thoughts and beliefs about the nature of HIV/AIDS (please refer to the appendix for examples of interview guide questions). The qualitative interview portion ranged from 25 minutes to two hours, with an average of 45 minutes. The briefer interviews were due to participants becoming fatigued due to very poor health; hence, those individuals that were hospitalized at the time of the interview tended to have shorter interviews than those that were in better health and were able to come into the research center to be interviewed.

Prior to the in-depth interview, an interviewer-administered questionnaire (IAQ) was also completed with participants. This five to eight minute survey gathered demographic and health status information (e.g., current housing situation, employment



situation, public assistance status, recent hospitalizations, outpatient HIV care provider visits, and use of ART medication).

In this study, engagement and ART adherence were assessed first in an interviewer-administered questionnaire (IAQ), and afterward discussed in-depth in semi-structured interviews. The IAQ and the qualitative interview operationalized engagement/disengagement and adherence/non-adherence in distinct ways. The IAQ, which was completed first, assessed engagement and adherence with items that asked participants about any outpatient HIV care they had received in the prior six to 12 months, including scheduled but missed appointments, as well as the spacing between each clinic visit. ART adherence was assessed with items asking participants if they were currently taking ART at the time of the interview, and if the ART was taken as directed. If participants indicated they were not currently on ART at the time of the interview, the IAQ assessed their intentions to begin taking ART in the next six months.

After the IAQ, the semi-structured interview took place. The qualitative approach to categorizing participants by engagement status allowed for a descriptive, but less rigid, operationalization of engagement and adherence. Qualitatively, participants could be classified as consistently engaged, inconsistently engaged, or disengaged. The “consistently engaged” category indicated uninterrupted engagement over a period of at least the past 6 months, which necessitated both clinic attendance and ART adherence. “Inconsistently engaged” was a broad but descriptive category in which people may have only very recently re-established care (for a example, a few weeks prior to the interview), were taking their ART consistently but frequently missing HIV care appointments, or were attending their HIV care appointments regularly, but still struggling to take their

ART as directed. The category of “disengaged” indicated participants that were inconsistently attending clinic and not taking their ART on a regular basis or as directed.

### *Data analysis*

All interviews were audio recorded for professional transcription. Twenty percent of the transcriptions were randomly selected for quality control and accuracy conducted by the first author (JJ). Analyzing qualitative data necessitates the development of a rigorous and organized method of managing and analyzing a complex set of data. This method must also ensure that the analysis plan does not compromise the conceptual richness of the data. The first author (JJ) implemented a multi-step method to systematically identify and contextualize the themes present in the data, which included developing a coding scheme and using it to discern patterns, themes and subcategories. The scheme was a hierarchically organized tool that ranged from the more general and abstract to more specific concepts. At the top of this hierarchy, the author (JJ) identified the analytic foci, which were coded as headings, then the core codes that refer to specific aspects or dimensions of the headings, and finally, sub-codes that refer to specific dimensions of the core codes. An example of a core code is “good patient-provider relationship,” as defined by participants, and examples of related to this code subcodes are “provider genuinely cares for patient” or “provider listens closely to patient.” After all of the transcripts were read multiple times and then coded, text segments organized by codes/subcodes were extracted in order to begin discerning higher levels of abstraction and to identify relationships among the various codes. The software Atlas.ti was used to organize the qualitative data. Data from the Interviewer-administered questionnaire data

were analyzed using SPSS and used to generate a description of the sample of participants.

## **Results**

### *Quantitative findings*

Of the 27 participants, 59% were female (n=16), 41% male (n=11), 78% non-Hispanic Black (n=21) and 22% Latino (n=6). Participant age ranged from 28-55. Seventy-four of the sample reported living in an apartment, SRO or room supported by public assistance and/or HASA (n=20). Twenty-six percent reported living specifically in an SRO (n=7) (of which are sometimes paid by HASA); 11% nursing home or hospice (n=3); one person reported being incarcerated at Rikers Island, and another was attempting to get their HASA re-instated after a paperwork mistake and was staying with a friend to whom they were paying rent. Thirty percent reported that they were homeless in the past 12 months (n=8).

One hundred percent of the participants had Medicaid; two participants had both Medicaid and Medicare. Eighty-nine percent reported being unemployed at the time of the interview (n=24), one person was employed part-time, and two were employed full time. Specifically, 74% reported that they were unable to have a full time job due to not feeling well enough (n=20); 37% were not sure if they will stay well enough to maintain a job (n=10); 33% were fearful of losing medical benefits or other benefits if they worked (n=9); and 8% reported having to care for someone else, such as an ill family member (n=2).

Seventy percent reported that they had gone for emergency care at a hospital emergency room (n=19) in prior six months to the interview. Among those that indicated they had gone to an emergency room (n=19), there was an average of 2.6 hospitalizations in the past six months; 95% of these participants reported that they were hospitalized overnight or longer.

Using a 12-month interval, 78% of participants had visited a doctor or clinic for HIV care at least once (n=21), and 70% (n=19) reported having been to two or more scheduled medical visits at an HIV outpatient clinic and these visits were separated by at least three months. In the prior *six* months, 74% of participants had attended a scheduled visits and were examined by an HIV care provider (n=20); of these, 77% reported having missed at least one scheduled appointment (n=17). Finally, 81% (n=22) reported being currently on HIV medication at the time of the interview.

**Table 1**

Participants' characteristics		N
Gender	Female	16 (59%)
	Male	11 (41%)
Race / Ethnicity	Black Non-Hispanic	21 (78%)
	Hispanic /Latino	6 (22%)
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%)
Employment status	Homeless	8 (30%)
	Unemployed	24 (89%)
	Employed full or part time	3 (11%)
Health Insurance	Medicaid	25 (93%)
	Medicaid + Medicare	2 (7%)
ER use past 6 months	Yes	19 (70%)
	No	8 (30%)
Attended HIV care past 12 months	Yes	21 (78%)
	No	6 (22%)
Attended HIV care past 6 months	Yes	20 (74%)

	No	7 (26%)
Attended $\geq$ 2 HIV visits past 12 months	Yes	19 (70%)
	No	8 (30%)
Currently taking ART	Yes	22 (81%)
	No	5 (19%)

Adds up to <100% because some participants considered themselves homeless in addition to the housing category they selected (often an SRO or other form of temporary housing)

### *Qualitative findings*

#### **Theme 1: The art in taking antiretroviral treatment (ART)**

Participants were eager to discuss their various experiences and struggles with ART. The first subtheme, addressing obstacles related to taking ART consistently, was discussed by both those currently adhering to their ART regimen, as well as by those desiring to start or re-start ART in the near future. Although many contended with side effects, participants seemed especially interested in discussing challenges unrelated to side effects (e.g., pill fatigue, temptation to sell the ART, or being overwhelmed by the quantity of pills), and the strategies they devised to overcome or manage these challenges. Challenges often had both a physical and a mental aspect, which could mean that the obstacle was perhaps physical but required a psychological strategy; or that the obstacle itself was both physical and mental in nature, such as in the case of pill fatigue, where participants were physically and emotionally tired of taking daily HIV medication.

The second subtheme, beliefs related to ART, revealed participants' beliefs related to the notion that taking ART was necessary for long-term survival. Overall, participants had to think about and employ strategies to overcome various obstacles to their consistent life-long adherence, and positive ART beliefs facilitated their desire to remain adherent or to become adherent.

### *Non-side effect related challenges to ART adherence and management strategies*

Although fear of side effects, or experiencing distressing side effects posed serious potential and actual barriers to adherence or re-starting ART, participants also discussed other physical and mental challenges related to taking daily HIV medication, such as pill fatigue, problems swallowing the pills, and forgetfulness. For example, some struggled with what they often termed “pill fatigue,” and expressed the desire to take “pill holidays,” or other reported aversions to swallowing pills. Participants were both thoughtful and eager to reflect on their adherence challenges, and their devised strategies for overcoming them. Moreover, they were often very aware of their respective tendencies that led to non-adherence, such as past experiences with selling their ART, or the reasons underlying their aversion to swallowing pills, and discussed possible ways of addressing these tendencies that undermined their health and threatened their life.

Participants often used the phrase “pill fatigue” to describe being tired of taking HIV medication daily. This phrase indicated both being physically and mentally worn out from having to take ART daily. For example, Maria, a 34-year old Latina woman, was undetectable for the first time in her life, and was living in a nursing home at the time of the interview. She attributed her previous disengagement from medical care to her alcohol abuse. However, she had managed to become and stay sober since 2014, and this enabled her to manage her multiple health issues, including HIV and recently diagnosed narcolepsy. She also was part of an ART adherence program, which required her to send a text message when she took her medication. In the past, Maria had struggled with what she described as “pill fatigue,” but had enrolled in a cellphone/web-based adherence support program:

*Interviewer: Do you think you'll have—what will happen if you start encountering pill fatigue again or you don't want take your HIV meds? How will you deal with that?*

*Maria: Well, I have an alarm set on my phone, so it constantly goes off if I don't. I get annoyed...If I don't type "okay" in a certain amount of time, it keeps going. It's with a program called [name]...It's been working good. Sometimes I take my medication, I forget to text "okay," so I gotta go online and go to the website and let them know.  
[Maria]*

Luis, a 55-year old Latino male, was diagnosed in 1988. At the time of the interview, he was preparing to leave his nursing facility of two years to move into an SRO until HASA could help him find an apartment. He had recently re-started ART, and was determined to take them consistently and avoid taking what he called “pill holidays”, i.e., periods of time when he would not take his medication. He also revealed that the motivation for taking a pill holiday was to feel normal and in control of his life, whereas when on medication, he felt he relinquished control of his life to the pills:

*Interviewer: Since we saw you last, two years ago, have you had any of those feelings, that medication is just a negative reminder? [note: the participant had articulated that taking ART had been a constant “negative reminder” of his status in his first interview].*  
*Luis: Sure, sure. To say no, I would be lying. Of course, I still get like that from time to time, that I say, damn. I have to take these pills for the rest of my life, and it's a constant reminder...We have a thing—people that have the virus have a thing called—they take a [pill] vacation... Off for a couple of [meds], and I think I'm just gonna enjoy life. Just forget about everything. Just put everything down and try to be as normal as I can... I do that now and then, yeah. When I do it [take a pill holiday], I feel like I'm in more control of my life, man...I feel that I look at these pills and these things [are] controlling me...when I take the holiday and vacation, I feel in more control of my life. I'm not sick. I don't have HIV for today. I don't have no heart condition. I don't have nothing. [Luis]*

To help keep himself adherent, Luis also planned on asking his HIV provider for a pill tracker to assist him in remembering to take his ART:

*As far as taking my [meds]—I'm gonna do everything in my power to keep up. I'm gonna get one of them—have a thing where they have—where it has days, and you got the pills in there... I'm gonna ask [my doctor what] to do—issue me one of those so I can*

*put everything in that, yeah. Get me a watch with a timer, or on my phone. [Luis]*

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. She reported having struggled with taking her ART consistently due to her aversion to swallowing pills. She had tried to crush them or break them apart, but the taste was equally challenging. Over time, she had to train herself to swallow the pills whole, which helped her become adherent. This obstacle, which was physical in nature, required her to develop a psychological strategy to overcome it:

*... I just never liked to swallow pills, and I had to learn to take my meds if I wanna live. I tried the crushin' up thing, like I told you before. I don't like the way the pills taste...I had to learn how to swallow my pills. One time, my husband had to break 'em in half, and I take it like that. I didn't like that way, so I had to force myself to let it slide down. I had to drink a lotta water. Once I got used to doin' that, I said, I could do this. I took my meds. [Tanya]*

At the time of the interview, Jada, a 28 year old Black woman who was born with HIV, was inconsistently taking her ART, but desired to become undetectable in order to become eligible for a kidney transplant. Her difficulties becoming consistently adherent were exacerbated by her extreme aversion to pill-taking, which she described as a psychosomatic reaction stemming from a lifelong need for various medications to manage her multiple chronic conditions, that is, primarily HIV, but also diabetes and a kidney-related illness.

*... I have to find the space where I understand that it's mind over matter...It doesn't matter what med it is. It really doesn't. It can be HIV meds. It can be diabetic meds. I think any meds will make me nauseous...Just the thought alone still makes me ill a little bit, uneasy in my belly. I don't know how it got programmed in there like that. I don't know if I'm traumatized as a child... I don't know how to eliminate that out of my*



*mind...I'm workin' on it...I'm trying ways of taking meds and then not having to really be coherent after... I'm noticing that it's better. It's getting better this way—...It's like, maybe, [taking it at the] end of the day stuff or early morning, morning. Then it's just like when you go in the day, everything else starts to occupy your mind so you're not thinkin' about it. When you go to bed, you take 'em...Then you're dreaming all night. Even if it is bothering your tummy, you never leave [the house]. That's how I'm working with it. Otherwise, if I try to take it, 2:00 p.m., then say, "Hey. This is my lunch break. Let me go eat some lunch. Take 'em." Maybe I won't go back to work. Now, I'm in the bathroom, like, "Oh, God. I feel like I gotta vomit...." It's just now I'm all in a frenzy... Where did all this stuff come from? The back of my mind. My mind knew it was medication time. [Jada]*

Donna, a 33 year old Black woman diagnosed in 2008, planned to re-start ART again after a period of inconsistent adherence due to pill fatigue. Being offered a one-pill-a-day option (e.g., Atripla, Stribild) helped her feel able to commit to taking ART again:

*Donna:: My thing is I have a thing with a lot of pills. If it's two pills, three maybe I can do it but when it's like six, seven pills I'll be like, "No, I don't feel like taking it today." ...At that time I was on a lot of different pills. I'll look at them, but I just won't pick them up. ...*

*Interviewer: What goes through your mind when you're looking at all the bottles.*

*Interviewee: It's like, "I'll take them later."*

*Interviewer: When you were on it you said there were several pills. How regularly did you end up taking it?*

*Interviewee: Maybe like twice a week...I'm tired of taking pills. I'm tired of having to eat before I take the pills, then they tell don't take the pills right away. Then you get an upset stomach. I have this thing where I do not like when my stomach is hurting, I don't like to feel nauseous all day, so after a while I just stopped...[my doctors] gave me some nausea medicine but it didn't work...*

*Interviewer: ... So you think you might start medication again in the near future?...How do you think you'll deal with the fact that it might be more pills?*

*Interviewee: Thankfully it's only going to be one... it's just one pill and I can handle that. It's just that more than one pill I can't really. [Donna]*

Although not all people living with HIV are a good match for the one-pill-a-day regimen, those who had switched to this simpler regimen reported that a single pill (versus multiple pills a day) helped them consistently take their medication. The challenges associated with taking multiple pills per day - e.g., pill fatigue, side effects, forgetfulness, trouble with swallowing - were greatly ameliorated for the participants on a one-pill-a-day regimen.

For those who felt overwhelmed by receiving a month's supply of ART, choosing to pick up their ART daily or weekly was an effective strategy that helped them adhere. Juan, a 49 year old Latino man, was diagnosed in 1984. He re-started ART the day of the interview, after being off ART for nearly a decade due to living in Mississippi, according to his interpretation (he stated that Mississippi did not provide HIV care to low-income residents who were reliant on Medicaid). Juan was concerned that having a month's supply in his possession would tempt him to sell his medication, as he had done when he was prescribed ART years earlier. To avoid this temptation, he asked his patient navigator to arrange daily pick-up:

*Juan: The pharmacy they sent me to won't give me the jars... Individual days. Everyday I gotta go.*

*Interviewer: [For] how long?*

*Juan: Til I'm ready to take 'em home that I know that I'll take 'em on my own. I'm not ready for that yet. I know that if they give me the jars, I'm gonna sell 'em. Oh yeah. I made an agreement with [the patient navigator] that send me somewhere where I can get them already broken down...I said to her, listen. Even though I'm 49 years old, I'm irresponsible, and I know that if they give me HIV meds, I'm gonna go sell 'em. Even though I get money, it's just out of habit, you know? "Well, we gotta place where you can go to, a pharmacy that will give you a weekly Metrocard every Friday. You go everyday and take your meds." I said, "okay." [Juan]*

Tina, a 53 year old Black woman quoted below, was diagnosed in 1995 and like many participants, had past struggles with pill fatigue, and forgetting to take her medication. She also did not want to receive a full month of HIV medication at a time. Her concern was not the temptation to sell her meds, as with Juan above. Rather, she found that a weekly pick-up enabled her to be mindful of her ART regimen, and avoid forgetting about the pills during the course of a busy or stressful day. Even though weekly pick up entailed traveling from Brooklyn to upper Manhattan, she preferred to obtain a less daunting quantity of pills that enabled her to feel capable of taking them daily:

*...I'll be doin' so many other things that I'll just lay there and just won't take 'em. I know what. That's why I like to come pick 'em up [in Manhattan, from Brooklyn] once a week 'cause then—...Because if I have so many pills, I forget. If I got one case, I'll keep lookin' at that one case. If I got all them cases...sometimes I'm just not thinking about it. [Tina]*

The different use- and adherence-related obstacles described above appeared to make people feel controlled and/or restrained by a daily regimen of ART. By devising strategies to overcome their respective challenges, participants were able to feel more agentic and capable of consistently taking their medication. As all participants in the study had been recently disengaged from outpatient HIV care (with some of them having successfully re-engaged or re-started ART at the time of the interview), problem-solving strategies were necessary in order to achieve their goals of remaining adherent to their medication regimen despite these challenges.

### ***Beliefs related to ART: The Effectiveness of the Current Therapies***

Participants' ART-related beliefs revealed they recognized that HIV was a chronic illness manageable by consistent ART adherence. 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 or 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. All participants shared the belief that ART provided them with the opportunity for a longer, healthier life, and that without it, they would surely die. These positive beliefs about the medication efficacy helped facilitate their adherence, or their

desire and motivation to re-start it. Thus, affirming beliefs about the effectiveness of ART, in combination with other adherence-related strategies, appeared to help override the physical and mental challenges associated with taking ART.

Many participants contrasted AZT-era medication with newer, more effective and less toxic classes of HIV medication. Luis, a long term survivor of HIV, remarked:

*... 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. To a certain degree. 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]*

Tanya, quoted below, 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 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 her happiness that effective medications were now available:

*The medication, it's helpin' me. It's not like it's doin' any harm to me. It's really 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 to 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:

*Interviewer: Are you comfortable with taking medication?*

*Myra: Yeah. I'm cool with it. 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. [Myra]*

For some, including both long-term survivors and those more recently diagnosed, re-starting occurred after being off ART for one or two years; for others, their periods of disengagement or inconsistent engagement were five, ten years or longer. However, regardless of how long they had been living with HIV, people differentiated the highly toxic and ineffective treatments of the AZT era from the currently available classes of ART; this comparison appeared to help them recognize and believe that HIV can be a chronic illness made manageable with consistent adherence.

## **Theme 2: The role of providers in supporting ART use and adherence**

Participants' descriptions of their experiences with and thoughts about ART naturally extended to discussing their past and present interactions with their HIV providers.

Participants recognized, and greatly appreciated, providers that practiced patient-centered medicine. Two subthemes emerged as characteristics participants desired in their relationship with HIV care providers: 1) genuine concern; and 2) feeling heard (respected, included in treatment decisions and being given treatment options). These

subthemes reflect the core features of patient-centered medicine. Participants desired these characteristics in their relationships and interactions with providers, and providers who conveyed these attributes appeared to contribute to participants feeling comfortable and confident, particularly around the issue of taking ART. In discussing these interactions, participants were describing many of the tenets of patient-centered medicine. Having a provider that embodied these characteristics appeared to facilitate engagement in care, and more specifically, retention and adherence.

### ***The value of provider genuine concern***

Participants reported various types of interactions with HIV care providers. Some had been with the same provider for ten plus years, but were not on ART, while others had only recently engaged with an HIV provider on a consistent basis and were on ART. Regardless of whether their relationships with providers were long term or newly established, participants highlighted the importance of feeling that providers were genuinely concerned about them. For example, Jay, a 31 year old Black man, was largely disengaged from outpatient HIV care and not on ART at the time of the interview. He was interviewed at his bedside while hospitalized for fatigue, shortness of breath, and “probably a little pneumonia,” in his own words. At the time of the interview, Jay had been hospitalized for similar reasons twice in the preceding two months. Although he expressed appreciation for the way in which his HIV doctor interacted with him whenever he visited her, he continued to struggle with accepting his status, “I don’t even wanna think about it ... it makes me angry, so I really don’t wanna talk about it.” This lack of acceptance appeared to largely account for his frequently scheduled but missed

appointments, although he stated that he planned to make a clinic appointment to see his provider after his hospital discharge. Jay's doctor appeared to be at least one facilitating factor in his new "goal" to become healthy for at least the sake of his children, "I'm gonna do everything I need to stay around for my children. That's the goal, that's the main goal":

*[Dr. S is] my best doctor...She did everything for me. She lets me know what's gonna happen if I don't do this and don't do that. She just talks to me where I don't have to talk back...She's smart. She always helps me out. Just looking after me. [Jay]*

Cee Cee also expressed why she was confident that her HIV doctor was genuinely concerned about her wellbeing:

*My doctor...She's very—she's into your health. She called me late at night, gave me her cell number. She made me go the hospital...my protein level was high, and my potassium was high. This was about two weeks ago, or three—two or three weeks ago, I was in the hospital. They kept me over night. Then, they brought me back home cuz of the swellin'. I still get edema or whatever in my limbs. She said, "Name." She thought I was gonna through a—she thought my kidneys were gonna stop workin'. She made me go. She's very concerned. [CeeCee]*

Similarly, Sandra, quoted below, described how her HIV doctor's concern for her health conveyed genuine caring, rather than an interest in increasing patient "business":

*I was sick one day, and she, my doctor, just wanted to just wheel me down the emergency room. I was like, "No. I'm okay. I'm okay. I'm okay. I just need some rest. I need to go home and rest." She's like, "It's up to you, now. I'm your doctor, but I really can't force you." I had a little abdominal pain, but it went away. She was so concerned. When I got home that day, she called me, asked me was I all right. That's what also keeps me goin' because there are people out there that really care. They're not people out there just wanna get in your business. There are people that really care, and I think that she's one of the doctors that do care. [Sandra]*

***The value of feeling heard by one's provider***

Related to the value placed on feeling genuinely cared for, participants also emphasized the importance of feeling heard by their providers. Feeling heard entailed feeling included in decisions about their care, especially ART-related decisions such as being given a choice or presented with options in terms of their regimen or discussing together how to select a regimen. These interactions made participants feel respected and promoted a sense of agency, a core feature of patient-centered medicine.

*We talk about everything, so I like her... Meds, my health, and what—how my viral loads go down and what makes ‘em go up and things I should do and shouldn’t do. She’s nice...I feel like she’s honest. I don’t know if she is, but she’s honest with me...She told me certain things, and I believe her. I have no reason not to. She’s my doctor. She talks to me. Most doctors don’t talk to you...none of them other doctors I had didn’t talk to me. They just give me my meds and send me home, or take my pressure and stuff and send me home. They don’t sit and listen to me. [Tina]*

In addition to feeling listened to, feeling heard as experienced through being given the opportunity to co-construct care was also valued:

*[My provider]’s helpin’ me. He changed my meds when I asked him to change my meds. I don’t have no problem with my doctor. [Tanya]*

Janae, a 43 year old Black woman, had been taking ART consistently for a month prior to the interview. She had recently switched to a new medication due to side effects, after an extended period of feeling ignored by her provider. She highlighted how coming to a point where they could “work together” on managing her ART issues with her doctor was essential to establishing a good relationship:

*Janae: ... the [HIV] medication they kept puttin’ me on I kept gettin’ sick. I was catchin’ stomach pains... catchin’ headaches, throwin’ up a lot. Even if I drink water it’s like it was not holdin’ down... They said my T cell was getting’ low...everything was just like—it was not even workin’ at all, at all. I kept goin’ [to the doctors], “I’m not takin’ it,” because it give me night sweats, it make me have bumps and chills and everything. They said, “Oh, it’s part of the side effects.” I said, “I can’t take it because I can’t eat with*



*the meds.” ... I’m not gonna keep takin’ somethin’ that’s gonna make me sick. I’m not gonna take it, you know? I’d just rather leave it, leave it as is. Sometimes I just felt like givin’ up ‘cause I’m like, “If y’all not gonna gimme no pills then just leave it.” Just let it go, ‘cause I’m not gonna keep takin’ somethin’ and I’m gettin’ sick, throwin’ up all the time, not eating, not lookin’ like—not care for my children, not carin’ for myself or the household or anything. This [new] pill is workin’ . ...*

...

*Interviewer: Do you trust your doctor?*

*Interviewee: Yeah, now I do. At first I didn’t, because she didn’t give me the right meds. Now she find me the right one, because, I felt that you ain’t wanna help me. I had that attitude that you did not want to help me....[The clinic] told me she was a good doctor... I’m not gonna down her. She’s damn good... When I come at you—I’m comin’ at you because somethin’ is not workin’. Somethin’ is bothering me. Don’t look at me and say, “Hmm, well maybe you’re not takin’ it right.” I’m like, “You downin’ me? You think I’m not takin’ my meds? Okay, if you don’t trust me, I won’t trust you.” That’s how I felt until we had that communication. I’m like, “Okay, calm the attitude down,” and just tell her, “Well, okay. This is how it is.” I told her how it is and we was workin’ together. Ever since then I ain’t got no problems, no problems. [Janae]*

For Janae, perceiving her provider as not trusting her, or viewing her as a competent patient was initially extremely frustrating, but finally achieving “that communication” enabled Janae to trust her and facilitated her adherence. Janae’s use of the term “downing” to describe feeling disrespected also reflects her desire to share the power and to co-construct a collaborative, mutually respectful relationship with her provider. This collaborative relationship reflects one of the core tenets of patient centered medicine, which is for providers to respect and respond to patients’ concerns. Specifically, her doctor’s recognition that Janae was having a very difficult time living her life as a mother suggested a patient-centered relationship.

Terrence, a 39 year old Black man, was diagnosed in 1989 as a young teenager, but had only sought care in his early 30s, having remained relatively healthy until 2007, when he was diagnosed with AIDS and began ART for the first time. He reported having gone to

clinic very infrequently, and not being able to continue his ART consistently. He attributed his lack of adherence to the “regimented” nature of having to take his medication every day to avoid becoming resistant, and his lack of consistent clinic visits to his good health that lasted from his early teen years to his early 30s. Terrence contrasted his current situation with his past negative experience with a provider. Again, this was expressed in terms of ART options, suggesting that choice, agency, and an atmosphere of collaboration were highly valued. He contrasted his past provider to his current as follows:

*I think it was his workload. I think a lot of it was just it became a generalization. It became seeing patients, patients, patients, and not having the time to separate and say, “Hey, wait.” I don't think he had the time for that. It was like, “Hear me out and listen really well. Take notes and everything.” ...My [current] doctor, she'll give you the [HIV medication] options and say, “Look. I think this,” and get insight from me, and see what my thinking is. “How do you feel about that? What's gonna work for you and the dogs?” It's more in depth. It's more personable, if you will... No, it wasn't about that for my [previous] doctor. It was about, “We're gonna see what works for you.” For me, that was huge, seeing that actually happen. Not her keeping her word, but being just really consistent... To have someone who's real steadfast and really in the middle, whether it be my doctor, or my mother, or my partner. It gives me a lot of comfort... Yeah, she gave me my options and went over my labs with me. When something's good, she—not like makes you feel more good than you need to, but you can hear the genuine, “Okay. We got this. We're on the right path. Keep it up. You're doing good,” sort of a thing. That kind of encouragement kinda pushes me to wanna stay on my meds.  
[Terrence]*

Here, Terrence’s provider demonstrated to him that she was interested in his “insight”, and was genuinely thinking about to the significant role of his dogs into his life. This participant’s main source of strength and support were his two small dogs, Trixie and Pixie. Terrence almost had to give up Trixie and Pixie due to his previous housing instability, and his provider was clearly attuned to the importance of his dogs in his life.

This reflects how Terrence's doctor saw him as a person not just a patient, which is another feature of patient-centered medicine.

In contrast to Terrence's provider who was highly responsive to the most salient aspects of her patient's life, Pablo, quoted below, explained how some providers fail to convey a feeling of genuine concern by appearing inaccessible, or failing to work with the patient to jointly arrive at a solution. Pablo, a 46 year old Latino man, was diagnosed in 2001 and had been enrolled in an outpatient methadone clinic for one week at the time of the interview. He "got in[to drugs] at 12 years old", and had since been struggling with staying sober. At the time of the interview, he felt he was "dying" and needed to immediately start taking care of his health, which required him to begin to manage his substance use. Like many of the participants, Pablo had multiple comorbidities, including hepatitis C-related cirrhosis and diabetes. He had not been on ART for at least the prior seven months (partially due to a paperwork lapse in his Medicaid, but also due to substance use challenges), but expressed a determination to re-start ART, "I'm suffering a lot... I have to start on my medication back. The first thing I'm gonna do, get my medication..." Pablo described the characteristics he appreciated in a provider, as well as expressed frustration at doctors that appeared to not genuinely care or listen to their patients:

*...You got [to have a] doctor that take the time to talking to you. You got doctors that not... You see some doctors, they're not worried about you. They don't really want to work. They no worry about you. They don't have time to ask the questions about it. They gonna tell you whatever he want to say. They're not looking for some solution that you really want ... They respond, [but] you can't say, "Okay, I'm positive. I can't do this. I can't do that." [Pablo]*

In Pablo's experience, a provider that is, "gonna tell you whatever he want to say" as opposed to opening a dialogue with the patient suggests that she or he is not -committed to working with the patient, and more specifically, to "hearing" the patient's concerns and opinions.

Aliyah, a 28-year old Black woman, also reported that she was interacting with a provider that did not appear to be interested in "hearing" her concerns. Aliyah, born with HIV, had been adherent to her HIV medication (one pill a day for the last year), but had been avoiding her HIV care provider around the time of the interview. She had been recently transferred from the pediatric HIV clinic to the adult clinic, and explained that she felt forcefully transitioned against her wishes. During the six months prior to the interview, she had been hospitalized six times for potassium-related issues. Aliyah largely attributed her inconsistent, precarious engagement, i.e., not attending regularly scheduled appointments and only going to see her HIV provider if she had a non-HIV related problem, to the way in which her care was transferred from pediatric to adult care, as well as her provider's apparent lack of concern about her drastic weight loss:

*I was in [the pediatric HIV clinic] and then they basically told me when I was in the—I was in the hospital that they made me an appointment with this [new doctor at the adult HIV clinic]. I basically had no choice but to go to him. That's what I felt. Now I feel like I'm stuck with this doctor...the last time I did the interview I had to be about maybe 180, 170 [pounds]. Right now I'm 114. That's a lot of weight to lose and not try to lose it. It's just coming off and just because I've been under a whole lot of stress...My doctor that I have now doesn't—like he tells me that it's the medicine. Basically if I take the medicine I'll gain weight. That's what I've been doing. I've been doing the medicine but I'm still losing weight, and he doesn't want to do anything about that.... Personally I feel like he's just telling me what the—I guess what the doctor books say, you know, "Just take your medicine and you'll be okay," but it's not—I'm still losing weight and no matter how much I eat... That's why I really don't like him too much. Any times I do go to him, like I'm in extreme pain or like ...I'll have an ear infection, which I did have and I*

*went to him. I really don't go to him for my other stuff that's going on. I don't do it. It's something physically wrong with me, like my foot hurts or my back is aching, I might go to him to try to fix it. Dealing with the HIV, I don't go to him for that.*  
[Aliyah]

Overall, the value placed on feeling heard, which entailed not only being listened to, but having one's opinions solicited and taken into consideration, largely was expressed in the context of ART and making ART-related decisions. In addition to ART decisions, participants also discerned and desired the following features of patient centered medicine: being seen as a person, not a just a patient; their provider engaging in communication and behavior that allows a more equitable distribution of power; and establishing a therapeutic alliance. Underlying these subthemes was the value participants placed on feeling genuinely cared for by their HIV care providers, which was underscored by being included in important decisions about their care, a process that engendered patient agency.

## **Discussion**

People's ability and desire to engage or re-engage in care and/or re-start ART varied and depended on multiple factors, structural (e.g., housing, benefits' eligibility, or access to substance use treatment), interpersonal (e.g., primarily relationship with HIV provider), and intrapersonal (e.g., acceptance of one's serostatus or use of substances). This paper focused on just a few of these interconnected factors: contending with non-side effect related ART challenges, positive beliefs regarding ART, and experiences with providers. The physical aspects of ART-related challenges included difficulties taking their medication, such as an aversion to swallowing pills. Psychological obstacles included pill fatigue, or having negative associations with pill-taking, primarily being

reminded of one's seropositive status. There was often an overlap between physical and psychological barriers. For instance, overcoming a swallowing issue is both physical and mental by nature and necessitates thinking about and employing strategies to manage or overcome both aspects of the problem (e.g., changing to one-pill-a day regimen and working to accept one's HIV status and the need to take medication). Most common strategies to manage these barriers included changing medications to avoid or decrease side effects (e.g., changing from a multi-pill to a one pill regiment), devising routines that mitigated the challenges (e.g., enrolling in an adherence program to remain motivated to adhere or address forgetfulness), and generally trying to understand the underlying causes of their particular obstacles (e.g., recognizing that a monthly supply of ART generated the temptation to sell them and using the money to engage in substance use).

Control over health seemed to symbolize or connote control over one's life, a notable finding given how socioeconomically disadvantaged the participants were, and how limited control they had over most domains of their lives. Here, Cockerham's theory of health lifestyles is useful for illuminating the interface between structure and agency [22]. Informed by Bourdieu's concept of habitus [23], this sociological theory highlights the relationship between structure and individual agency, and postulates that structure (defined as life chances) and agency (defined as life choices) interface and produce a person's habitus. This framework renders visible the complex ways in which people's health dispositions (health habitus) and practices are influenced by social structure. In particular, social structure deeply influences people's experiences with the health care system and their health-related decision-making and behavior, including disengagement and ART non-adherence. Over time, health practices become solidified into health

lifestyles [22]. Importantly, these findings suggest that when offered opportunities, participants who in the larger socioeconomic context have been deprived of agency, were able to develop strategies to improve their ART adherence, and to participate and desire patient-centered care. For example, by effectively addressing the obstacles to ART adherence and experiencing improved health, participants expressed feeling more in control of their illness and lives. Similarly, having positive beliefs about the medication efficacy helped facilitate their adherence, or their desire and motivation to re-start it. Therefore, a type of latent, but significant outcome of adherence to treatment for participants, was a strengthening of their agency. Affirming beliefs about the effectiveness of ART, in combination with other adherence-related strategies, appeared to help override the physical and mental challenges associated with taking ART. These findings support previous research that has suggested agency, often measured as self-efficacy in public health, is conducive to ART adherence [24,25,26].

Having a provider that practices patient-centered medicine appeared to help participants contend with their respective ART challenges, and this also strengthened participants' agency [27]. Participants discussed the importance of having a provider that makes them feel genuinely cared for, and respected, which was often expressed as feeling heard and making joint decisions regarding ART regimens and other aspects of their health care. These provider-patient relationship characteristics reflect the model of patient centered medicine. These findings affirm previous studies that have emphasized the importance of patient-centered medicine in the context of HIV care [28-31]. For example, a 2013 study found that feeling "known as a person" by their provider was a facilitating factor in engagement and retention for urban PLWH in Baltimore, MD [29], which was

very similar to the context and data presented here that emphasized the importance of patients "feeling heard" by their providers.

It is significant that participants recognized who practiced this type of medicine, and that their provider doing so facilitated their ability to engage and adhere consistently. In particular, the issue of jointly choosing a regimen, or being offered treatment options and being invited to choose a regimen with one's provider, was highly valued as a signifier of respect and collaborative care, the kind of care that bestowed dignity to the patient and bolster his or her agency. Importantly, although most participants reported having access to social workers, case managers and other clinicians, they largely emphasized the importance of their HIV care physician in terms of their adherence. This in part could be due to the physician's role in changing their ART regimens. Thus, even though many participants experienced clinical team-based care, the unique importance of their HIV care doctors stood out as highly salient.

Given the salience of the challenges posed, whether physical or emotional, the experience of being given choices, and perceived as a partner in care, appeared transformative in helping people feel confident and optimistic about being able to adhere. Overall, these findings suggested that the presence of these interpersonal facilitators engender agency, motivate and support people to remain engaged in care and adherent to their ART.

### **Limitations and challenges**

The study presented here utilized purposive sampling to enroll 27 HIV-positive participants, and had been recently, or were currently, disengaged from outpatient HIV care at the time of their respective interviews. Although the sample size was modest, the



thematic saturation was achieved with the completion of 27 semi-structured interviews. Additionally, the sample enrolled participants that were at various stages in their re-engagement process, thus making this sample is a good reflection of the larger population of low-income people of color contending with engagement and adherence challenges. While some had successfully become re-engaged and consistently adherent to their ART regimens after periods of disengagement and/or non-adherence, most participants were still contending with challenges related to consistently engaging and adhering. It is important to note that all participants in the sample had been disengaged from outpatient HIV care within at least one to three years prior to their interviews; thus, this study was able to explore the challenges related to engagement and adherence among a group of people that were either currently struggling with consistent engagement and ART adherence, or had recently managed to re-engage or re-start ART.

This study also sought to differentiate the operationalizations of engagement and adherence in regard to the quantitative data and the qualitative data. The survey's response choices for the items that were used to evaluate engagement and ART adherence were limited to fixed categories, which appeared to have inadvertently resulted in a social desirability bias. The combination of the instrument design-related bias and social desirability bias appeared to have resulted in a higher percentage of participants reporting they regularly attend clinic and consistently take their ART than was actually the case, as discerned during the in-depth portion of the interview. Thus, some participants' quantitative data did not neatly match the survey data provided during the semi-structured portion of the interview. However, it is likely that the social desirability bias was offset during the in-depth interview, as a greater sense of trust and rapport was

built between the interviewer and participant over the course of the qualitative portion of the interview. Moreover, qualitative probing allowed for participants to provide nuanced responses to questions regarding their experiences with disengagement and re-engagement and adherence challenges.

Finally, although the topic of “conspiracy beliefs” is often regarded as controversial or even taboo, thus possibly increasing the likelihood of desirability bias, the interviewer took special effort to avoid introducing pre-judgments about participants’ beliefs and experiences. In order to provide an open, non-judgmental environment, the survey did not include items these kinds of beliefs, thus allowing the topic to emerge as organically and neutrally as possible during the course of the semi-structured portion of the interview. Participants often raised the topics themselves, but in absence of that, the interviewer employed neutral language to inquire about beliefs regarding the efficacy of ART, the possibility of a cure, the role of the government, if any, in the epidemic, and the nature of the possible origin of the HIV. These strategies, in addition to the extensive training the interviewer underwent on how to elicit sensitive information, reduced the potential for social desirability bias, and encouraged participants to speak openly about their HIV-related beliefs and their experiences with HIV care.

## **Recommendations**

Interventions at the provider-patient level can foster trust and help patients internalize the belief that engagement in care and consistent ART adherence renders HIV a chronic, manageable disease. Related, participants’ emphasis on wanting to manage side effects *with* their providers suggests that the HIV provider has an instrumental role in

not only lowering viral loads and achieving viral suppression, but also in helping patients feel agentic and able to remain engaged and adherent to their ART. HIV providers that communicate genuine care, concern and respect for their patients and that strive to involve patients in their care and thus recognize them as people with agency have the potential to reverse these negative patient emotions that undermine their engagement in care. Thus, HIV care providers most often serving as primary care physicians for their patients and playing many different supportive roles beyond the clinical, are uniquely situated to work closely with patients to effectively face engagement challenges together.

Making people feel worthy of care and agentic was one way in which providers contributed to people's ability and desire to manage their HIV. In general, many factors coalesced to influence this ability and desire, but the management of mental and physical barriers posed by ART, and negotiating ART decisions/changes with providers, was more likely to be successful if all of these components were present. Participants' experiences with and reasons for engagement were varied, but the issues of effectively managing side effects and other pill-related barriers, having positive ART-related beliefs, and developing collaborative relationships with their providers were revealed to be highly salient aspects of their trajectories.

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## **Final chapter**

### ***Summary of public health and sociological approaches to understanding “conspiracy beliefs”***

Prior to the start of the study, an extensive literature review was conducted in order to map out both the theoretical positions on and empirical knowledge about the phenomenon of health-related “conspiracy beliefs”, with a particular interest in those ideas and beliefs that pertain to HIV. There are numerous empirical studies that test the association between health-related and specifically, HIV-related “conspiracy beliefs” and a variety of health behaviors and outcomes, including birth control use, HIV testing and treatment practices, and participation in biomedical research. I was particularly interested in the way in which public health, as a body of literature, framed HIV-related “conspiracy beliefs” as a type of medical mistrust that developed in the shadow of the Tuskegee study, and to a lesser but still key extent, slavery in the United States. For public health researchers, these types of ideas and beliefs are conceptualized as manifestations of primarily historical racism.

Although the public health literature predominantly focuses on the role of the Tuskegee study in causing race-related medical mistrust [1-2], the sociological literature locates phenomenon in a racialized context, Waters (1997) notes “conspiracy theories held by African Americans that seek to explain ethnic inequality are intrinsically interesting as a subset of conspiracy theories because they may indicate areas of tremendous uncertainty in interethnic relations. In addition, they may shape behavior by providing parameters for political and social action in racial conflicts. In short, conspiracy theories express deep-running ethnic tensions while they influence the

directions of interethnic interaction.” [3] Waters’ analysis suggests that “conspiracy beliefs” held by African Americans may represent manifestations of the various ways in which society is shaped by rigid, interlocking structures of racism, sexism and classism. Similarly, Mackenzie argues that “conspiracy beliefs” should be reframed as “counter-narratives”, which serve to “create a rhetorical space for challenges to power through the articulation of oppositional ideas about dominant scientific knowledge.” [4] Recently, Heller (2015) posits that HIV-related “conspiracy beliefs” are not in fact rooted in ignorance, but can be better understood as the "1) result of historical experiences that have engendered distrust, 2) a result of continuing distrust, and 3) an indication of social anxieties associated with the HIV/AIDS epidemic, drug use (as a source of HIV and as an arm of the genocide attempt), and African American's place in American society" [5]. Heller considers such beliefs are a “measure of trust” between African American communities and the health care system. Although some studies have suggested education as a means of dispelling “conspiracy beliefs”, Heller notes that increased knowledge will “work only if people trust the sources of official information”, which often comes from government agencies such as Centers for Disease Control and Prevention, or state health departments. Therefore, “conspiracy beliefs” can also be seen as a “measure of trust” between African American communities and the government in general [5].

One purpose of the present investigation was to obtain a more nuanced understanding of the nature of people’s beliefs, and to tease out how endorsement may (or may not) affect people’s engagement in care, particularly among a group that was recently disengaged or currently disengaged from care (i.e., at the time they were

interviewed for this study). Qualitatively exploring this issue facilitated the emergence of diverse variations of so-called “conspiracy beliefs.” Regarding origin-related beliefs, some participants strongly expressed their belief that the government and/or the pharmaceutical industry deliberately created HIV to target racial and ethnic minority populations (and occasionally, substance users or gay men). Others strongly criticized these origin-related ideas, and vehemently disagreed with the underlying assumptions of deliberate genocide.

For some participants, the discussion of both origin and cure-related ideas elicited a dismissive reaction: “It doesn’t matter where it came from, I have it [HIV].” This straightforward response was often accompanied by a dismissive attitude about whether or not they believed these ideas were true. These dismissive dispositions were interpreted as avoidant, as participants in this subgroup did not focus on whether or not they believed such ideas, but rather, were quick to express that they were, unwilling to invest energy and time to even contemplate the veracity of the ideas. Importantly, endorsing these beliefs – or merely contending with them and thinking about them— did not appear to be a direct driver of disengagement or barrier to re-establishing care or re-starting an ART regimen. Rather, for the engaged and the inconsistently engaged/adherent participants, endorsing or not endorsing “conspiracy beliefs” was not a significant factor in their adherence or retention, while those who were still disengaged at the time of the interview appeared to be dismissive and/or avoidant. For the latter group, being avoidant or dismissive – even when acknowledging some of the ideas may in fact be true- suggested a realization that contended with these kinds of beliefs could potentially be destabilizing to their life circumstances. These participants were already experiencing uncertainty and



unstability, for instance, in terms of their housing situation or related to their substance use and described lives particularly insecure and anxiety provoking. This avoidance could thus be interpreted as signaling powerlessness, but also perhaps resistance to expending emotional energy dwelling on a fundamentally unjust society. This resistance could signify a refusal to allow their health to be further derailed by the power complex.

For these dismissive participants, the daily reality of living with few financial and social resources and trying to manage HIV was far more pressing than investing time thinking about the possibly nefarious origins of HIV. In fact, many participants did not seem to even want to contend with or entertain these thoughts and avoided assigning any significance to “conspiracy beliefs” and allowing them to influence their lives, even when some of them seemed to endorse or almost endorse some of the ideas.

Participants’ narratives illuminated both the targets of the conspiracy (poor minority people) and the conspirators (the government-pharmaceutical complex) in each scenario. Endorsing ideas about government or scientific conspiracies was found to be associated not only with race, but also with socioeconomic status. This is an interesting finding, as the public health literature closely links health- and HIV-related “conspiracy beliefs” with race (perhaps more specifically, racism stemming from historical injustices). In this sense, these narratives offer an intersectional understanding of these beliefs by highlighting not only racism, but also poverty-based exploitation (i.e., classism) by the government-pharmaceutical industry power complex.

For many participants, pharmaceutical companies represented “big business”, and were perceived as reaping big profits from the sale of ART. Therefore, it seemed obvious they would be motivated to withhold a cure for HIV. Several participants used the phrase

“big business” to imply that pharmaceutical companies and the federal government are chiefly concerned with realizing big profits, in a manner that is unethical and even beyond the law. These sentiments culminated in a widespread belief that a cure does currently exist, or a cure may very well exist, and is being withheld or will be withheld if discovered in the future, from poor patients, like the participants covered by Medicaid. Thus, participants’ self-identification as poor – typically described as being eligible for Medicaid benefits—was an important aspect of contextualizing their beliefs.

Many argued that the drug companies are exploiting them by charging their insurance thus generating profit for the amorphous pharmaceutical industry. Participants placed the government and the pharmaceuticals on the same side and did not discuss the main contradiction in their argument, that is, that the government pays for their Medicaid insurance and therefore, the pharmaceuticals also exploit the government. This contradiction was not perceived by participants, as they generally believed that the government colluded with drug companies to make “billions”, and thus profited as well. Thus, these beliefs reflect a systematic exclusion from life opportunities rendered visible by the ways in which participants defined the powerful in our society. Moreover, participants largely expressed these beliefs in a racialized context. Thus, the perceived socioeconomic exploitation and discrimination was intertwined with racial exploitation and discrimination.

Participants were also eager to share and discuss their struggles with taking ART consistently. Being able to take ART consistently required them to confront both physical and mental challenges, both of which, if managed effectively, helped them achieve successful re-engagement and/or become consistently adherent to their ART regimen.

The physical aspects included contending with difficulties taking the pill[s], such as having an aversion to swallowing pills. Psychological obstacles included pill fatigue, or having negative associations with pill-taking, e.g., being reminded of one's positive HIV status. Both types of barriers- and there was often an overlap (e.g., overcoming a swallowing issue has both a physical and a mental component)—necessitated thinking about and employing strategies to overcome these various challenges. Strategies to manage these barriers included changing medications to avoid or reduce the negative effects (e.g., changing from a multi-pill to a one pill regiment), devising routines that mitigated the challenges (e.g., enrolling in an adherence program to remain motivated to adhere or prevent forgetfulness), and generally trying to understand the underlying causes of their particular challenges (e.g., recognizing that a monthly supply of ART generated the temptation to sell them and engage in substance use, or trying to reflect upon the reasons why they have not accepted their positive status).

By effectively strategizing and addressing their respective obstacles to ART adherence, participants expressed feeling more in control of their illness, and thus their lives. Control over one's health seemed to gauge control over one's life, and having positive ART beliefs contributed to this sense of agency and resilience. Importantly, all participants believed that ART, particularly in comparison to AZT-era medication, makes HIV a chronic, manageable disease. Thus, having positive beliefs about the medication efficacy helped facilitate their consistent ART adherence, or their desire/motivation to restart the medication treatment. Ultimately, affirming beliefs about the effectiveness of ART, in combination with the physical and psychological strategies used to improve

adherence, appeared to help mitigate the physical and mental challenges associated with taking ART.

Participants also suggested that HIV care providers can be a trusted source of health information, and more importantly, hope and support in protecting or regaining one's health. Thus, participants' emphasis on wanting to manage ART-related challenges *with* their providers suggests that the HIV provider can play an instrumental role in lowering viral loads and achieving viral suppression via helping people accept their HIV and having to take ART for the rest of their lives. Accomplishing this type of relationship was accomplished by co-constructing a patient-centered relationship with one's doctor. HIV providers that communicated genuine care, concern and respect for their patients and that strived to involve the patient in his or her care and thus recognized the patient as a person with agency had the potential to reverse these negative emotions that undermined participants' engagement in care. In most cases, providers emerged as a source of treatment and illness information that participants trusted and this in all likelihood accounted for the fact that regardless of whether they endorsed or not the treatment-related "conspiracy beliefs", participants recognized that ART made HIV a chronic, manageable illness. Thus, HIV care providers, most often serving as primary care physicians for their patients and fulfilling many different supportive roles beyond a clinical scope, are uniquely situated to both accompany and work closely with patients to effectively face adherence and engagement challenges as a team. Thus, consistent with the literature on patient-physician relationships [6-8], the data also suggests that HIV care providers have an opportunity to have an extremely meaningful role in their patients' lives. Participants also discussed negative experiences with providers, which led them to

articulate the traits they hoped to find in a future provider. These same kind of characteristics, which describe the core features of patient-centered medicine, were discussed by those participants who reported having providers that helped them remain engaged and adherent. Overall, while many factors coalesce to influence the ability and desire to engage, the management of mental and physical barriers posed by ART, and especially negotiating ART decisions/changes with patient-centered providers, were facilitating factors for people re-engaging in care, or remaining consistently engaged in care and adherent to their ART.

### **Theoretical approaches to contextualizing the data**

There are a few theoretical approaches that are particularly useful for contextualizing the data sociologically. Bourdieu's concept of habitus, as theorized in the context of health lifestyles by Cockerham, as well as Garfinkel's concept of cultural dope, and Foucault's notion of bio-citizenship, are lens with which we can use to zoom in on the sociological meaning of these HIV-related origin and treatment beliefs.

### ***Bourdieu's habitus and Cockerham's theory of health lifestyle***

Cockerham's theory of health lifestyle proposes that gender, social class and race/ethnicity are among the primary facets of the social structure that deeply influence people's experiences with the health care system and their health-related decision-making and behavior, including disengagement and ART non-adherence [9]. Informed by Bourdieu's concept of habitus [10], this sociological theory highlights the relationship between structure and individual agency, and postulates that structure (defined as life

chances) and agency (defined as life choices) interface and produce a person's habitus. Therefore, this theory renders visible the complex ways in which people's health dispositions (health habitus) and practices are influenced by social structure. Moreover, the theory postulates that the historical and collective experiences of social groups (including racial and ethnic groups, as well as other socially marginalized populations) also shape their habitus. Over time, health practices become solidified into health lifestyles [9].

These complex processes make one's habitus a durable and hard to change feature of one's disposition and behavior; this analysis suggests that the nature of so-called "conspiracy beliefs" is part of this durable disposition individuals have towards their health and life. For example, contextualized within the long histories of vulnerable populations and minority groups' social, economic and symbolic exclusion, research abuse and ongoing discrimination can easily account for the construction and the durable nature of HIV-related "conspiracy beliefs." For groups that have been historically marginalized, the notions that the government is deliberately infecting them with the HIV virus, experimenting on disempowered groups, and/or is withholding a cure in order to profit and perpetuate their marginalization become less of an unreasonable system of beliefs. In fact, this system of beliefs might be an accurate representation of the social, economic and symbolic exclusion of the groups that find themselves at the lower ranks of the race and class hierarchies.

### ***Garfinkel's cultural dope***

The data provide an opportunity to reframe how we think about "conspiracy beliefs." Here, Garfinkel's concept of "cultural dopes" [13] -society members that

mindlessly reproduce social norms- is useful for drawing attention to a more nuanced understanding of the meaning of origin- and pharmaceutical-related beliefs among low income people of color. Rather than approaching these ideas as irrational ideas to be debunked or dispelled, participants' narratives revealed how they are not in fact cultural dopes. Instead, they provide an account of the perspectives of people who are often made powerless by intersecting structures of racial and socioeconomic inequality. Rather than being cultural dopes- specifically *minority* cultural dopes that endorse stereotypical, paranoid tropes associated with racial and ethnic minority groups- participants were largely reflective and articulate about their own lived experiences as persons with HIV.

***Foucault's bio-power and being a good bio-citizen***

Applying Foucault's notion of bio-power to these findings helps illuminate how people may demonstrate resilience and agency via the close management and surveillance of their health. Bio-power, Foucault's the idea that nation-states regulate the bodies of its citizens via a variety of techniques [14], is particularly applicable to management of one's HIV, which requires extensive self and provider/system surveillance to be managed effectively. The data suggest that successful re-engagement and retention may entail acceptance and desire to play the good bio-citizen role. Even though the participants acknowledged that they, as a socially and economically marginalized subgroup of color, are largely excluded from the social contract (both historically and presently), being a good bio-citizen was the only path to feeling healthy. Participants chose to focus on personal accountability as a way to exercise agency over their health, and to feel agentic and empowered by their decision to re-engage in care and commit to ART. In this sense, they recognized that effectively managing their health was

one of the few domains in which they have some control and they exercised it; this is in sharp contrast to the powerlessness embedded in origin and pharmaceutical/cure-related beliefs. That is to say, participants expressed motivation and a desire for being accountable for managing their HIV and their health, even if they held worldviews that were rooted in deep suspicion and mistrust of the power complex.

### **Future research and recommendations**

It is of considerable public health importance to more critically approach how HIV-related beliefs, particularly origin- and pharmaceutical-related ideas, are shaped by a combination of historical, social and economic influences. Public health, as a field and as a body of literature, over-emphasizes the role of the Tuskegee Syphilis Study, which makes it difficult to critically integrate theoretical approaches that connect mistrust not only to ongoing racial inequality and classism, but to experiences and perspective on powerlessness and social exclusion. The dominant public health discourse about “conspiracy beliefs” evokes misunderstanding on the part of the believers, or worse, paranoia and irrationality, thus discrediting the social groups (racial minorities of low SES) that hold such beliefs.

Making rhetorical space for reframing these ideas necessitates a shift in the language we use to describe them. Although widely used in the public health and medical literatures, the term “conspiracy beliefs” is problematic and needs re-framing in order to reposition how we understand both historical and ongoing racism and classism as fundamental causes of social and health inequalities. The use of the phrase “conspiracy beliefs” should be discontinued in favor of more precise terms that describe people’s beliefs in a less judgmental and discrediting way. If we refer to such ideas more



descriptively- for example, as HIV origin-related beliefs, or pharmaceutical/cure-related beliefs, they can be viewed less as irrational, and more clearly as possible manifestations of people's perspectives and experiences living in a social structure that is shaped by racism and classism (and of course other forms of intersecting inequalities, such as sexism and homophobia), thus fostering ideas from the margins.

Ultimately, the data suggested that providers had the potential to be a significant and meaningful source of not only trusted health information, but also hope. Making people feel worthy of care, and agentic, was one way in which providers contributed to people's ability and desire to manage their HIV. Pharmacies and hospitals were sometimes included in this government-pharmaceutical complex, but rarely HIV care physicians. This is likely because participants did not perceive their providers to be profit-driven or to benefit unethically from their prescribing ART. Thus, greed and dishonesty were necessary characteristics that defined the conspirator complex, and providers were largely viewed as not possessing this kind of exploitative power. Further research on the patient-provider relationship, particularly from the perspectives of providers themselves, would elucidate how HIV care physicians think about and approach these ideas with patients, and help inform public health efforts to support agency and resilience among populations that are socially marginalized.

*Summary of specific recommendations for public health interventions seeking to improve engagement, adherence and retention:*

1) Developing interventions that focus on providers and patient-provider relationships, rather than “educational” interventions that aim to specifically dispel or dislodge so-called “conspiracy beliefs.” The data suggested that people can endorse these kinds of beliefs and still successfully re-engage in care and consistently take ART. For example, efforts on the part of providers to foster positive ART beliefs, e.g., messaging about how while there is not a cure currently available, ART is a very close second, and conveying to patients that they are receiving the best medication that has ever been available to treat HIV. Since Magic Johnson has become a symbol of the withheld cure, messages that indicate that patients are offered the same medication that Magic Johnson takes, can also be strategic.

2) Changing people’s attitudes toward ART is more feasible than trying to convince that the government did not in fact create HIV to target poor people of color. Indeed, participants indicated that they were educated about HIV (e.g., they had knowledge about T-cells and viral load as indicators of disease severity, resistance to medication if non-adherent and other aspects of the disease). Thus, fostering positive beliefs about ART may be more helpful than attempting to dispel “myths.”

3) Cultivating a patient-centered relationship. This would entail, for example, offering choices whenever possible about ART decisions to counteract the idea of “just pushing Merck.” Based on the patient-centered medicine model [15], providers have the potential to establish a therapeutic alliance because they have earned most patients’ trust that they are not pill pushers.

4) Related to fostering a therapeutic alliance, providers should take care to differentiate themselves from pharmaceutical companies. This includes not giving visual cues such as using pharmaceutical company pens and notepads, or recommending a particular medication without a clear explanation of why they feel that option is the best one for their patient. Participants generally did not seem to include providers in the government-pharmaceutical industry scheme, so further reinforcing this distance would be beneficial.

5) The finding that participants were very eager to play the role of a good bio-citizen can also be integrated into providers' strategies to establish a therapeutic alliance with their patients.

## **Conclusion**

Although public health often promotes social determinants models, the issue of “conspiracy beliefs” has not been framed in this way. I suggest that sociological frameworks can contribute to helping researchers and public health practitioners understand the impact of population-level material inequality on health dispositions, behaviors and outcomes. Specifically, a more nuanced approach is needed that considers how people, as individuals but also as members of groups, experience and interpret social and economic exclusion and injustice, and how this may influence their health behaviors. Cockerham’s theory of health lifestyles, as informed by Bourdieu’s concept of habitus, is particularly useful for changing the lens through which we try to understand both the durable nature of such beliefs, and the potential impact of these ideas on people’s

everyday lives. Further, despite their place at the lower ranks of the race and class hierarchies, persons with HIV are the opposite of cultural dopes, they are thoughtful and strategic about protecting their health and prolonging their lives. Finally, contrary to the current discourse on “conspiracy beliefs”, persons with HIV seem to have a desire and motivation to be good bio-citizens, despite or maybe because they had been deemed unproductive or irresponsible citizens due to their poverty and lifestyles that contributed to becoming HIV positive. Moving forward, creating rhetorical and intellectual space for simultaneously expanding and refining our understanding of this phenomenon can help inform interventions that seek to improve outcomes related to the HIV care continuum. In this sense, addressing material inequality alone, or attempting to “re-educate” people, is insufficient to address the complex roles of racism, discrimination, political exclusion, and systemic poverty in creating the conditions in which structural inequality has shaped many of the environments in which socially and economically marginalized people live. Although the participant narratives presented here speak to life on the margins, they also suggest a genuine and resilient desire successfully manage HIV- and be healthy and happy-despite, or even within, such an unequal society.

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## **Appendices**

### ***Bedside to Community (B2C) engagement criteria***

Sample Eligibility: To be eligible individuals must: 1) be age 21 or older; 2) self-identify as non-Hispanic Black or Hispanic (of any race); 3) self-identify as HIV-positive; 4) be confirmed as HIV-positive based on medical record; 5) report having been diagnosed with HIV for at least two years; 6) be currently hospitalized in the CUMC Adult AIDS unit; 7) have their most recent CD4 cell count under 350 based on medical record; 8) report that they have not seen any HIV outpatient clinician for at least 6 months. Patients will be excluded if clinical staff evaluates them to have significant cognitive or developmental impairment (i.e., unable to give informed consent).

We will require participants be 21 and older because at CUMC those under 21 with HIV/AIDS typically receive inpatient and outpatient care through the Center for Pediatric HIV Disease rather than the Adult AIDS unit. Given that adolescent and young adult patients in pediatric HIV clinics (at CUMC and elsewhere in NYC) tend to receive care intensive follow-up and support services designed to engage and retain them in medical care, we anticipate that the experiences of these younger patients who are disengaged from ongoing HIV care will differ from those of their adult counterparts.

The inpatient population of the CUMC Adult AIDS unit is approximately 30% non-Hispanic Black, 60% Hispanic (predominantly of Puerto Rican and Dominican background), but only 5% non-Hispanic White and 5% other ethnic/racial groups. Therefore, it is unlikely that we could accrue a sufficient number of participants who are White or from other ethnic/racial groups to conclude anything meaningful about this

group. Therefore, the sample will be restricted to only non-Hispanic Black (henceforth Black) and Hispanic (of any race) participants. Furthermore, the extant literature has consistently identified Black and Hispanic patients as at greatest risk for disengagement from HIV care and preventable hospitalizations.

HIV status will be confirmed by the nurse recruiter (who will be a clinical staff of CUMC) by consulting the patient's medical record prior to their being invited to participate in the study. However, because patients must be aware of their HIV diagnosis to understand the need for HIV outpatient care and to engage in behaviors to maintain their health (e.g., starting antiretroviral therapy), we will also require patients to self-report being HIV positive. Participants must also be at least 2 years post-diagnosis. This will allow us to focus on those who have had time to form a health lifestyle in which they could have engaged in care, but instead have not or have disengaged in from HIV care. This criterion is also imposed because when diagnosed with HIV, some individuals go into a period of denial that can often extend a year or more. Such patients cannot effectively participate in an interview about their HIV outpatient care while denying their HIV- positive status. Their early failure to obtain care may not be representative of their later pattern of HIV care, because after the initial reaction many might initiate regular outpatient HIV care. By restricting the sample to patients who have been diagnosed with HIV for two or more years, we ensure we are not capturing cases who are just in early denial of the diagnosis, but who once they accept their diagnosis will engage in care.

Given the proposed study's focus on individuals whose immune function and health have been significantly compromised due to their lack of care, we have included criteria that participants will be required to have CD4 count of 350 or less at the time of

hospital admission (as indicated by the medical record). This is important because ART (and regular outpatient monitoring) is clinically indicated for all patients (by both aggressive and non-aggressive treatment providers) at these levels. We will also restrict the sample to those whose health has been compromised due to a lack of HIV care and therefore require hospitalization in the AIDS unit. All HIV- positive patients at CUMC, regardless of their reason for hospitalization, are assigned to the Adults AIDS unit unless they require surgery. Therefore requiring patients to be admitted to the AIDS unit will not result in the loss of potentially eligible patients who are hospitalized in other care units.

We will require all participants to not have seen any HIV outpatient provider (at any location) in the past 6 months, because of our focus on understanding HIV-positive individuals disengaged from HIV outpatient care. However, we will not exclude those who may have utilized the emergency department, HIV-related social services, or substance use treatment services in the past 6 months. This 6-month criterion was chosen because this time period is considered by most researchers and providers as the maximum time gap that should occur between HIV care visits. Furthermore, Giordano et al. found that HIV-infected men who went two or more quarters (6 months) without an HIV primary care visit were nearly twice as likely to die as those who visited a provider in all four quarters of the year.



**HIV Practices and Beliefs Study**  
Interviewer Administered Questionnaire

Interview Date:    -    -    Start Time:    :    AM/PM End Time:  
                  \_ : AM/PM

Study Participant #:

*To begin with, I would like to ask you some brief questions about yourself that we are asking everybody so that we will be able to describe the group of people who are participating in the study. These questions will take approximately 10 minutes.*

1. Which of the following best describes your living situation in the past year... (CIRCLE ALL THE APPLY)

- 1 – An apartment or house that you or your family own
- 2 – An apartment or house that you or your family rent, without any financial assistance
- 3 – An apartment or house that you or your family receive assistance from relatives to pay the rent
- 4 – An apartment or house that you or your family receive assistance from public assistance or another program to pay the rent (Specify program or type of benefit: \_\_\_\_\_)
- 5 – “Doubled up” with a friend or relative (and you do not pay rent)
- 6 – A room in an SRO or hotel paid for by public assistance or another program (Specify program or type of benefit)
- 7 – A room in specialized AIDS housing paid for by public assistance or another program (Specify program or type of benefit \_\_\_\_\_)
- 8 – Drug treatment program housing
- 9 – Shelters
- 10 – Street or another public place
- 11 – Hospital
- 12 – Nursing home, hospice
- 13 – Jail or prison
- 14 – Other (Specify: \_\_\_\_\_)
- 97 – REFUSED

1A. IF ANSWERED CATEGORIES #1 – 7 ABOVE, ASK: Whose name is on the lease (or mortgage)?

- 1 – Your name alone
- 2 – Your name and other people
- 3 – Someone else
- 4 – Agency maintains the lease
- 5 – Not applicable – group housing/program housing
- 6 – Not applicable – no lease

97 – REFUSED

1B. How long can you stay in this housing? Is there a time limit?

- 0 – No time limit
- 1 – One month
- 2 – Three months
- 3 – Six months
- 4 – One year
- 5 – Two years
- 6 – Longer than 2 years
- 97 – REFUSED

1C. Is there a social worker or case manager who is supposed to help you who lives there, has an office there, or who visits you as part of a housing program?

- 1 – Yes, there is a case manager on site, in the building
- 2 – Yes, a case manager visits regularly as part of a housing program
- 3 – No social worker or case manager associated with housing
- 4 – A social worker or outreach worker has visited you where you live, but they are not part of housing program
- 5 – Don't know
- 97 - REFUSED

2. Do you consider yourself to be currently homeless? (Again, by "homeless", we mean you do not have your own place to sleep--not an apartment you are renting and not even a friends or family member's place you are welcome to stay at) (Choose one)

- 0 = No (SKIP to 9)
- 1 = Yes (ASK 8C)
- 97 = REFUSED

IF YES, ASK: 2B. How long has it been since you had your own place? (Choose one)

- 1= Less than a week
- 2= Between 7 days and 30 days
- 3= From one month to six months
- 4= From six months to a year
- 5= More than a year
- 97= REFUSED

3. Which best describes your employment status....?

- 0 – Not employed
- 1 – Irregular, occasional, part time work (less than 35 hours per week)
- 2 – Employed part-time, regular job (less than 35 hours per week)
- 3 – Employed full-time (35+ hours per week) (SKIP TO Q 5)

4 – Employed more than full-time (works more than 1 job, totaling more than 40 hours per week) (**SKIP TO Q5**)

5 – Not working for pay, but volunteering regularly at a program or agency (receive stipend)

6 – Not working for pay, but volunteering regularly at a program or agency (does not receive stipend)

4. What are some of the reasons for not having a full-time job or going to work right now? (**CIRCLE ALL THAT APPLY**)

1 – Don't feel well enough

2 – Not sure will stay well enough

3 – Fear losing medical benefits

4 – Fear losing other benefits

5 – Cannot find a job

6 – Lack of education

7 – Lack of job skills

8 – Need to take care of children/someone else

9 – Going to school

10 – In drug treatment

11 – I cannot find a job because of discrimination

12. Retired

13. Other (Record \_\_\_\_\_)

97 – REFUSED

5. In the last 6 months, have you gotten any MONEY from. . . . ?

5A. Regular job, either full or part time 1 = Yes

0 = No 97 = Refused

5B. HASA (HIV/AIDS Services Administration) 1 = Yes

0 = No 97 = Refused

5C. Disability/Social Security 1 = Yes

0 = No 97 = Refused

5D. Public Assistance 1 = Yes

0 = No 97 = Refused

5E. Selling Drugs 1 = Yes

0 = No 97 = Refused

5F. Recycling, e.g., selling cans, returning bottles 1 = Yes

0 = No 97 = Refused

5G. Sex for money, tricking 1 = Yes

0 = No 97 = Refused

5H. Temporary work or odd jobs – off the books 1 = Yes

0 = No 97 = Refused

5I. Temporary work or odd jobs – on the books 1 = Yes

0 = No 97 = Refused

5J. Spouse or steady partner 1 = Yes  
 0 = No 97 = Refused  
 5K. Family or friends 1 = Yes  
 0 = No 97 = Refused  
 5L. Other (Record: \_\_\_\_\_)

6. Do you have any of the following kinds of medical insurance? Such as....

6A. Medicaid? 0 = No 1 = Yes  
 3 = Applied 97 = Refused  
 6B. Medicare? 0 = No 1 = Yes  
 3 = Applied 97 = Refused  
 6C. Veterans benefits? 0 = No 1 = Yes  
 3 = Applied 97 = Refused  
 6D. ADAP (AIDS Drug Assist. Program) 0 = No 1 = Yes  
 3 = Applied 97 = Refused  
 6E. Private Insurance  
*(that you pay for yourself, through work/union, or through a spouse?)* 0 = No 1 = Yes  
 3 = Applied 97 = Refused  
 6F. Other Insurance? 0 = No 1 = Yes  
 3 = Applied 97 = Refused

(Record \_\_\_\_\_)

7. During the past 6 months, have you gone to a hospital emergency room for emergency care? Include any visits to the emergency room, even if you were admitted to the hospital from there. Please include emergency rooms of psychiatric and medical hospitals.

0 – No  
 1 – Yes  
 97 – Refused  
 8 – Don't know

IF YES, 7A. How many times have you been hospitalized in the last 6 months?

Record \_\_\_\_\_  
 97= REFUSED

IF YES, 7B. During the past 6 months, were you a patient in any hospital for medical or psychiatric care overnight or longer?

- 0 – No
- 1 – Yes
- 97 – Refused
- 8 – Don't know

8. IF YES, 7C. During the past 6 months, how many times were you a patient in any hospital overnight or longer?

Record

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97 = REFUSED

8. What was your lowest T-cell count ever?

1 – Lowest T-cell count \_\_\_\_\_

Date \_\_\_\_\_ / \_\_\_\_\_ Month / Year

2 - Does not recall lowest T-cell count

97 – REFUSED

8A. Have you ever been told that your viral load was undetectable?

- 0 – No
- 1 – Yes
- 2 – Does not recall
- 97 – REFUSED

IF YES, ASK 8B: What was the date of your most recent undetectable viral load?

Date \_\_\_/\_\_\_\_ Month / Year

9. Have you ever gone to a doctor or clinic for HIV care? (By HIV care, I mean a clinic visit in which you addressed your HIV or AIDS medications or blood test results, such as T cell count and viral load)

- 0 = No (**SKIP TO 10**)
- 1 = Yes
- 97 = REFUSED

IF YES, ASK: 9A. In the past 12 months have you gone to a doctor or clinic for HIV care?

0 = No (**SKIP TO 10**)

1 = Yes

97 = REFUSED

IF YES, ASK: 9A.1. In the past 12 months, how many times have you gone for HIV care?

Record \_\_\_\_\_

97 = REFUSED

IF YES, ASK: 9A.2. In the past 6 months, how many times have you gone for HIV care?

Record \_\_\_\_\_

97 = REFUSED

10. Many times people have to miss appointments because things come up. How many times in the past 6 months have you had to miss a scheduled appointment for HIV care?

Record \_\_\_\_\_

97 = REFUSED

11. How likely or unlikely is it that you will go for HIV care in the next 6 months? Would you say that it is: (**CHOOSE ONE**)

1 = very likely

2 = likely

3 = neither likely nor unlikely

4 = unlikely

5 = very unlikely

97 = REFUSED

12. Do you currently take any HIV medications?

0 = No (**SKIP TO 13**)

1 = Yes

IF YES, ASK 12A. Do you currently take all your HIV medications as directed? (As directed means taking your medications at the right time and the prescribed amount.)

- 1 = NO, I do not, and I am not considering taking my HIV medications as directed
- 2 = NO, I do not but I am considering taking my HIV medications as directed.
- 3 = NO, I do not, but I am planning to start taking my HIV medications as directed w/in the next month.
- 4 = YES, I always take my HIV medications as directed.

IF 12A. YES, ASK 12B. How long have you been taking your HIV medications as directed?

- 1 = 2 months or less
- 2 = 3 to 6 months
- 3 = 7 to 12 months
- 4 = Over 1 year but less than 2 years
- 5 = 2 years or more

IF 12A. YES, ASK 12C. How certain are you that you will continue taking your medications as directed during the next 6 months?

- 1 = Completely certain
- 2 = Somewhat certain
- 3 = Somewhat uncertain
- 4 = Not certain at all

13. Have you ever taken medications for your HIV in the past?

- 0 = No
- 1 = Yes
- 97 = REFUSED

14. Are you thinking about, considering taking HIV medications?

- 0 = No
- 1 = Yes

15. Are you planning to start taking HIV medications within the next month?

- 0 = No
- 1 = Yes

15A. IF YES Tell me right now why you are taking HIV medications.

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15. B IF NO Tell me right now why you are not taking HIV medications.

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Thank you. We will now move on to the conversation part of the interview.



## Dissertation Interview Guide

1. How have things been going for you, how have you been doing since you talked with us last?
2. Where are currently living?
3. Have you been in jail or incarcerated since we talked to you last?
4. Have you been hospitalized since we talked to you last (after your hospitalization where you talked with us first)? (DATE \_\_\_\_\_/ INTERVIEWER \_\_\_\_\_)
5. How were you doing in terms of your physical and emotional health the few days after you left the hospital? What was going on with your health? Where did you go after leaving hospital? Did you have a friend or family member to help you after leaving the hospital?
6. Did your experience being in Presbyterian hospital shape in any way how you manage or deal with your HIV care now?
7. Are you currently in HIV care?
8. Are you currently using antiretroviral medication (ARTs)?
9. At the beginning of this conversation, you told me you are/are not currently seeing an HIV outpatient provider/in HIV care.
  - a. *Regardless of participant's answer, ask:* Tell me a bit about this, why are you/aren't you seeing an HIV outpatient provider?
10. When you first talked with us about \_\_\_\_ months ago , you said there were a few things in particular that were challenging you (**Challenge 1 from initial interview**) and \_\_\_\_\_ (**Challenge 2 from initial interview**).

- a. Let's talk about Challenge 1 (*Concrete challenge, i.e., joblessness, housing instability, lack of benefits, etc*). How were you handling x once you got out of the hospital?
- b. Did that way of dealing with it work for you?
- c. (*If still facing challenge*): how are you handling [challenge 1] now? Is this a challenge you think you will be dealing in a short-term way, or long term? Tell me why do you think so?
- d. Is dealing with x affecting how you deal with your HIV care?
- e. What would have to happen to help you resolve this challenge? Tell me a bit about this.

11. The second main challenge you talked about was y (*Less tangible than challenge 1, if applicable, i.e., stigma, distrust, shame, hopelessness/depression/lack of motivation, self-destructive tendencies etc*).

- a. You told (*name of interviewer*) \_\_\_ months ago, that you were dealing with Challenge 2. How have you been dealing with [Challenge 2]?
- b. How has \_\_\_\_\_ (way of dealing w Challenge2) been working for you? Tell me a bit about that.
- c. How has [Challenge 2] been affecting your HIV care?
- d. Is dealing with x affecting how you deal with your HIV care?
- e. What would have to happen to help you resolve this challenge? Tell me a bit about this.

12. If not been dealing/managing Challenge 2, ask: Tell me a bit about that, Why haven't you....?
13. Is there anything else you would like to share with me about these two challenges we just discussed?
14. Is there anything else that has come up since we last spoke that is affecting you HIV care?

### **Medication questions**

*Ok, now I am going to ask you a few questions about medication. You told me a few minutes ago that you are/are not taking medications. (These questions will depend on if the participant was/was not already on medication at time of initial hospitalization, if the P began/did not begin ARTs during/after hospitalization, and their reported relationship with meds, generally. The P's med trajectory will be outlined prior to the F/U interview attempt).*

15. You had said during that first interview \_\_\_ months ago that you were/were not planning on beginning medication. What made you decide that?
  - a. If yes, on medication...When did you start on ARTs?
  - b. How long have you been on ARTs continuously?
  - c. How is it going with the medication? How have you been feeling on the meds? (i.e., side effects, restored sense of well-being etc)
  - d. What is difficult about taking your medication as directed?
16. If no, not on medication....Tell me a bit about this
  - a. What made you decide to not take ARTs?

17. Have your thoughts or opinions about taking ARTs changed since you were hospitalized \_\_\_ months ago ?  
Have they changed because of any other reason?
18. Is there anything else you want to share with me about how things have been for you since we last spoke \_\_\_ months ago?
19. What is your advice for things that could be put in place to help ensure that people with similar situations as you, are able to manage your HIV (i.e., go to outpatient care, stay on medication if prescribed, etc)?

### **Lay beliefs about HIV/AIDS**

*I'm now going to ask you some questions about topics we haven't necessarily addressed so far.*

20. We've talked to lots of people with HIV or AIDS and about their experiences with living with the illness. Some people have told us that they believe that HIV/AIDS is man-made. Others have said that there is a cure but it is being withheld. We have also come across people who think that HIV was created to infect particular groups.
- a. Have you ever heard these ideas or any ideas similar to these?
  - b. *If "yes", have heard about these ideas* → What are some of the things you've heard? Who brought up these ideas? *Probe*: Was it a friend, a relative, an associate, someone you work with, other? Did the person(s) who discuss these ideas have HIV? What did you make of that?
21. What are your thoughts about these ideas?

*(If Participant shares these thoughts →)* Tell me more about this.

- a. What is your understanding/what do you think causes AIDS?

- b. What do you think about the purpose of ART? What makes you say that?
- c. What have you experienced or observed that lead you to think that?
- d. Have you ever shared these ideas with anybody? Can you tell me with whom and what did they say? Has anybody ever given you a hard time about believing this?
- e. Have you ever talked to a health care provider about your beliefs? If so, what did you discuss, and how did they respond?
  - i. Do you feel like they respected what you had to say? Whether yes or no: What do they say or do that makes you think they respect your views? If not, why not?
- f. How does this affect your relationship with the provider?
- g. How does it affect your going to the doctor (in general) or the clinic?
  - i. Going to an HIV care provider?
  - ii. Going on ART, if your doctor says you need to?

22. ***If Participant does not share these thoughts*** → Tell me more about this.

- a. What about these ideas do you not believe? What makes you say that?
- b. What is your understanding/what do you think causes AIDS?
- c. What is the purpose of ART?
- d. What have you experienced or observed that lead you to think that?

e. Why do you think some people think this?

23. ***If “no”, have never heard about these ideas*** → Have you ever heard people talk about the government having a role in creating AIDS, or keep some groups “down”?

a. What do you think about these ideas?

b. Why do you think some people think this?

c. What are your thoughts about these ideas? What makes you say that?

d. What have you experienced or observed that lead you to think that?

e. Have you ever shared your thoughts about this with anybody? Can you tell me with whom and what did they say?

f. Has anybody ever given you a hard time for thinking this way?

24. What advice would you give to someone who is HIV positive about taking care of themselves and their health?

25. Is there anything else you would like to add or talk about before we end our conversation?

Thank you so much for your participation.