

# Medication-Taking Practices of Patients on Antiretroviral HIV Therapy: Control, Power, and Intentionality

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## Abstract

Among people living with HIV (PLWH), adherence to antiretroviral therapy (ART) is crucial for health, but patients face numerous challenges achieving sustained lifetime adherence. We conducted six focus groups with 56 PLWH regarding ART adherence barriers and collected sociodemographics and ART histories. Participants were recruited through clinics and AIDS service organizations in North Carolina. Dedoose software was used to support thematic analysis. Participants were 59% male, 77% black, aged 23–67 years, and living with HIV 4–20 years. Discussions reflected the fluid, complex nature of ART adherence. Maintaining adherence required participants to indefinitely assert consistent control across multiple areas including: their HIV disease, their own bodies, health care providers, and social systems (e.g., criminal justice, hospitals, drug assistance programs). Participants described limited control over treatment options, ART's impact on their body, and inconsistent access to ART and subsequent inability to take ART as prescribed. When participants felt they had more decision-making power, intentionally choosing whether and how to take ART was not exclusively a decision about best treating HIV. Instead, through these decisions, participants tried to regain some amount of power and control in their lives. Supportive provider relationships assuaged these struggles, while perceived side-effects and multiple co-morbidities further complicated adherence. Adherence interventions need to better convey adherence as a continuous, changing process, not a fixed state. A perspective shift among care providers could also help address negative consequences of the perceived power struggles and pressures that may drive patients to exert control via intentional medication taking practices.

## Introduction

AMONG PEOPLE LIVING WITH HIV (PLWH), timely initiation of antiretroviral therapy (ART) and adherence to therapy as prescribed are crucial for better individual health outcomes.<sup>1,2</sup> In the United States (US), only about a third of persons diagnosed with HIV are on ART, and of these, only 54–75% are virally suppressed.<sup>3,4</sup>

Advances in HIV pharmacotherapy have greatly extended patients' lives and simplified available medication regimens by reducing the number of pills and doses per day, alleviating severe side effects, and expanding treatment options.<sup>5</sup> A quarter of annual new HIV infections are among those ages 13–24 years old,<sup>6</sup> a group that—on therapy—can expect to live a near-normal life span into their 70s.<sup>7</sup> At the same time,

over one-fifth of HIV-infected persons in the US are over age 50<sup>8</sup> and dealing with the physical and psychosocial challenges of multiple co-morbidities and medications.<sup>9–12</sup> Both of these phenomena pose challenges for long-term, optimal adherence.

In order to maximize the benefit from continued advances in HIV pharmacotherapy, the research and clinical care community must adapt care management approaches to the challenges patients face in achieving sustained, daily adherence in the context of HIV infection as a life-long condition alongside other chronic and acute health conditions. Much attention has focused on developing practical tools to support adherence (e.g., directly observed therapy, alarm devices, pill organizers)<sup>13</sup> and evidence-based interventions have included skill building, social support, and cognitive-behavioral components.<sup>14</sup> Persistent

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suboptimal adherence suggests that these initiatives may be important yet insufficient for fully addressing the barriers to life-long adherence that many patients face.<sup>15,16</sup>

Adherence improvements found in trials that have tested multi-component interventions lend further support to the complexity of this behavior.<sup>17</sup> Social-ecological models of ART adherence have been tested among pediatric and adolescent HIV patients,<sup>18,19</sup> showing a range of barriers to adherence to address at the individual and caregiver levels. Similar models are needed among adults and older adults to guide understanding of the shifting struggles of ART adherence over time in a patient's illness.

In this study, we adapted a contextualized approach to understanding factors that influence adherence, following the work of Broyles and colleagues who suggest replacing the dichotomous concept of adherence and its narrow focus on the patient with the concept of "medication practice" in order to create space for understanding the influences of power structures and institutions on ART medication taking.<sup>20</sup> By opening up this space for patients to describe their medication taking practices at present and to reflect on how these practices change on a day-to-day basis and over longer periods of time, we aimed to gain a more nuanced understanding of ART adherence and inform improved patient care and interventions for supporting optimal, sustained medication taking.

## Methods

From February to July 2012, we conducted six 2-h focus group discussions among 56 PLWH receiving ART. Two focus groups were held in each of three geographically distinct regions of North Carolina, selected to represent a large metropolitan area, a small city, and a rural area. Focus group guides were developed to explore perceptions regarding the HIV diagnosis experience, ART initiation decisions, and facilitators and barriers to ART adherence. Three groups were held with all men, one with all women, and two were mixed gender. One group was held with Spanish speakers. Participants completed a brief paper survey at the start of the focus group for sociodemographic characteristics and ART history. Survey responses were entered into an Excel file and SPSS version 21 was used to compute descriptive statistics.

Focus groups were recorded and transcribed verbatim. The Spanish transcript was translated by a bilingual Spanish-English speaker. A team of five researchers trained in qualitative data analysis worked together to identify themes across the six focus groups and code and analyze the data. First, each transcript was read by all team members to identify themes within the predetermined focus group guide questions (e.g., facilitators and barriers to adherence) as well as emergent themes (e.g., "the process of becoming adherent"). These themes were used to create a codebook that included one or more codes to capture each theme, a definition for each code, and illustrative sample quotations. This codebook was then uploaded to the Dedoose® web-based qualitative data analysis software and used by all team members to code Transcripts 1 and 2.

After each transcript was coded, the team resolved discrepancies and inconsistencies in the application of codes and further refined the codebook. This process resulted in a final list of 33 codes. Transcripts 1 and 2 were then re-coded with

the final codebook and each remaining transcript (3 through 6) was read and coded independently by two coders. A third coder reviewed all six transcripts to identify any remaining inconsistencies, which were then discussed by the full group to reach consensus.

To support analysis of relationships between codes, we used the Memo and Code Co-occurrence functions within Dedoose. Reports consisting of all coded blocks of text were generated for each code as well as the most commonly co-occurring codes. Syntheses were then written for each theme based on its codes and key sample quotes were selected to illustrate the theme. We drafted conceptual models to understand how themes were related and used these to guide the presentation of results within this article.

This research is part of a larger study, The Estimation Antiretroviral Medication Adherence (ESTEEM) Project, focused on the development of a brief clinical screening tool for predicting future ART adherence. The University of North Carolina Biomedical Institutional Review Board approved this study. Participants chose pseudonyms to use during the focus group to protect their confidentiality.

## Results

### *Sample characteristics*

To contextualize the qualitative findings, Table 1 lists the demographics and ART history overview of focus group participants by study site. Participants included 1 transgender woman, 21 female, and 34 male HIV-positive participants, of whom 43 were black, 7 white, 3 Hispanic, 1 Native American, and 2 participants of other race/ethnicity. Average age was 49.9 years old (range, 23–67 years) and mean years living with HIV was 14.7 (range, 3–28 years) with some variation across sites. A quarter of participants reported missing one or more of their prescribed ART doses in the past month.

### *Overview of qualitative themes*

Participants' discussions about ART reflected a fluid and complex nature of taking HIV medications as they talked about how they learned through trial and error to take their medications in ways that worked for their day-to-day lives. They described phases of taking and not taking medications infused with language that reflected power and control struggles across numerous arenas (Table 2). ART adherence was a central behavior through which these power dynamics operated, revealing aspects of intentionality in medication taking practices that functioned beyond—and in addition to—the goal of treating one's HIV infection. These processes were facilitated and shaped by participants' life contexts, especially managing multiple co-morbid conditions, navigating complex social welfare systems (e.g., the AIDS Drug Assistance Program—ADAP), and coping with HIV stigma.

For a number of participants, how they took (or did not take) ART became an assertion of personal agency—whether health-promoting or self-destructive, whether consciously or unconsciously. Four arenas where power and control struggles appeared most relevant for HIV medication adherence emerged from the discussions: (1) struggling against HIV disease; (2) struggling with ART and one's own body; (3)

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS OF 56 PLWH FROM SIX FOCUS GROUPS

	Site 1 N=18	Site 2 N=19	Site 3 N=19	All N=56 (%)
Age in years				
Mean	48.9	52.0	47.2	49.9 (6.81) <sup>a</sup>
Range	42–57	23–67	40–60	23–67
Gender				
Male	11	13	9	33 (58.9)
Female	7	5	10	22 (39.3)
Transgender	0	1	0	1 (1.8)
Sexual orientation				
Gay	8	9	3	20 (35.7)
Lesbian	1	0	1	2 (3.6)
Straight	6	10	14	30 (53.6)
Bisexual	2	0	1	3 (5.4)
Other	1	0	0	1 (1.8)
Race/ethnicity				
Black	17	12	14	43 (76.8)
White	0	5	2	7 (12.5)
Hispanic	0	0	3	3 (5.4)
Native American	1	0	0	1 (1.8)
Other	0	2	0	2 (3.6)
Mean years living with HIV	20.1	16.3	11.2	14.7 (7.69) <sup>b</sup>
Missed ART dose, past month	5	3	6	14 (25.0)
On initial ART regimen	7	5	8	20 (35.7)
Has health insurance	14	14	12	40 (71.4)

<sup>a</sup>Mean age in years = 49.9 (standard deviation = 6.81).

<sup>b</sup>Mean years living with HIV = 14.7 (standard deviation = 7.69), range: 3–28 years.  
ART, antiretroviral therapy; PLWH, people living with HIV/AIDS.

TABLE 2. ARENAS OF POWER AND CONTROL, RELEVANT SUB-THEMES, AND ILLUSTRATIVE QUOTES

### Struggling against HIV disease

Desire for control over one's life and death, fear of ART, fear of death

Denial of HIV status

Beliefs about HIV, CD4, and viral load

Beliefs and skepticism about how ART works against HIV

*Example: "My brother, I saw all his friends, just fell off the map one by one...Why, should it [ART] work for me, it didn't work for the last 20 people that died...so I disobeyed the medicine at first and said, at least I'm gonna go [die] comfortable." (Participant #49, male, age 48)*

### Struggling with ART and one's body

Pill burden

ART's perceived impact on the body, side effects attributed to ART (past and present)

Developing medication taking practices that work for one's life

Managing co-morbid conditions

*Example: "You just get sick and tired of feeling terrible from taking the medicine sometimes... and just want a relief from it and I have quit for that very reason. The medicine makes you feel so terrible, you just give up on it and quit for a while." (Participant #20, male, age 61)*

### Struggling with ART and healthcare providers

Perceived limited treatment options, shock at diagnosis

Tensions with providers (stigma, paternalism, mistrust, misrepresenting ART taking practices)

Advocating for and educating oneself

Supportive providers

*Example: "I actually ask my doctor a lot of questions. I made him, I basically made him tell me what I wanted to know...He told me that, that I would be taking 12 pills a day...I said I can't do that and I won't do that. So I basically made him do his research...He got to the point where he found three pills that I can take." (Participant #1, female, age 44)*

### Limited control within multiple systems

Maintaining access to medications (pharmacy problems, drug assistance programs, co-pays)

Unintentional treatment interruptions (incarceration, hospitalization, life events)

*Example: "Every year you gotta redo your ADAP. Cut that out man! We aren't going to get rid of it [HIV]...so why I got to keep going each year...if you can, cut that out." (Participant #24, male, age 46)*

struggling with ART and health care providers; and (4) experiencing limited control within multiple systems.

Despite overlaps and interrelationships across these arenas, we find this framework useful for organizing the persistent themes that dominated focus group discussions, and for demonstrating that power dynamics were operating across multiple areas in relation to medication adherence. Table 2 presents this framework, along with sub-themes drawn from the coded text, and supporting sample quotations from the transcripts. Each of the four arenas and sub-themes are described in turn below.

*Struggling against HIV disease: “Not taking the meds kept me in a safety zone of denial.” (Participant #12, male, age not reported, put off starting ART for 18 years)*

We identified four sub-themes related to struggling against HIV disease: strong fears of ART and death that prompted a desire for control over one’s life and death, denial of one’s HIV status, beliefs about HIV, CD4, and viral load, and beliefs and skepticism about how ART works against HIV (Table 2).

After diagnosis, most participants described facing overwhelming fears of death, HIV, and ART itself. As the majority of participants had been living with HIV for over 10 years, most knew HIV-infected people who had died while taking ART. Participants described struggling with this knowledge to understand the relationship between HIV, ART, and death. Participants used words like “poisons,” “toxic,” and “dangerous” to describe ART drugs—especially earlier regimens. Fears and skepticism about the effectiveness of ART were consistent themes across all six focus groups. In coping with these fears, a common response described by participants was a desire to take control over one’s own death (and life) through intentionally choosing to take or not take ART:

*My brother, I saw all his friends, just fell off the map one by one...Why should it [ART] work for me, it didn’t work for the last 20 people that died...so I disobeyed the medicine at first and said, at least I’m gonna go [die] comfortable. (Participant #49, male, age 48)*

*Q: Let me make sure I understand, what helps you take your [ART] on time is that you found that you tried to commit suicide and couldn’t do it?*

*Participant: Uh huh. God, if you can’t kill yourself, why you going to let somethin’ else do it? (Participant #31, male, age 49, describing the relationship between three suicide attempts and his current adherence to ART)*

Initial fears of HIV, ART, and death were also common among participants who were more recently diagnosed. Furthermore, even for participants who were reflecting back 15–20 years ago, their discussions were very clear, detailed memories of a diagnosis event that continued to impact their life every day since diagnosis.

Alongside fears of death, HIV, and ART, a number of participants described a struggle coming to terms with the dual concept of HIV infection as a life-threatening condition, and manageable through medication. For these individuals, denial of their HIV status kept them from care and from taking ART:

*I was in denial. I didn’t want nobody to know I had HIV for a long time. So that kept me away from the doctors. I hid it. I knew I had it, but I didn’t want to face it. (Participant #49, male, age 48)*

For some participants, struggle with denial of their status and desire to avoid or stop taking ART resulted in endorsing the belief that they were “different” and would not need medication:

*You want to think that you’re different, you’re cured. You know that’s what I want to think, you know I’m good and I’m special...I feel better now. (Participant #3, male, age not reported)*

*I felt like I was doing good. Every time I came to get it checked, everything checked out fine; I said maybe I’ll just wean myself off of them [meds] and ... might not have to take them. So I did. (Participant #41, female, age 45)*

Feeling healthy allowed some participants to remain in this state of denial. As described by Participant #33: “I had went like two and a half, three years without [meds]...because I was undetected. I became undetectable. No, I don’t need it [ART]. Why should I?” (male, age 49).

In contrast, ART caused side effects that made participants feel sick. This dissonance meant that for many participants there was a need to come to terms with new understandings of what taking medication meant, including that they would need to take medicine even when they did not feel sick; that, even if they did feel sick, taking medicine might not make them feel better; and that the side effects of medications might make them feel sicker. Some participants explained how they could test these concepts by taking and not taking medication:

*I want to go a whole 60 days...without taking medication. Period. And see how it will [work]. (Participant #5, female, age 52)*

*I can sort of like feel it [HIV] in my face...feel it in my mouth, you know when that disease is prevalent or high. And when I’m feeling great, I don’t feel it...I want to test it [not take medication] and see if I’m gonna feel like this for a while anyway. (Participant #3, male, age not reported)*

*I feel good, as far as taking that stuff [ART], I’m confident. I know I’m feeling better...If I missed it for 3 weeks, I felt bad, you know. I can feel the change coming in my system. (Participant #24, male, age 46)*

The examples above also illustrate the beliefs participants developed about how ART and HIV worked. These conversations generally reflected a mixed language of medical terminology and sensory experience. As suggested by Participants #33 and #41 above, and described further below, depending on a person’s beliefs about how ART and HIV worked, good test results could deter or support medication adherence.

*Struggling with ART and one’s body: “You just get sick and tired of feeling terrible from taking the medicine” (Participant #33, male, age 61)*

The second arena in which power, control, and intentionality affected adherence focused on ART’s perceived and experienced effects on the body. Important sub-themes included high pill burden, ART’s perceived impact on the body, side effects attributed to ART (past and present), developing medication taking practices that work for one’s life, and managing co-morbid conditions.

For many participants, side effects were described as significant barriers to adherence that wore people down physically and emotionally over time:

*Really you just get sick and tired of feeling terrible from taking the medicine sometimes...and just want a relief from it and I have quit for that very reason. The medicine makes you feel so terrible, you just give up on it and quit for a while. (Participant #33, male, age 61)*

*I stopped. I mean I was just so nauseated and just so sick and it's like I was tired of taking it; I was sick and tired of taking medicine. (Participant #42, female, age 45)*

The severity of side effects and participants' inability to control them led to intentional decisions to stop taking ART at various time points. While some participants described physical symptoms which limited their functioning (e.g., daily diarrhea which precluded work or taking public transit), others dreaded bad dreams, or attributed depression to their ART.

*Taking pills all your life like this...it bothers our mentality...(Participant #2: We're depressed.) I'm telling you it's very depressing, you got to take it every day, every day, every day, and that's not every day living. And sometimes you want to say Lord, I want to take a break. I'm tired of taking pills. (Participant #5, female, age 52; Participant #2, female, age 49)*

*Consequences! If you don't take it, this is what happens...Throughout my whole life it's been: if you don't do this, you get consequences...I do want to live, but I also want to live a quality of life. I don't want to live dragging through the mud. (Participant #12, male, age not reported)*

As suggested above, some participants felt a sense of powerlessness in the face of their ART regimens' impact on their physical and emotional lives. Some wearied of—and pushed back against—the constraints that accompanied rigid medication regimens, such as having to schedule meals and social lives around their pill schedules.

Thus, taking ART involved intentionally developing medication-taking practices that worked for participants' bodies and their lifestyles. As medication regimens and side effects interrupted participants' lives, they re-asserted control by intentionally altering how, when, and whether they would take their medication.

*My best advice is, don't let the meds rule you. Yes, I take my meds daily, twice a day. I try to take them between six in the morning and eight, and the same, in the afternoon. If I don't take it right at six I don't worry about it. When I think about it, I take it. I didn't let the meds rule my life. (Participant #19, male, age 62)*

*I used to just tell myself, "Oh, it's casual Friday. I won't take the pills today." (Laughter) That was my reasoning. So once a week I would just miss pills. And I never was on a schedule. I'd take mine when I remember in the morning. (Participant #25, male, age 56)*

Here participants #19 and 25 describe examples of the intentional decisions which were within participants' power to make and resulted in their regaining control of how ART would factor into their lives.

Newer, simpler ART was generally perceived as less toxic and described as producing fewer side effects, facilitating greater acceptance of ART among many participants. However, in all six focus groups there were participants who continued to experience side effects with their current regimens (e.g., nightmares, diarrhea and other gastrointestinal problems, vomiting, nausea, sweating, and racing heart beat) that they attributed to ART. In the following two quotes, both participants describe continued struggles with their once-a-day regimens:

*I only take one pill, one pill at night, okay...But, thank God, the only side effect of that is I have real crazy dreams, nightmares type situations. (Participant #12, male, age not reported)*

*I still have the side effects, the nightmares, the sweats, the cramping, throwing up and stuff...the problem with it [is] I have to take it every day at the same time. (Participant #2, female, age 49)*

Side effects led some participants to ask their doctors to switch them back to more complex regimens (e.g., from one pill once a day to multiple pills multiple times a day). Others tried to rearrange their lives and medication taking practices to accommodate their current regimens (e.g., not taking pills at night that caused nightmares), or simply skipped doses as needed.

Some participants believed there were connections between their HIV medications and longer-term side effects in the form of other health conditions. These beliefs placed individuals in the position where they felt that following their prescribed HIV treatment was exacerbating or causing other health conditions.

*I started getting depressed...and I had never known myself to be depressed and I actually thought it was the medication...that was making me depressed so I took a break for about a month. (Participant #1, female, age 44)*

*When I started taking the HIV medicine, I developed diabetes, high blood pressure and all that, which I never had none of it...and there wasn't none in my family...what they don't tell you, the HIV medicine you taking end up causing you more health problems and you end up taking medicine for that too...And I just get fed up with taking all them pills all the time. (Participant #22, male, age 42)*

As seen above, beliefs about ART's impact on broader health led some participants to intentionally stop taking ART at times, while others became frustrated, discouraged, or mistrustful.

Struggling with co-morbid conditions was the most consistently mentioned barrier to adherence discussed extensively by the majority of participants in all six groups (Table 3). Thirty-five participants described at least 69 different health conditions other than HIV. Since a detailed medical history was not collected for each participant, this is likely an underestimate of the total burden of co-morbid conditions among our sample. Trying to keep control over other chronic co-morbid health conditions and HIV presented additional complexities impacting participants' ability to take ART as prescribed:

*I take something like 14 different medications, can you imagine opening the bottles and going through 14 medications twice a day...it would take over your whole day just about going through medication bottles...I probably skipped medications many times because I didn't have time to fool with going through the bottles. (Participant #20, male, age 61)*

*I have other issues going on with severe depression and PTSD...I take this medicine to stop the nightmares and help you go to sleep...on Ritalin and the anti-depressants...I take about 10 or 12 medicines a day, but only three of them are related to the HIV. (Participant #28, female, age 55)*

The most common current co-morbid conditions discussed were depression, heart conditions, and diabetes. Depression and substance use (generally referred to as a past problem) were described as particularly interfering with taking ART.

TABLE 3. CO-MORBIDITIES DESCRIBED (UNPROMPTED) BY 56 HIV-INFECTED FOCUS GROUP PARTICIPANTS

Condition (as described by participant)	Participant ID numbers	Total
Diabetes	19, 22, 25, 26, 34	5
Kidney disease	42	1
Stroke	7, 8, 11, 33	4
Seizure/epilepsy	8, 21	2
Neuropathy, chronic pain	8, 36	2
Heart disease	7, <sup>a</sup> 8, <sup>a</sup> 19, 24, 26, 56 <sup>a</sup>	6
High blood pressure	19, 22, 34, 42, 48, 53, 54	7
High cholesterol	19, 53, 56	3
Addiction/substance use <sup>b</sup>	9, 29, 34, 35, 40, 42, 45, 49, 53	9
Depression	1, 3, 28, 31, 41, 47, 53, 56	8
Manic depression	8	1
PTSD	28	1
Schizophrenia	37	1
ADHD	28	1
Memory loss/amnesia	5, 8 <sup>c</sup>	2
Sleep disorders	28, 36	2
Cancer	7 <sup>d</sup> , 21 <sup>d</sup> , 27, <sup>e</sup> 39 <sup>f</sup>	4
Asthma	54	1
Unspecified <sup>g</sup>	3, 20, 24, 28, 29, 31, 42, 53, 56	9
Any co-morbid condition	35 unique individuals	69 conditions

<sup>a</sup>Participant mentions specific hospitalizations for “heart attack.”

<sup>b</sup>The majority of participants who described addiction/substance use framed it as something they had to overcome in order to become adherent to ART, and/or as something they turned to earlier on in their diagnosis to cope with the diagnosis and/or remain in denial about HIV.

<sup>c</sup>Participant attributes amnesia to her stroke.

<sup>d</sup>Brain cancer.

<sup>e</sup>Unspecified cancer.

<sup>f</sup>Breast cancer.

<sup>g</sup>Applied if a participant describes taking daily medications for a condition other than HIV but does not specify the condition.

*My depression got so severe that I just wanted to die. I stopped taking my meds altogether; that's when my T-cell count dropped to 12. My viral load was off the charts because I didn't want to live anymore...there's a lot of things that goes through your mind; you're like oh my God, I'm so sick and tired of taking this medicine, I just want to die. I don't care. (Participant #53, male, age 57)*

*In my process of me taking my meds, I had to understand and realize that I couldn't do the dope, I couldn't do the drugs no longer, I couldn't do the alcohol (Participant #9, female, age 52)*

The majority of participants in this sample had other comorbid conditions in addition to HIV. The process of trying to become or stay adherent to ART thus involved finding ways to take ART that worked with their other evolving health conditions, leading at times to medication taking practices different from what was prescribed. In some cases, a lifestyle change was necessary to accommodate ART, while in other cases participants altered their medication taking in an attempt to avoid short or long-term side effects, or simply were not able to successfully manage these multiple conditions at certain times (e.g., Participant #53 above).

**Struggling with ART and healthcare providers:**  
*“[Doctor] said take it on an empty stomach. I wouldn't. I would at least eat a cracker, and that seemed to help me tolerate meds.” (Participant #19, male, age 62)*

In discussing interactions with healthcare providers, participants described the trauma and shock of their initial diagnosis, feeling that they had limited treatment options, and tensions with providers, as well as strategies they used to

advocate for themselves, and the supportive provider relationships that helped facilitate adherence.

For most participants, their HIV diagnosis was a traumatic experience, exacerbated by interactions they perceived as cold or stigmatizing.

*[Health Department worker] just point blank said, “You're going to die in less than a year. You can't have sex, you can't do...” She was real nasty... (Participant #25, male, age 56, diagnosed early 1990's)*

*The doctor that told me I had HIV, he was very cold. You know, like I was nothing. I was in a coma. I woke up and he's standing over me and he says, “Oh um, you know you have HIV. Here's your prescriptions”. And he just walked away. This is 2007 and this was in Boston! (Participant #32, female, age 59)*

These two diagnosis experiences occurred about 15 years apart, yet both recall strained patient-provider interactions.

In addition, many participants described being in a state of shock upon receiving their results including difficulty processing information, reduced hearing, feeling numb, and shutting down. During this time, they were being presented with a large amount of information or being asked to make choices about their treatment that they could not process.

*My first reaction when the doctor informed me that I was HIV positive, it was a blank stare, I shut down...I was in shock (Participant #47, female, age 43)*

*I had a kind of core blank feeling because I couldn't accept that it was me. I almost was feeling numb (Participant #13, male, age 45, all other seven participants in his group nod in agreement)*

Importantly, the healthcare provider who gave an initial diagnosis was often not the doctor who would eventually

provide care. However, participants' descriptions of their negative diagnosis experiences were linked in many cases to a trajectory of care involving future avoidance of doctors and delayed ART initiation.

After receiving their diagnosis, participants described feeling like they had limited control over the treatment options and choices presented to them. Most participants did not describe their doctors as decision-making partners, nor did they describe themselves as compliant or good patients. In some cases, they felt powerless as physicians presented them with options that were not actual choices about when to start ART or how to take medication:

*I felt I was a number during the diagnosis...It was something that was set out before me and it was almost like being on a treadmill, where it was rolling and there was nothing I could do to stop it...So what choice did I have? (Participant #15, male, age 47, talking about whether he felt like he had a choice when initiating ART)*

*I remember the doctor telling me; "If you don't take it, don't take it today and then take it tomorrow, just stop taking it completely." And that's what I would do. I would just stop taking it. And I would take it and go a month at a time without taking it, but when I'd go get blood work done, the next thing I know she's calling me, "Well [name redacted] you're not taking your medicines..." (Participant #42, female, age 45)*

Diagnosis shock combined with perceived limited options turned many participants off to care, while leaving others feeling unprepared to start ART or unsupported in taking ART as prescribed.

In addition, patient-provider interactions involved negotiations where issues of power and control were very much present. Healthcare providers' power was centered in their medical authority, prescribing power and possession of information. Yet patients also exerted power within the doctor-patient relationship. For example, participants acknowledged misrepresenting their ART taking practices to providers, avoiding appointments, and trying to outsmart blood tests:

*Q: When you took your break, did you talk to your doctor about it?*

*Participant: No. Because I didn't want him to yell...(laughter) I didn't want, I didn't want to have to hear what he had to say when I went, you know, to, to see him. (Participant #15, male, age 47)*

*[I'd] take the medicine [only when] it was time to go to the doctor. Like if I'm supposed to go to the doctor on Thursday, I'll take it Tuesday, Wednesday, and Thursday so it will be in my system...knowing that he could look at the blood work and tell when you was taking the medicine. (Participant #17, male, age 53)*

Some participants also advocated for themselves, negotiating for a more simplified regimen or to change medications to avoid specific side effects.

*I actually ask my doctor a lot of questions. I made him, I basically made him tell me what I wanted to know...He told me that, that I would be taking 12 pills a day...I said I can't do that and I won't do that. So, I basically made him do his research...He got to the point where he found three pills that I can take. (Participant #1, female, age 44)*

This statement highlights how healthcare providers were perceived to control information and knowledge. Many participants' descriptions about acquiring knowledge about HIV

and ART reflected a process of (re)taking some of this control and creating a more equal power balance.

Importantly, when discussing how doctors supported ART taking practices, some participants described the importance of their healthcare providers being caring, compassionate, and understanding. In participants' discussions about providers, supportive relationships engendered trust and encouraged medication taking:

*My doctor was the lovingest, most compassionate doctor and he was concerned. That's what made me really think about taking [ART] because he was really concerned about the person. (Participant #37, female, age >50)*

*Q: What did your doctor say when you told your doctor you stopped [ART]?*

*Participant: To be a 100% fair with you, I don't think he chastised me too hard...I think he sort of understood because it had been so long. (Participant #20, male, age 61, describes a 4 month break in ART)*

Following their physicians' lead, participants embraced the clinical language of CD4 cell counts and viral load levels as primary indicators that ART was working for them. A number of participants described how these numbers helped them keep taking ART.

*Every time I go to the doctor, they tell me my CD4 count...and the virus is undetectable.... That just encouraged me to keep right on doing right. (Participant #35, male, age 60)*

*She [doctor] always tell me how well I'm doing with it. She's like "wow"...and I actually kept the card, so I got these [CD4] counts. I look at them...and it's so great and she's so thrilled with it and so am I. (Participant #13, male, age 45)*

Of note, the quotes above illustrate how "good counts" (CD4, viral load) helped some individuals persist with taking ART as prescribed, in contrast to tempting them to wean themselves off medications, as described earlier in the results. This contrast points to the importance of patient-provider communication and awareness of nuances in patients' understandings of how ARTs and HIV operate within the body.

*Limited control within multiple systems: "Who in the world can pay \$2000 a month for pills?" (Participant #24, male, age 46)*

The final sub-theme raised across all focus groups centered around participants' limited control within the multiple systems they experienced as part of their medical care and day-to-day lives. Maintaining access to medications was challenged through pharmacy problems, drug assistance program logistics, and multiple copayments. Unintentional treatment interruptions were also common particularly around both major and minor life events including travel, hospitalization, and incarceration.

Maintaining access to medications through logistical issues with pharmacies and drug assistance programs, as well as affording co-payments, posed problems for a number of participants. For some, these problems were as basic as learning to place prescription refills sufficiently ahead of time to account for pharmacy stock-outs. For others, navigating the program requirements for Medicaid and the AIDS Drug Assistance Program (ADAP) were viewed as unnecessarily complicated barriers to receiving ART:

*It takes...4 months to 8 months to get on medication in [city name redacted]... you get processed and you have to go see this one for 8 hours, you got to go see the doctor for this... you got to go see the case worker. And they give you this little card and it say that every 6 months, or every so often you come and get this renewed...keep everything in line. Once you mess up and you miss that date they cut you all off... So that kept me off for like a, almost a year. (Participant #51, male, age 47)*

*Every year you gotta redo your ADAP. Cut that out man! We aren't going to get rid of it [HIV]...so why I got to keep going each year...if you can, cut that out. (Participant #24, male, age 46)*

A few participants also described the difficulties they faced in making sure they could still receive free medications when their ART regimens changed.

*Shorten the forms so that you won't have to put so much information down and...if you're on a certain type of meds, and then they switch you up and then you have to go and fill out another form for those meds...every time they switch you off a drug then that forces more forms that you have to fill out. (Participant #27, male, age 49)*

*If you got the kind of insurance I got, it takes 2 to 3 months for them to okay you, before you can get a prescription. And you can't afford this medicine out of your own pocket. It come to the point, am I going to pay my rent or do I want to get this medicine? (Participant #22, male, age 42)*

Since ADAP often mails ART medications to patients' homes, participants who traveled or moved could experience inadvertent treatment interruptions, which also caused emotional stress and time to resolve.

A few participants mentioned personal financial barriers to receiving medications, while more expressed concern that others (though not them) could not afford ART medications. Talk of personal costs primarily focused on medication co-payments. Given the large number of co-morbidities described by participants in Table 2 above, it is not surprising that co-payments could add up to a substantial monthly expense.

*All of us don't have the money to pay for that copayment...some drug stores will charge you five dollars, some charge you ten, some charge you three; you still don't have the money. They think Medicaid pay for all of them but it really don't. (Participant #7, female, age 45, on 16 different medications with total monthly co-payments of \$160–\$180)*

*[ART] cost you...especially co-pay. I don't have Medicaid and...the medications, you know they are very costly. I'm on a fixed income...a lot of times I can't afford it...I was able to get with the ADAP program, but there's still some...costs, still costly...couple thousand dollars...out of pocket. (Participant #8, female, age 52, describing annual cost of care)*

Although financial barriers to accessing medications were only mentioned by a few participants, others expressed concern and fear about their lack of control over their ability to indefinitely receive free ART.

*It wouldn't surprise me that when you come for this [ADAP] signing up every year, or now I heard 6 months, they didn't tell you, you know we can't fund it...that you gotta get cut off because you make this and this [salary]...with the way the economy and the cut backs here, it's kind of a scary thought in the back of your head. (Participant #23, male, age 43)*

*There's been a huge cut back for the ADAP medication that's covered. It used to be every one of my meds was covered. Now it's just four...Next year I'll probably be eligible for Medicare*

*and that's going to be a whole new ball game. (Participant #19, male, age 62)*

Similarly, one participant who was returning to work after having been unemployed shared his concern that he could not afford to work because he would no longer be eligible for ADAP and the co-payment for ART in his employer-based health insurance would be too expensive. These fears added stress and worry as participants described knowing their monthly supply of ART would cost thousands of dollars if not subsidized.

Life events including incarceration, hospitalization, and public assistance systems limited participants' abilities to make decisions regarding their health, and in numerous instances interrupted their access to HIV treatment. Some people talked about treatment interruptions caused by short- or long-term hospitalizations, which were a common occurrence.

*I was in the hospital for a very long time and a nursing home, there was times that I didn't get my medication on time or twenty-four hours later. Being in the hospital, sometimes you're subject to not getting your medicine when you should. (Participant #21, male, age 67)*

*Being in the hospital for a number of times, and even though you tell them the regiment that you're on and the times that you take it, usually it'll happen where you're not getting it for a day or so and you miss out. Or, in my case, I was in a coma for a couple of weeks and I didn't get any meds. (Participant #27, male, age 49)*

Given the large number of co-morbid conditions participants experienced, problems of access to medications within hospitals were a serious concern.

Five out of six participants who had been incarcerated relayed examples of having diminished control over their ART treatment options while incarcerated. They recounted not having a choice regarding when or how to take their medications, and how their HIV-positive status was disclosed to prison staff or inmates without their permission. Two participants shared techniques that they used, such as hiding HIV medication provided to them by the prison system, to protect themselves from stigma, discrimination, or targeting by fellow inmates:

*Well, actually I was locked up (short laugh) and I would just hide my meds...I didn't want nobody to know I was taking HIV meds. (Participant #13, male, age 45)*

*I was told when I went to prison that I had to keep my medications under lock and key...Because if those, the people in the yard got whiff that I had Sustiva, they was going to come to me to get it because it's a form of hallucinogen. (Participant #31, male, age 49)*

For three other participants, entering the prison system caused treatment interruptions ranging from 2 days to 3 weeks when they were unable to access their regular ART.

## Discussion

These focus group discussions reflected how the rigid, indefinite nature of participants' HIV medication regimens required them to enact a large amount of consistent control within multiple systems. Yet participants described having limited power within these systems, including regarding their own body's health and reactions to taking medications. Ultimately, ART adherence was the product of a complex set of internal and external struggles and conditions. Many participants felt that they had to look out for themselves against this



disease, their treatment, and the systems that they encountered (e.g., ADAP, hospitals, prisons).

Participants intentionally adapted how they took ART to work within their circumstances or lifestyles, and explained struggling to maintain control of their health and healthcare. In this process, their understandings and beliefs about ART were important in determining how they took their medications on a daily basis and over time. Others have described similar ART taking practices as adherence on a “dose-by-dose basis” emphasizing multifaceted models influencing how and whether a dose is taken.<sup>21</sup> The persistence of fear and mistrust around ART in this sample emphasizes the importance of health providers seeking out and addressing patients’ perceptions of the connection between medications, side effects, and co-morbidities.

Participants’ intentional medication taking practices could also be seen as a form of “self-tailoring.”<sup>20</sup> Self-tailoring of prescribed treatment has been described as a form of self-regulation within a variety of other conditions including epilepsy,<sup>22</sup> co-morbid chronic conditions,<sup>23</sup> and chronic obstructive pulmonary disease.<sup>24</sup> Our work contributes to this literature by looking at how power, control, and intentionality were at play across multiple areas of participants’ lives (not just within the self and the patient–provider relationship) and influenced ART medication taking practices.

Our results underscore the need to better understand and adapt responses to patients’ perceptions of the impact of their medication self-tailoring on their HIV health. We found a range of understanding in this diverse sample from those who “tested” the impacts of not taking ART on their bodies, to those who clearly articulated the connection between stopping taking ART and changes in their viral loads. Patients’ interest (as compared to indifference) in how medication acts on their bodies suggests opportunities for greater communication and intervention around medication taking.

Side effects were a commonly reported challenge across the focus groups and contributed to the daily struggle many participants had with medication taking. While many of these experiences had occurred years prior, a number of participants continued to report gastrointestinal and neurologic effects while on more modern ART regimens. Some participants had worked with their doctors to switch back to older regimens, while others chose to bear these side effects—a choice that had implications for quality of life and achieving optimal adherence.

A connection might be drawn to recent work regarding the negative impact of self-silencing (“concealing feelings to avoid conflict, loss, and protect self-esteem”) on ART adherence among women with HIV.<sup>25</sup> Brody and colleagues theorize that self-silencing could impede the communication skills that patients need for building positive relationships with their care providers.<sup>25</sup> In the current sample, those who are prone to self-silencing could experience the power imbalance in their provider interactions more acutely; at the same time, the unequal patient–provider relationship may further reinforce patients’ self-silencing behaviors.

Other medical conditions featured prominently across all focus group discussions and in individual participants’ narratives. This finding is consistent with a growing body of literature describing co-morbidities among older adult HIV patients and the new challenges multiple health conditions present for healthcare and quality of life.<sup>9–11</sup> Interventions are needed that address HIV-infected patients’ longer-term

issues of HIV as a chronic disease and the challenges of navigating their health and healthcare systems with HIV and other chronic—and acute—conditions. Depression—the second most common condition described by participants in this sample—has been associated with higher number of co-morbidities among HIV-positive older adults.<sup>26</sup> Intentional decision-making around ART also played a role here as some participants felt that taking ART as prescribed was causing or exacerbating their other health problems.

Health care systems and programs that provide medication assistance, that is, systems designed to provide care, were at times paradoxically oppressive, challenging participants’ agency for obtaining medications. Requirements for frequent renewal of ADAP and other programs that provide access to HIV medications were considered to be onerous and presented obstacles to adherence. Power and control operated through ART taking practices in both health-positive and health-destructive ways. At times, intentionally taking or not taking medications became an assertion of agency, (re-)claiming control within the few areas of participants’ lives where they felt they had the ability to do so.

As argued by James Scott, within oppressive social arrangements, those with less power find ways to give “the impression of compliance without its substance” (1985, p. 26).<sup>27</sup> This form of “everyday resistance” allows individuals to “minimize compliance at the level of actual behavior” (Scott, 1985, p. 26) and maintain individual agency/control within an unequal power relationship.<sup>27</sup> Everyday resistance by those who have less power is a sign that they are not fully consenting to the position of powerlessness.<sup>27</sup> Examples of this could be seen in participants who described misrepresenting their ART taking practices to providers, altered how they took ART—including stopping entirely or trying to influence their blood tests by taking medications in particular ways.

Findings from this study also connect with earlier work on identity formation among PLWH. A 2012 focus group analysis of patient–provider relationships among PLWH found that stories of personal transformation and “autonomous motivation” were critical to the process of becoming consistently adherent.<sup>28</sup> As Laws and colleagues describe, “These participants...became adherent to medication regimens and medical appointments only after undergoing personal transformations that represented incorporation of illness identity, acceptance of the reality of their condition, and a new or renewed sense of agency, including a will to live” (p. 899).<sup>28</sup> Our findings on power and control struggles as barriers to adherence align with this work as participants ultimately framed adherence as their own intentional decisions or efforts within these power struggles.

For many participants, being adherent required accepting an identity of having HIV—a process that took years for those who faced shock, denial, and fear. The subsequent behaviors required for perfect adherence are complex and take on new moral dimensions within the power limitations of multiple systems. For example, if one can only receive their ART medication in-person, in-state, every 30 days, then decisions about travel for work, family, or leisure also become decisions about being a good patient and ultimately a good person. These types of fraught decisions, alongside the physical strains of coping with side effects and other co-morbid conditions wore participants down over time—a theme echoed in focus groups among other older

HIV-infected patients.<sup>12</sup> Resilient patients who are able to achieve high adherence despite this multitude of struggles lend further support to recent work on the positive relationship between resilience, ART adherence and virologic suppression.<sup>29</sup>

These focus group discussions revealed how the meaning of ART adherence in one's life is inadequately described by a dichotomy of adherent/nonadherent. In the course of a patient's illness, medication taking practices changed on a day-to-day basis and over time. Vervoort and colleagues discuss the role of acceptance of one's HIV status leading to either a determination to be adherent, or to ART being "subordinate to other priorities in life."<sup>30</sup>

Adherence practices then follow from this position, leading the "ART determined" group of patients to overcome challenges to adherence, while the other group will be selectively adherent depending on how disruptive adherence is to their lives.<sup>30</sup> While our results support this conclusion, we also found that the process of becoming and staying adherent was more fluid and complex than simple determination or subordination. Those who provide HIV care may need to adjust adherence messages to reflect patients' experiences of medication adherence as a process rather than a fixed state.

There are a few limitations to this study. First, we utilized a qualitative convenience sample, which is not representative of the full scope of ART-taking patient experiences and medication taking practices. However, the sample did include participants from multiple sites across a range of ages, gender, sexual identity, and race/ethnicities. Second, we did not include newly diagnosed PLWH or those not currently taking ART. We did ask participants to reflect back to their diagnoses and did include participants who had started, stopped and restarted ART. A future study could compare the adherence barriers faced by patients who are newly diagnosed on ART or who have stopped (and not restarted) ART with those on ART.

Lastly, participants' narratives are subjective descriptions of experiences as they understood them at the time of the focus group. These narratives may be affected by social desirability bias, recall bias, and participants' interpretations of their experiences, which may change over time. The focus group method helps build validity of our analysis as we found a large amount of agreement among participants within and across groups, however future quantitative studies are needed to test the relationships between barriers we identified and ART adherence.

Power and control struggles in medication adherence practices are well-documented within the history of medicine.<sup>31</sup> The shift from "non-compliance" to "adherence" language suggests a move toward acknowledging the need to alter the power dynamics we found so pervasive in these focus group discussions, but more intentional work is needed. Measures could be incorporated into clinical care and public health intervention to address perceived power struggles and reduce pressures on patients that may be driving practices of exerting control via medication taking—and not taking—practices.

At the same time, we have attempted to emphasize the power and control struggles that patients faced across multiple sectors in order to avoid what Broyles and colleagues caution against: "a counter-productive anti-medicine orientation where blame is shifted from the individual to the presumably insensitive, resistant clinician" (p. 374).<sup>20</sup> As demonstrated in our findings, patient-provider relationships were only one component in a more complex process of

medication taking practices. Continued health policy and coordination of care work is also needed to simplify the multiple systems and institutions with which patients interact and facilitate improved management of HIV infection and co-morbidities.

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