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## Explanatory Models and Illness Experience of People Living with HIV

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### Abstract

Research into explanatory models of disease and illness typically explores people's conceptual understanding, and emphasizes differences between patient and provider models. However, the explanatory models framework of etiology, time and mode of onset of symptoms, pathophysiology, course of sickness, and treatment is built on categories characteristic of biomedical understanding. It is unclear how well these map onto people's lived experience of illness, and to the extent they do, how they translate. Scholars have previously studied the experience of people living with HIV through the lenses of stigma and identity theory. Here, through in-depth qualitative interviews with 32 people living with HIV in the northeast United States, we explored the experience and meanings of living with HIV more broadly using the explanatory models framework. We found that identity reformation is a major challenge for most people following the HIV diagnosis, and can be understood as a central component of the concept of course of illness. Salient etiological explanations are not biological, but rather social, such as betrayal, or living in a specific cultural milieu, and often self-evaluative. Given that symptoms can now largely be avoided through adherence to treatment, they are most frequently described in terms of observation of others who have not been adherent, or the resolution of symptoms following treatment. The category of pathophysiology is not ordinarily very relevant to the illness experience, as few respondents have any understanding of the mechanism of pathogenesis in HIV, nor much interest in it. Treatment has various personal meanings, both positive and negative, often profound. For people to engage successfully in treatment and live successfully with HIV, mechanistic explanation is of little significance. Rather, positive psychological integration of health promoting behaviors is of central importance.

### Keywords

HIV; Explanatory models; Identity theory; Illness experience

### Background

Interest in so-called explanatory models of disease and illness emerged in the 1970s, largely from the field of medical anthropology, with an emphasis on non-western cultures [1], later

applied to medical care in the US [2]. For decades, medical anthropologists have distinguished between “Disease” and “Illness” models [3–5]. “Disease” refers to the biomedical perspective, which historically in the US and Europe has been characterized by mind–body dualism [6, 7], and biological reductionism [8, 9]. Diseases are abstract entities—biological processes or states—which are thought of as similar regardless of the psychosocial setting or the afflicted individual. “Illness” refers to the patient’s experience. It is broader, particular to the individual, and patterned by psychological, social and cultural factors. In Kleinman’s classic formulation, explanatory models are constructed from five topics: Etiology; Time and mode of onset of symptoms; Pathophysiology—the disease process; Course of sickness, including its severity and likely progression or resolution, and the patient’s sick role; and Treatment—what measures are likely to be efficacious, how they work, and their adverse effects [1, 10].

Patients’ explanatory models emerge from their experience with a particular episode of illness, whether chronic or acute, and can change over time. It has long been argued that adherence and other health promoting behaviors can be improved by understanding patients’ explanatory models [11], but that success depends on concordance between physician and patient interpretations [12].

The explanatory models concept is built on categories characteristic of biomedical explanation. While patients’ may explain pathophysiology, for example, in ways that do not accord with their physicians, the term nevertheless implies ideas of causation and mechanism. Other studies of illness experience use different framing. For example, Bury, in 1982, focused on the disruptions in lives and self-concept attendant to the diagnosis of rheumatoid arthritis and the symptoms of the disease [13].

Many subsequent studies have focused specifically on stigma as a challenge to identity or otherwise a central problem of the illness experience, as in the case of epilepsy [14]. Erving Goffman was an early theorist of health-related stigma, which he defined as “an attribute that makes [a person] different from others in the category of persons available for him to be, and of a less desirable kind.” [15] (p. 3) In referring to the “category of persons available” he means that stigma may depend on social context, i.e. that an attribute may be stigmatizing only for people who are otherwise in a particular social role, or within a particular group. However, he acknowledges that some conditions are very broadly stigmatizing. Chronic disease and disability are examples of stigmatizing conditions to which he refers frequently, along with homosexuality and addiction. Among his key observations are that the acquisition of a stigmatizing condition can be deeply disruptive of identity, but that people can successfully build new identities, and even become members of communities built around the stigmatizing condition. Stigma is not synonymous with discrimination, which refers to ill-treatment by others of people with a stigmatizing attribute; nor is it synonymous with shame, which is the internalization of stigma.

Stigma has perhaps been the most common organizing frame for studies of the HIV illness experience, with a review published in 2008 finding 126 publications focusing on North America or Western Europe in the category of “stigma assessment,” i.e. interview or survey studies to explore stigma experience of people living with HIV or stigmatizing beliefs by

others [16]. However, the reality of living with HIV has changed markedly since late 1995 when the FDA approved the first protease inhibitor (saquinavir), ushering in the era of highly active antiretroviral therapy (now referred to as antiretroviral therapy or ART) [17, 18]. Previously, except for a few fortunate long term non-progressors, HIV inevitably led to sickness and death. Even after the development of ART, it took a few years before it became clear that ART therapies could make HIV infection chronic, manageable condition [19]. Studies done before this century, therefore, are of questionable applicability to the present [20–22].

More broadly, much of the literature on the experience of living with chronic illness has been framed by identity theory, of which stigma is only one component [13, 23]. In one common formulation, the “self” is relatively stable, as people think of themselves as remaining the same person throughout the life course; but “identity” is comprised of one’s various social role relationships [24, 25]. These include “master statuses” which are highly salient and are implicated in most or all relationships, such as gender, ethnicity, or sexuality (depending on the degree of disclosure); and specific role relationships such as employee or sibling. The diagnosis of a chronic illness can be highly disruptive of these statuses and relationships. In the case of HIV, for example, it may challenge sexual relationships, force disclosure of sexuality or illicit drug use to family members, or result in stigma which affects a range of personal and professional relationships.

There have been few qualitative studies of identity reformation in people with HIV in the United States since the availability of effective therapy in the late 1990s. One is based on just 14 interviewees, all of whom were diagnosed prior to 1992, who had been interviewed for a previous study and who survived long enough to benefit from effective therapy [26]. This study did find that the incorporation of the HIV diagnosis into identity required considerable time, and included a period of what the author calls “denial” lasting as long as 5 years, after which respondents experienced a “turning point” in which they accepted that they had HIV and moved on in the process. For this group, the development of effective antiretroviral therapy became a second turning point.

We originally set out to understand the concordance of the explanatory models of people living with HIV with physicians’ explanatory models, and the relationship between people’s explanations and their treatment and self-care decision making, including medication adherence. As we have reported previously, we found that most of our respondents had very limited understanding of the scientific concepts concerning HIV and HIV treatment, and in fact their understanding was largely erroneous. Nevertheless, accurate scientific understanding was not generally associated with treatment adherence, with the exception of some specific erroneous beliefs [27]. We also found, however, that categories of meaning and explanation other than biomedical were more salient for most respondents and of far more importance in their treatment decision making and adherence.

These categories of meaning may be understood in terms of what Mishler has called the “voice of the lifeworld,” in contrast to the “voice of medicine,” [28] drawing on Habermas’s theory of communicative action [29]. Habermas’s construct of the “lifeworld” is complex,

but a central component of his thought is the distinction among three kinds of “criticizable validity claims,” or three “worlds.”

The first is the world of intersubjective reality. Within this realm we can further distinguish between immediate apprehension and credible direct reports on the one hand; and expertise or complexly derived conclusions on the other. The latter is the domain of science, including biomedicine. The second world is the social and moral order. Assertions in this realm are about what ought to be, the appropriateness of social relations, the categories of social status. Finally, the third world is our inner experience, our likes and dislikes, feelings and esthetic experience. Here we report mostly on second and third world responses, although at times a “first world” response is noted because it has salient importance to the other worlds. These may also be labeled as emic meanings, as opposed to etic meanings, which generally refer to observations and conclusions from an outsider or objective observer such as a scientist.

Our objective is to apply the explanatory models framework explicitly to these categories of meaning, as a way of illuminating the contrast between biomedical disease, and experienced illness. Specifically, while the explanatory models framework applies well to mechanistic (first world) explanation, we were interested in how useful or applicable it is for categorizing people’s second and third world meanings, and how these could be elicited using the framework.

## Methods

This study is based on semi-structured interviews with people living with HIV in two cities in New England. The data collection methods are described in the earlier paper [27]. Briefly, after preliminary and formative work [30, 31], we developed an interview guide with an initial structured portion including basic demographic and background information such as race/ethnicity, formal education, and living situation. Health insurance status turned out not to be an issue as these states provide near universal access to medical care and antiretroviral treatment for people living with HIV. The semi-structured portion then covered domains including the experience of receiving the diagnosis, and living with HIV, and how feelings about it may have changed over time; treatment history and relationships with physicians and other health care providers; comorbidities; current and past medication regimens; living situation, employment and natural supports; and disclosure to others. Items intended explicitly to elicit patients’ explanatory models included such questions as “If you were going to explain to a friend what HIV is, what would you say?” and “How would you explain what T cell, or CD4 count, means?” Similar items covered the various elements of the domains of explanatory models as identified by Kleinman, including etiology, time and mode of symptom onset, pathophysiology, sickness course, and treatment. Specific items of note include the explanation of drug resistance and consequences of non-adherence.

### Recruitment and data collection

Respondents were recruited through flyers placed in a hospital-based HIV specialty care clinic, and an AIDS Service Organization, in each city. Interested individuals called a research assistant (RA), who then scheduled an interview with an RA or an investigator,

either at the clinic or at a nearby office, depending on the participant's preference. Interviews were audio-taped and transcribed for analysis.

The only eligibility requirements were that respondents be 18 years of age or older, diagnosed with HIV, and able to converse comfortably in English. The goal was to have a diverse sample in terms of education, race/ethnicity, gender, and history of injection drug use. Because this diversity emerged naturally, we did not have to screen for these characteristics. We planned to continue recruiting until 50 interviews were conducted or saturation was reached; we found that little new information was emerging after completing 32 interviews. However, we did not succeed in recruiting people who were not currently receiving medical care, although many respondents recalled times when they were not in care. This study was approved by the Institutional Review Boards of Brown University, and both hospitals where the clinics were housed.

### Data analysis

Analysis of the transcribed interviews was initially conducted by the author and a RA using Atlas.ti software (©Scientific Software Development GmbH). Initially, we applied broad topic codes to highlight patient explanatory models, decision making processes, and indicators of the illness experience. (Information about explanatory models emerged at various places in the interviews, not only in response to items intended to elicit them.) Codes indicated such concrete topics as “What is a virus?” and “What is viral load? “What is CD4 count?”

Transcripts were initially open coding by the RA with a principal interest in biomedical modes of explanation, and the coding was reviewed by the first author and consensus was achieved after discussion. At this stage, we found that most of the time, respondents' initial responses were not framed in biomedical terms, but referred to other categories of meaning. These included such issues as stigma, shame, responsibility, moral evaluation, responsibility to others, and the evolution of illness identity and acceptance of the diagnosis. In these instances the interviewer would then probe to determine respondents' biomedical understanding and beliefs. We analyzed and reported on biomedically framed responses separately.

For this study, the author then did more detailed coding to classify the non-biomedically framed responses, which may be thought of as essential elements of the illness experience, and to map these onto the explanatory models framework, noting when this seemed natural and appropriate, and when it fit awkwardly. We have previously presented results for biomedical understanding [27].

## Results

### Respondent characteristics

Of the 32 interviewees, 22 were male. Eight self-identified as African American, four as Hispanic, 17 as White, two as Native American, and one was a newly arrived refugee from Namibia. Respondent age ranged from 22 to 63 years, but only one was under 30. Reported year of diagnosis with HIV ranged from 1983 to 2010. The 1983 date is likely an erroneous

memory. In order to have survived, he would probably have to have been asymptomatic in 1983. But there was no test for asymptomatic HIV infection until 1985. As interviews were conducted in 2012–2013, this means that no-one was newly diagnosed. The typical respondent had a high school education; only three had completed college. In the respondent IDs, R refers to one site and T to the other.

### **Course of Illness: Initial Responses to the Diagnosis and Identity Change**

While we could only interview people at a single point in time, we asked them to describe their experiences retrospectively. Although “course of illness” is the fourth item listed in the explanatory models framework, interpretation of the responses requires understanding where respondents were in this journey at the time of the interview; therefore we present this information first, to establish context for the other elements. It is clear that living with HIV is a process, not a state, and that a snapshot is not representative of the past or future. We also observe that the course of illness and course of disease are inter-related, inasmuch as the disease state directly affects the illness experience, and people’s changing beliefs about the disease course also may profoundly affect their illness course.

**Equanimity**—Only three respondents said they received the HIV diagnosis with something like equanimity or indifference. Two (R23, a 57 year old man diagnosed in 2003, and R9, a 47 year old man diagnosed in 2005), said they already expected they were HIV positive. Another (R10, the man who said he was diagnosed in 1983) reported a fatalistic reaction: “It just didn’t bother me. I’d seen everybody die around, but I just knew that there was nothing that would really do anything... I just accepted it.”

**Initial Denial or Delayed Acceptance**—All other respondents reported various negative reactions to the diagnosis, and most of them did not fully accept their status or respond constructively for some time. For some, the most important barrier was simply lack of knowledge that effective treatment was available and the diagnosis was not a death sentence. R2, a 48 year old woman who was diagnosed in 2008, said, “It took me a while to be okay with it, because it was new, I was scared, I just knew people died of it, that’s all I thought.” She received counseling and was reassured that HIV is treatable, but still delayed treatment for 6 months. Similar stories of delayed acceptance are common. R6, who was initially diagnosed while in prison, said “I wouldn’t take my meds. I was like, man, no way. If I start taking these meds then I have to admit it to myself... And I went and got three different tests at different hospitals and they all came back the same... I’ve just had a hard time dealing with it.” R13, a 37 year old white man diagnosed in 2010, delayed telling anyone due to the Christmas holiday. “I had like two days to pull it together and act like there was absolutely nothing wrong. Meanwhile... I had the health department calling me and asking me questions... so it made me feel like a freak.” R24, a 60 year old white woman, contracted HIV from her boyfriend. “I was really, really angry because why did somebody do this to me? I didn’t know he was using needles.” She delayed getting treatment for 1 year, until the boyfriend died.

R1, a 55 year old African American man who was diagnosed in 1992, initially said that “It was only 2 weeks I was depressed and stuff, after that I lived like I haven’t had it.” However,

he in fact continued to struggle with cocaine addiction and alcohol abuse, was incarcerated twice since then, and was an active cocaine user at the time of the interview, working as a driver for illicit drug dealers and sex workers. He later said “Because I used to always think if I’m on medicine—because I wasn’t taking medicine, I’m better, I’m the best, because I don’t have to take it my body is healthy, and once I stopped taking it then I think that sting was there or, you know, that stigma of taking it and then, you know, you think you’re doing bad.”

**Suicidality**—R11, a 48 year old woman diagnosed in 2007, said she attempted suicide when she was diagnosed in the hospital: “I tried to jump out the window but the windows were too thick,” and “I did not know, I was afraid of everything.” After participating in an HIV education program, she came to terms with the diagnosis.

Four additional respondents reported suicidal ideation or behavior following the diagnosis. R25, a 60 year old African American woman diagnosed in 1985, did not give a clear explanation. R14, a 45 year old Puerto Rican man diagnosed in 2008, made a serious suicide attempt: “I tried jumping the bridge. I cut my veins,” because, he said “When my family found out I had it, they didn’t want nothing to do with me... And then my ex-wife, when she found out I had it, they kicked me out of the house. When I started drinking I lost my job,... so I said it’s not worth it.” R6, a 42 year old man diagnosed in 2006, said “I didn’t care if I was here. I as just like, I just wish I would die... And that’s why I didn’t take my meds. I really didn’t care.”

R17, a woman who was diagnosed in 1991, also reported feeling suicidal simply because she didn’t think she had long to live. Like several respondents, she also reported a substantial period of denial or non-acceptance of the diagnosis. “When I first found out I think I let it go for 5 or 10 years.” She only sought treatment when she became sick, but “I didn’t want to know that I had it, and... I didn’t tell anybody.” Although she was in treatment, “there were times when I was in my addiction when I didn’t go to the doctor, didn’t take my medication.” She said she had finally fully accepted her situation about 2 years ago and “I’ve been on my meds religiously and everything... has just fixed itself.” She attributes the change to the risk of losing custody of her child, who was 6 years old at the time.

**Substance Abuse**—Nineteen of the 32 respondents reported a substantial history of substance abuse and addiction. R10 said he has used cocaine and methamphetamine, but did not consider his use abusive. For the most part, active substance abuse was not consistent with ARV adherence, or even any engagement in care. Respondents mostly reported that this was simply because ARV adherence was not important to them while they were using, for example R16, a 56 year old African American man diagnosed in 2005: “I’d be busy... too busy to do what I’m supposed to do because I’m getting high. That’s a given.” Hence overcoming addiction was, for many, an essential component of coming to terms with the HIV diagnosis.

**Identity Reformation**—Many succeeded in building a new identity in which successfully living with HIV is a central positive element. These stories of personal redemption were often dramatic, for example R11 described her struggle with alcoholism:

Well, I went to three actually detoxes. I said—'cause when I got out there, they kept on switching me from one to another. I wasn't—I was quitting and, well, I got kicked out of one of them 'cause I had sex in a closet with a nun. [sic]... So they said, "You gotta get out." But I went to three detoxes. I don't want to get off.

But then (I = interviewer):

I: So how have your feelings about living with HIV changed over time? How are you coping now?

R11: I'm fine. It's not a death sentence. It's kinda like a new start on life. It's kinda like a godsend more or less because I don't do anything anymore. I don't drink. I don't do drugs. It stopped me from doing a lot of things that I used to, so I do have a second chance on life you know. And before I used to talk about this and I used to cry like a son of a gun. I don't cry no more because I do everything I have to.

And R10:

I: You talked about kinda your identity changing a bit.

R10: I think it's the best thing that happened in my life.

I: Really. Okay why?

R10: Because I live differently and I helped a lot of people. If it wasn't for that, I wouldn't have my career in advocacy and helping people. I would have been less compassionate, less forgiving 'cause I was very materialistic in the '80s in California, being in West Hollywood, so I had that conflict of being what you think you want to be and think who you are. So I wouldn't have known who I was if I wasn't HIV positive. I would've ended up dead like everybody in that false image of themselves.... Because I saw a lot of death, and I had to have a duality to live differently. I immersed myself in that culture, but I didn't let it take me over because I was HIV positive.

I: You're talking about drugs or -

R10: Yeah.

And R19:

I: How does taking the med make you feel?

R19: It makes me feel like Superman. Why? Because I just unbutton my jacket and I'm about to go help find a cure for it. It makes me feel like superman because I'm a superhero. That's how I look at it. Yeah, I'm going out to save people, find a cure, I'm superman.

Others were not successful. R7 said:

I think I can make it through, but I'm pretty upset still... I used to think when I was eight. that when I die, I was going to die slow and be suffering... And to get HIV is like make it all come true.



Some continue to struggle with substance abuse. R1 said that two of the sex workers who he drives for made a plan with him to claim he was suicidal so he could be admitted to a psychiatric hospital, which would give him a week of abstinence and a head start toward recovery. R2, although she is taking suboxone, said she was still using illicit drugs. R16's doctor has actually offered to pay him out of pocket for a clean urine screen, but he has been unable to deliver one. Some others report quite recent abstinence, within only a few months.

**Stigma**—Although, as we have seen, stigma was a major component of initial negative responses to diagnosis and delayed acceptance, most respondents, by the time of the interview, were much less troubled by it, if at all. While many said they were selective in who they disclosed to, only three, including the African refugee, said that they continued to be troubled by stigmatization within their families. R7 reported that her mother remains distant from her, and that she had skipped doses of medication for fear of being seen taking them. R6 does not reveal his HIV status to fellow AA members, fearing being judged. Others, however, have no reluctance to disclose. R22 said:

It's been so long now that I always... think people know anyway because I know so many people. And I tell people, so I don't know who knows and who doesn't... I don't worry about it.

While R23 seems proud to disclose:

I'm almost militant about it [disclosure]. I've been very open about it with most people, "By the way, I'm HIV positive."

## Etiology

The dictionary, helpfully, gives two definitions for "etiology" (American Heritage® Dictionary of the English Language, Fifth Edition. © 2011 by Houghton Mifflin Harcourt Publishing Company):

- a. Assignment of a cause, an origin, or a reason for something.
- b. The cause or origin of a disease or disorder as determined by medical diagnosis.

Respondents generally understood that HIV can be transmitted by sexual contact, or shared injection drug equipment, and some mentioned iatrogenic transmission. However, their causal explanations often went well beyond these simple facts.

**Personal Blame or Responsibility**—R13, a 37 year old man with a graduate degree in psychology, said:

Where if you have cancer... it's a natural thing. You didn't go out and catch it, it's developed within you. HIV, there's only two ways you can get it unless you've had transplants or something... So the responsibility does fall on you. You know, they always say it takes two. So you'd be stupid not to take responsibility for your part of it. So ultimately, you make a mistake.

R4 was even more succinct:

I: So if you're going to explain to a friend what HIV is, what would you say?

R4: I did something wrong.

**HIV = Mode of Transmission**—Indeed, responses to the question, “If you had to explain to somebody what HIV is, what would you say?” frequently centered on transmission. For example, R10, after a garbled attempt at a pathophysiological explanation, said:

So that's HIV, and you get it from sex, blood transfusions and also partners. It's better to use a rubber because they don't know if you get it from having sex or not. [sic]

R11 said:

I don't have to explain to anybody what I have because if I'm not gonna have sex with you.

And R14:

I'd tell them HIV is a virus. You can get infected when you have a relationship with no condom. You've got to make sure what girl you're going to go through [sic] because... I went out with a girl, she doesn't tell you that she has it, then get infected. The girl passed away and then I found out I had it.

R17 was particularly clear about defining HIV in terms of transmission:

Well, they usually don't ask you what the virus is, they just ask you how are you gonna get HIV... It's basically am I gonna catch it, yes or no... I did have to explain, like I can eat from this spoon and you're not gonna get it... I had to explain how they could catch the disease but not the explanation of the disease.

There were several similar examples of people whose first response was to assert in one way or another that it is not dangerous to be around them. For R6, this was particularly salient because the mother of his daughter won't let him see her:

Let's see, if I was telling my son and he asked me. I would tell him how you contract it, through sex, needles... And I would tell him, don't be afraid of people that have it, even if they're bleeding, because once the air hits the blood it kills it. You can't catch it... So don't judge people.

### **Time and Mode of Onset of Symptoms**

All respondents essentially believed that they could defer serious symptoms, perhaps indefinitely, by taking ARVs, although a minority weren't confident that this would last for very long. Some had experienced symptoms, either because they were infected prior to 1996, were not diagnosed until they were symptomatic, or were non-adherent at one or more times. For them, the issue was remission of symptoms, not onset.

**Symptomatology Pertains to Others**—Given that most had well-controlled disease, and did not necessarily expect to become symptomatic, the most salient meanings of symptoms usually pertained to others they knew or had known. For example, R14:

AIDS is the death. You're going to start losing weight, you're going to stop eating, a lot of things. I know a guy who's got AIDS. I know how they look like, so I don't go there.

Seeing what had happened to others was a motivation for adhering to treatment for several others, but some responses were more complicated. R16 spoke of despair following loss of his wife.

My viral load is...undetectable. So I'm really good with that. My wife wasn't the same because she had issues with her medications... and she wouldn't take them like she was supposed to and she kind of died of complications... But then I like, on the other hand, when my wife first died I didn't want to live... because I had issues with trying to move on without her... And sometimes I wouldn't take my meds.

R24, who cared for the father of her son at home as he died of AIDS, had an idiosyncratic explanation for her own lack of symptoms:

When he got diagnosed, he only lived a year, and they said he's lucky he even lived that long because I took really good care of him, and he didn't have no bedsores... So I think I'm being blessed for this, and that's why I'm kind of healthy.

R11 has noticed symptoms in her boyfriend:

Right now, whatever—if I do anything with my boyfriend, he always he goes, "... "I'm not afraid of you." I said, "You have to wear one." But the only thing is, he's a state trooper, and I can't give his name, obviously, but he's—he lost 70 lb in the last 6 months. So I'm just wondering if he was seeing somebody else. I mean he's been my friend for 30 years. But I'm just wondering if he has it 'cause I say, "Why don't you go recheck this. There's free places." [but he refuses to be tested.]

[W]ell, he is married. And I said, "I believe they're not supposed to tell your wife if you ask for it or not... I mean I love him still, but he's just not the man that I knew before. I mean skinny, really skinny. It's disgusting.

## Pathophysiology

As we noted in the previous report on this data, very few respondents had anything close to a scientifically accurate explanation of the pathophysiology of HIV. Often they had acquired some relevant vocabulary but could not assemble it into a coherent narrative, like R10:

So it's an anaerobic disease that attacks the immune system which is there to help fight disease. Then you develop T helper cells, which is 8 or 4 which recognizes the HIV virus, so they try to—it starts attacking itself because the virus recognized that it's a foreign invader, but it also recognizes itself because it replicates your own DNA and RNA. T-cell, your helper T-cell 4 is that fights diseases, so it starts to replicate. But what happens is that it doesn't recognize each other's virus because the HIV virus is probably just your DNA makeup. So that's where the 8 comes in. And your 8 tries to take over to help the helper 4. So the T-cell counts help fight

diseases, but it has a difficult time because it starts attacking itself 'cause it sees itself as the enemy.

Or R6:

I would just say that your T-cells is your white blood cells. Your white blood cells is what produced oxygen for your body... If you ain't got many T-cells, you ain't getting oxygen and your body can't handle itself.

There are many equally inaccurate explanations of the pathophysiology of HIV. However, this component of the explanatory models framework has little meaning for any of the respondents. Some are not interested in it at all, or simply profess ignorance, like R17. When asked "How does HIV cause disease?" he said, "Well I just don't know, if you don't take meds, then HIV is growing." R18 said "It's just another virus, it's another disease that I have." When pressed how he would explain to a friend what HIV is, he said "Oh, I would tell 'em it was a disease just like any other disease. And that he's still a human being no matter what." R19 similarly said, "I'd say it's just another disease," and then referred to Magic Johnson.

Other did not refer to any mechanism of disease, but did mention possible symptoms. Many knew that HIV, if untreated, can lead to AIDS, which leaves the body open to other infections, but others were unclear about this. R24 said "[I]t's seven different kinds of cancer in your body. I don't know why seven, but most of my friends that have passed away, it had something to do with cancer." R19 also likened it to cancer: "It's a cancer in the blood. It's in the blood cells. You can't get a transfusion and be free of it, there's no way."

For the most part, respondents deflected the question and talked about the mode of transmission, or the need to take medications.

## Treatment

With few and only partial exceptions, respondents believed that antiretroviral treatment was effective, and necessary to save their lives. R19 is uncertain:

I don't know if taking medication is making me better or not. I'm not gaining no weight up here. Over here I am but not down there. ... Is the medication helping me? No, I don't think it is. You have to take your medication every day. I mean, it makes me sad. I can't swallow them because they're so big now... I'm having trouble swallowing again... and I get white things in my mouth sometimes.

It is not clear whether she attributes the possible ineffectiveness of the medications to her non-adherence. R6 is also unsure of whether the medications will work.

**Dependence on Physicians**—Only R7 and R9 had a coherent mechanistic explanation of how the ARV medications work. For the rest, it was sufficient that their doctors had told them it was necessary, and even for R7 and R9, the mechanistic explanation was not really important to their treatment decision making and adherence. As R7 said,

Dr. [name] will say... I think you should take your medicine. And I will say, well, I really don't want to take medicine. And then she'll say well, if you don't take

medicine, this is what's going to happen. And then I'm like, okay, Maybe I think I will take the medicine. And that's how it works.

Also contributing to her decision is her observation of her ex-boyfriend, who is non-adherent, and who has severe symptoms of HIV disease. T3 was explicit:

I don't dwell on it. I pretty much just rely on my doctors. You know, I'm not looking in textbooks and the latest this and the latest other thing, 'cause I mean, you have to go to medical school and I... just leave it up to the doctors, trust them to tell me what's going on.

However, it had taken T3 some time to start listening to his doctors.

No matter how many times my doctors told me, I mean you got to want it for yourself... You know, some people just don't want to hear it, and I didn't want to hear it. So until you figure out you want to get it done, you know, it's just you and the chair.

He said that he finally started treatment so his mother wouldn't worry about him. R6 is taking care of herself in order to regain custody of her children. R9 also reported resisting initiating treatment due to fear of side effects, and finally relenting when he became eligible for a clinical trial. However, trust in doctors did not always come immediately. R4 said of his doctors:

It's taken a good year and a half for me to trust these people and I know I should have in the first place, but I'm not that type of person. So I waited. I listened. I learned. I educated myself and now I'm at the point now where I think I'm ready.

**Idiosyncratic Responses**—For R25, it took the experience of getting sick:

Instead of me taking all the pills that they wanted me to take them, I wouldn't take 'em. And I could see myself getting skinnier, skin turning all black and all that so, I'm alright now, you know? [The Atripla]... started working, and gave me my life back again.

R3 also resisted starting treatment, and then:

I got a sign from the Lord. I had a dream where there was a big white—I can't say statue, but a big white light, and you could see someone, probably Jesus, with his hands out like this, and he was handing me a pill. I went to the doctors the next day and they said, we want to start you on this pill. I told them about the dream and all that, and I said, that's a sign to me.

R10 did take ARV medications, but did not trust his ID physician, who he believed was being paid by a drug company to prescribe a medication that he did not believe was in his best interest. He claimed that his parents in California mailed him a different ARV medication, for which he did not have a prescription, which he took instead. He would not explain how his parents obtained the medication.

**Personal Meanings of Treatment**—Despite generally being motivated to take ARVs, and for the most part adherent, people had a wide range of feelings about taking them and

ascribed many different meanings to the act. Some, like R10, just didn't like taking pills, for no specified reason:

[I feel] angry because I have to take them... I don't like taking them but I got to...  
It's the culture of America, you have to ingest something, you know.

Others specifically said that it's a reminder of the guilt or remorse they feel for the actions that led to their becoming infected. R11 said about taking medications "I can't stand it. I hate it. I cry." And later, "I just don't believe that I let myself go so [crying] bad. I can't—well, I hate that. I hate it."

R13 said:

What do I hate about it? The fact that it's a reminder every day. So, I understand that there are other people that have to take medications every day but it's very, very different. This is a reminder that you've somehow made a mistake. Where if you have cancer... it's a natural thing. You didn't go out and catch it, it's developed within you.

R7 is reminded of betrayal:

I just throw them in my mouth real quick. I don't look at them too long. I just take them. If I do look at them, they make me sad... Because it made me think that I was with somebody and they didn't care about me.

Many simply report neutral feelings about taking ARV medications, such as R15: "I'm just indifferent. There's no either way, whatever." And R16, "It's just something I have to do. It ain't that I feel any differently. It's just that, okay, well, I took 'em, I'm supposed to take 'em, it's done." Or R17, when asked how taking her meds makes her feel, said "Wat do you mean? It makes me feel like I took my meds today."

For some respondents such as R9, taking ARV medications has positive meaning.

Thankful, grateful that I have access to them... I'm thinking how many places in the world you can't get this, or you get some old regimen... Yeah, I'm blessed.

R3 thinks of himself as a role model:

There's nothing you can do once you're infected, but you can hope and pray that there's a cure one day. If not, step up to the plate and help others to avoid going through what you're going through. Taking your medication is part of you being an ambassador so the younger generation doesn't have to deal with what you're dealing with. If you're taking your meds, I mean, you're showing people that you can live longer by taking something that's helping you, as opposed to if you neglect it, leaving the earth before you make an impact for the next generation.

### **Future Course of sickness**

To conclude the interview, we asked people what they thought their health would be like in 1, 5, and 10 years. The majority expected to remain healthy and have a normal life expectancy if they continued to adhere to treatment. They commonly expressed that they expected to die of something other than HIV disease. They typically reported that this was

what their physicians had told them, but not always. R1 said he believes his health will be good in 10 years but then:

They told me sooner or later but I don't want to hear it. Dr. [name] had mentioned it, Dr. [name] always mentions it... Eventually you're gonna, you know, develop AIDS or something.

Presumably they have said this to R1 because he continues to abuse cocaine and is inconsistently adherent to his medication regimen. R2, who has extensive co-morbidity, said that her doctors had not given her a 5 year prognosis. Others, such as R15, say they don't look ahead that far, or simply express agnosticism about the future. R19 expects to be dead in 5 years, because of failure to take care of herself.

## Discussion

Elements of the explanatory models framework can be usefully applied to the illness experience, although the category of pathophysiology appears to be the least illuminating. However, the idea of "explanation" is sometimes a stretch. Believing that one made a mistake, or was betrayed, are readily interpretable as etiological explanations. However, the meanings attached to treatment more commonly pertain to consequences than to mechanistic explanation.

The categories and underlying conceptual basis of the framework, while intended to apply to illness as well as disease, are really characteristic of biomedical reasoning and the interpretation of disease. For people living with HIV, the most important challenges are not in the realm of explanation, but of adaptation. Explanatory depth can be very shallow, but still sufficient to ground adaptation.

Clinicians might benefit from an appreciation that, while believing that regularly taking ARV medications is essential to continued good health is a necessary condition for treatment acceptance and adherence, it is far from sufficient. Most of our respondents faced profound and substantial personal challenges before they could engage with care and consistently take ART. Modern ARV regimens are usually well tolerated, require only once or twice a day dosing, and in the states where we recruited our participants they are available and affordable. But very real and sizable barriers in emic meanings and personal identity needed to be overcome before patients could successfully participate in medical care of their HIV infection.

There is already considerable evidence that substance use disorders [32–34], homelessness and food insecurity [35, 36], and depressive illness [37, 38] are obstacles to engagement, retention in care, and adherence. But there are many other barriers which are less concrete, for which we do not have well-developed "medical" responses. How to support people in achieving acceptance, positive identity reformation, and psychologically satisfying integration of positive health behaviors after HIV diagnosis remains an insufficiently studied challenge, and one which health care systems are ill-equipped to cope with.

This is of course a qualitative study, based on a convenience sample, in a region of the US that is somewhat atypical in the substantial resources it offers to people living with HIV. The

region, and particularly the cities where the research was done, are also relatively socially liberal. The stigma associated with HIV and common risk factors for HIV is likely greater elsewhere as well. It may be that material barriers, stigma and discrimination are more important in other milieus. However, the lower salience of these challenges helps to isolate the issues we did observe.

There are further issues and nuances which we could not explore within the limits of a single journal article. However, we hope that these highlights, and the extensive opportunities we have presented our respondents to be heard in their own words, are instructive.

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