

# Illness and Medication Appraisals in People with HIV Deciding to Begin Antiretroviral Treatment

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Deciding to initiate antiretroviral treatment (ART) for HIV involves a number of factors, including how one thinks about disease (illness appraisals) and how one thinks about treatment (medication appraisals). We conducted semi-structured interviews with 20 adults who were deciding whether to begin ART, in which participants were asked to relate their experience of testing positive, their experience with medications other than ART, and their thoughts about ART. Digital recordings were transcribed for team-based narrative analysis. In response to HIV+ diagnosis, participants described the following appraisals: 1) HIV is a threat to mortality; 2) nonacceptance of the HIV diagnosis; 3) HIV is associated with stigma and rejection; and, 4) the HIV diagnosis meant betrayal by a cared for other. Medication appraisals included: 1) negative feelings about medications in general, 2) taking HIV medication would create a personal crisis; 3) the benefits of taking HIV medication would not outweigh the costs; 4) doubts whether they could adhere, and 5) taking medications would be stigmatizing. Illness and medication appraisals may represent barriers to initiating and adhering to treatment and should be taken into account in helping clients to cope with their diagnosis and manage their healthcare.

*Keywords:* Antiretroviral Therapy, HIV/AIDS, Health Care Utilization, Illness Appraisals

## Introduction

The decision to initiate antiretroviral treatment (ART) for HIV rests on a number of considerations ranging from the interpretation and implementation of formal treatment guidelines to informal assessments by providers and patients of a patient's likelihood to adhere to an ART regimen. Two central factors that subsequently influence the ability to maintain adherence are how people with HIV think about their disease (illness appraisals) and how they think about HIV medications (medication appraisals). An illness appraisal is an individual's beliefs about the course and consequences of an illness, which includes the interpretation of symptoms and the understanding of how the illness will affect future survival, health, and well-being. Illness appraisals (Moskowitz, Wrubel, Hult, Maurer, & Stephens, 2007; Moskowitz & Wrubel, 2005) have been described in terms of illness meaning (Browne et al., 1988; Farber, Mirsalimi, Williams, & McDaniel, 2003; Fife, 1994, 1995, 2005), illness representations (e.g., (Leventhal et al., 1997) personal models of illness (Skelton & Croyle, 1991), and illness perceptions (Weinman, Petrie, & Moss-Morris, 1996).

Some researchers have developed questionnaires designed to elicit people's appraisals of their illness (e.g., Fife, 1995; Weinman, et al., 1996). While useful in some contexts, there are limitations to this approach. Questionnaires provide pre-set and pre-defined appraisals and may miss important appraisals that are unique to the individual. Second, the meanings are cast as either positive or negative. (e.g., "My illness is something I will never recover from." "My illness is serious but I will return to life as it was." (Fife, 2005; p. 2136). In this way, the meaning of the illness for the person and the positive or negative outcome of having this appraisal are confounded. Further, as

Hunt, Jordan, Irwin and Browner (Hunt, Jordan, Irwin, & Browner, 1989) have pointed out, measures like the Health Belief Model (Rosenstock, 1974) use physicians' diagnostic categories and not the patient's understanding of the illness.

This last point illustrates the importance of distinguishing between disease, which is the biomedical assessment of disruption in the body, and illness, which is the lived experience of that disruption. Health researchers have recommended the examination of the insider perspective that speaks to how illness is experienced cognitively and emotionally by individuals in the context of their ongoing lives (Benner & Wrubel, 1989; Conrad, 1990; Eisenberg, 1977; Kleinman, Eisenberg, & Good, 1978; Zimmermann, 2004, 2007).

Taking the issue of distinguishing between disease and illness one step further, researchers have called for the study of the link between illness appraisals and medication appraisals, particularly among people with chronic illness. They have argued for a shift from a doctor-centered to a patient-centered understanding of medication-taking in order to see the full context of the effect of medications on people's lives and to understand how people actively incorporate medication practices into their lives (Conrad, 1985; Shoemaker & Ramalho de Oliveira, 2008; Stimson, 1974). Illness and medication appraisals have been investigated in people with asthma (Adams, Pill, & Jones, 1997), rheumatoid arthritis (Donovan & Blake, 1992), epilepsy (Conrad, 1985), HIV (Golub, Indyk, & Wainberg, 2006), and people with common but non-specific symptoms (e.g., dizziness, headache, fatigue) (Hunt, et al., 1989). These latter authors conclude: "To be of any real value the treatment for an illness must be usable. It must be capable of addressing illness as it occurs in the context of everyday life" (Hunt, et al., 1989; p. 330).

It is particularly with respect to antiretroviral therapy (ART) for HIV, which requires very high levels of adherence to be effective, that the need for understanding illness and medication appraisals has become a focus. As Remien, et al. (2003) have noted: "The 'meaning' of medication and Western treatments can differ across individuals and this in turn can influence adherence behavior." (p. 70)

Golub *et al.* (2006) propose reframing the traditional view of adherence/non-adherence from a treatment problem to an illness problem. In their study of 42 HIV-positive men and women, the authors identified the following medication appraisals: medication side-effects personally intolerable; daily activities more important than adherence; taking any medication aversive; feeling in control by altering prescribed regimen; pill-taking part of disease management; medications associated with feeling healthy. The authors proposed that instead of viewing adherence in terms of people's willingness to follow prescribed regimens, researchers should examine the reasons behind their willingness or unwillingness. In this way, it would be possible to develop interventions that could address the meaning of taking medications for people's identity, wishes for autonomy, self-management, and integration into daily life. These strategies could result in greater commitment to treatment which could lead to better adherence, more effective viral suppression, and lower HIV-related morbidity and mortality.

We propose that medication appraisals are a factor not only in adherence to medications, but also in the decision to initiate a therapy. The decision-making process about initiating ART can be challenging. People can be confused about the need for treatment and can be unclear about the possibilities of adverse side effects, treatment resistance, and the timing of treatment during the course of disease. This decisional process therefore offers a good vantage point from which to explore the co-occurring illness and treatment appraisals that may drive this decision and affect subsequent treatment adherence and clinical outcomes.

In the present study we report qualitative data on illness appraisals of HIV and appraisals of antiretroviral medication (ART) for 20 participants in a formative study of treatment expectancies. The goal of the study is to articulate the meanings that HIV seropositivity and ART hold for the participants in order to illustrate the underlying issues involved in the decision to initiate treatment.

## Methods

This study draws on data from a pilot study of treatment expectancies. Interviews were conducted from 8/2005 to 3/2006. Twenty men and women with HIV were recruited for one interview about HIV related issues and treatment factors. All participants were ART naïve and reported being in the process of deciding whether to initiate ART.

To be eligible for the study, the participants had to be English-speaking 18 or older, HIV-positive, never on ART, and reporting that they were maybe, very likely, or definitely planning to start ART in the next six months. Participants were recruited from flyers posted in clinics and community venues, referrals from other studies, and word of mouth. Interviewers obtained informed consent at the time of the interview. Participants were screened on the phone for inclusion and then sched-

uled for a study interview. The UCSF Institutional Review Board approved the study's procedures.

The sample of 16 men and 4 women had been diagnosed with HIV for an average of 8 ½ years (range 1 to 21 years) and had never been on ART. Fourteen participants gave their ethnicity as White, 4 African American, 1 Latino, and 1 Other. Twelve of the 20 were employed. Twelve participants had attended college. Of the remaining 8, 1 had not completed high school. This is a somewhat select sample because it excludes those people who started ART at the time of their diagnosis. Many participants in this sample had been diagnosed with HIV for a long time, and many had viral loads and CD4 counts at or below levels at which ART is recommended.

The focus for this analysis was the narrative responses to questions concerning the participants' experience of testing positive, their experiences with and attitudes toward medications other than ART, their thoughts about ART, their definition of adherence, and their thoughts about their ability to maintain adherence should they begin ART. Narrative data were audio recorded then transcribed for analysis. Transcribed interviews were entered into ATLAS.ti, a software program for coding and retrieving narrative data.

The narratives were content coded for themes concerning participants' responses to their diagnosis, including feelings, attitudes and beliefs about HIV at that time and at the present time. The interviews were also coded for attitudes and beliefs about medications in general and HIV medications in particular, and for their feelings about their ability to maintain adherence to ART. One team member coded the interviews and a second member verified the coded themes.

## Results

### Illness Appraisals

In response to the news that they were HIV+ the participants recounted the following illness appraisals: 1) HIV is a threat to mortality; 2) nonacceptance of the HIV diagnosis; 3) HIV is associated with stigma and rejection; and, 4) the HIV diagnosis meant betrayal by a cared for other. These 4 appraisals were not mutually exclusive. Six of the 20 participants expressed 2 of these appraisals.

#### HIV is a Threat to Mortality

This was the most common illness appraisal despite the fact that the effectiveness of current antiretroviral medications has led to HIV being more commonly viewed as a chronic illness. Half of the participants narrated concerns that the diagnosis meant that they would die soon.

The first thing that came in my mind was "I'm going to die." I think that's the way everybody thinks.

It is possible that some participants received their diagnosis before a wide range of ART options was available and had witnessed the death of many others from AIDS. However, none of the participants with this appraisal said that now they knew their diagnosis was not a "death sentence." Some participants voiced this appraisal while acknowledging that they personally knew people who had lived with HIV for over 20 years.

#### Nonacceptance of HIV Diagnosis

Eight participants narrated this illness appraisal, which was

the second most common in this sample. Some participants expressed disbelief in the diagnosis itself, others held the conviction that although they were positive for HIV, they were not ill and did not require medical attention.

I really didn't even believe it really, you know. I was like oh, that experience like never happened, you know?

I tested positive, but I was never sick, I never went to the doctor in all those years because I was never sick, no symptoms.

Several participants, viewing their disbelief of their diagnosis in retrospect, labeled their attitude as "denial."

I would have to say that at first I felt like in this denial process, like, okay, I'm positive but I won't do anything about it. I will continue my life just like normal, like I didn't pay attention to it. I put it like in the back burner of my brain somehow.

One behavioral consequence for participants who did not believe or did not accept their diagnosis was the avoidance of medical care. And even when they sought care for symptoms or other illnesses, they were not receptive to tests or assessments for their HIV.

The clinic I go to, they're constantly upset with me because I haven't completed blood tests. I'm very irresponsible, because I am very avoidant of medical care.

### **HIV is Associated with Stigma and Rejection**

Participants described both an initial (upon diagnosis) and an ongoing concern about stigma. Some participants had experienced stigma directly, others indirectly.

*Whether it's HIV or you're gay and you haven't come out, it's interesting because people then feel as though they can be honest about how they feel about gay people or how they feel about HIV. And it's kind of hurtful because you're standing there and they're talking about you and they don't know they're talking about you.*

*Yeah, for fear of rejection, I have told a few people but this past year, I don't know, I just have been unable to. So I do try to have safe sex. However, the father of the baby doesn't know I'm HIV-positive. I don't like that idea either, but he's a pretty violent person so I don't know how I'm going to handle that, but I know I have to tell him in a week or two.*

### **The HIV Diagnosis Meant Betrayal by a Cared for Other**

Stress appraisals can be generally described in terms of threat, harm or challenge (Lazarus & Folkman, 1984). Being diagnosed with HIV is a harm situation since it is no longer something that might happen. For some participants, the diagnosis involved an additional harm, that of having been betrayed by someone they trusted.

I was with a man and I asked him point blank about the, you know, risk of disease there, and he told me he was all good. And we stayed together for about three weeks and then one of his friends told me he had HIV. I tested for it, and it was terrible.

Unfortunately I am virtually certain that my significant other brought the virus into our relationship. He tested positive first. And I thought I was in a monogamous relationship that was negative.

### **Medication Appraisals**

The participants recounted the following medication appraisals in their narratives: 1) negative feelings about medications in

general, 2) taking HIV medication would create an existential crisis; 3) the benefits of taking HIV medication would not outweigh the costs; 4) doubts whether they could maintain adherence, and 5) taking medications would be stigmatizing. As with the illness appraisals, medication appraisals were not mutually exclusive. All participants recounted at least one of the following medication appraisals. Eleven participants narrated two of them.

### **Negative Feelings about Medications in General and ART in Particular**

Consistent with Golub *et al.*'s (2006) findings, one issue with adherence to ART is that many people find taking medication of any kind aversive. Twelve participants in this study expressed strong negative feelings toward taking medications.

*I look at pills and it makes my belly turn just looking at them, because I just hate taking pills.*

Some participants also felt that any medication should cure a disease, not just maintain the person in a chronic condition. Two participants expressed concern that taking pills regularly could reawaken addictive tendencies. It is in this context of negative beliefs and aversive feelings about taking medications that the participants' health care providers would have to propose starting antiretroviral therapy.

### **Taking HIV Medication Would Create an Existential Crisis**

A common response among the participants was the concern that taking ART meant acknowledging their seropositivity and incorporating it into their self-view. Ten participants gave voice to this concern. Particularly for those participants who expressed illness appraisals of threat to their mortality or of nonacceptance of their HIV diagnosis, the prospect of taking HIV medications threatened their self-view. Some expressed the belief that taking ART, or even becoming informed about the medications would make their HIV diagnosis "real."

*And I've been in other groups where people discuss meds but it's like it goes in one ear and out the other because it's not a reality for me yet.*

*Well for years I was in denial, you know, about HIV. I just thought maybe I might be one of these people that it doesn't affect for a long time. And I have avoided learning about the medication. It comes on the news, I change the channel. If it's in the newspaper I don't read about it. You know, I probably haven't had a really functional--[Chuckles]--attitude about medication.*

Another aspect of their changed identity if they started ART would be as a person who has an illness.

*Getting to the point where I admit that I need them, that's going to be a big challenge because I don't want to admit that I need them.*

A further change in self-view for some participants was the feeling that taking HIV medications would transform them into someone who was approaching death. The following narrative illustrates this concern as well as the emotional component of this meaning.

*I don't know, for some reason I associate the meds with the end. You know, people go on the medicines right before they die. I don't know why because I also know that's not true. I know there are people who've been taking their meds for 10, 15, 20 years and they're doing fine and it just, it has to become part of your daily routine. But part of me is really scared because for*

*some reason I have it associated with death and I can't get it out of my head. It's scary.*

### **The Benefits of Taking HIV Medication Would Not Outweigh the Costs**

Nine participants expressed a belief that the costs of taking HIV medications would be greater than the benefits.

*I don't know if getting sick to stay well is altogether worth it to me.*

For some, the costs were seen in terms of medication side effects.

*There's certain side effects that come with the medications so they can do one thing for the virus, but then they can also affect other things. There's sort of a catch 22—you're damned if you do, damned if you don't.*

Other participants questioned the efficacy of the medications and considered the possibility that the medications would "do more harm than good." These concerns included the notion that HIV medications were "toxic."

*Would it make me healthier than I am or would it do damage to what's already there or would I start getting sick if I did start taking them? Then I'd be real mad.*

### **Concerns about the Ability to be Adherent**

Another common response from the participants was the concern that they personally would not be able to be adherent. They were all aware that once on medications it would be crucial to maintain adherence.

*It's like I'm there and I'm feeling these feelings and I'm not even taking them yet. But I'm already feeling, you know, afraid-- can I do this? And it's just a source of anxiety for me, you know. If I don't do it, you know, it's like I'm going to die from missing doses, like I'm going to die.*

*I'm not a very compliant person when it comes to taking medication and that's what scares me. 'Cause you have to be compliant, I know that, and I don't know if I can do that.*

### **Taking Medications Would be Stigmatizing**

Some participants felt that taking medications would expose them to stigma. This is one of the sequelae of the illness appraisal of HIV as stigmatizing.

*I have no idea what that's going to be like. I mean, there might be stigma that would be challenging. I don't know if I'd want to be in a restaurant and have to break out a bunch of pills.*

A corollary of the view that taking HIV medications would expose the individual to stigma is the concern that the medications would create a change in physical appearance, altering a person's body in a visible and negative way.

*Medication is something that you have to take to stay alive, right? That's what I think. Unfortunately the first thing that I think about when I think of medications would be like the distortion of the people's appearance, and I don't want that to happen to me.*

## **Discussion**

The goal of the current in-depth inquiry was to articulate the meanings that HIV seropositivity and ART hold for the participants in order to illustrate the underlying issues involved in the decision to initiate treatment. Findings reveal that illness

appraisals of HIV disease are related to how people think and feel about the available treatments for that condition, and ultimately, perhaps, to the decisions they make regarding initiation of ART. Specifically, it is evident in this sample of men and women contemplating treatment that there was continuity from some of the illness appraisals to the medication appraisals.

The illness appraisal of HIV as stigmatizing, which can include fear of stigma, experienced stigma and internalized stigma, appeared in both the illness appraisals and medication appraisals. This points to the personal and public health consequences of stigma, and the need to address it on both an individual counseling level and in public forums aimed at education.

The illness appraisal of HIV as a threat to mortality was commonly translated into a medication appraisal that the costs of going on medication would outweigh the benefits. Participants counted as one of the costs the possible progression of the disease and hastening of their death. Remien and colleagues (Remien, Wagner, Dolezal, & Carballo-Diequez) in their qualitative study of ART adherence found that feelings of ambivalence about medications to be a common theme. Possibly a medication appraisal of ambivalence (*i.e.*, being aware of the positives and the negatives of taking ART) could be common among people who are at the decision point of whether to begin ART, as well as those who are already on an ART regimen.

These illness and medication appraisals all represent barriers to initiating a medication regimen and to maintaining adherence. Artificially separating appraisals of illness from the appraisals of treatment may neglect important factors that may be driving decision-making about treatment and subsequent adherence and maintenance of treatment. Indeed, the current data suggest that medication decision-making and the related medication appraisals may serve as a trigger to reactivate distressing representations of HIV disease, including fears of death, stigma, and rejection. In the case of people who either do not believe or do not accept their HIV diagnosis, the prospect of initiating ART requires them to change their self view and incorporate having an illness into their identity. This challenge for people with HIV has been described in other research (*e.g.*, Baumgartner, 2007; Lewis, 1999).

Decisions regarding the initiation of ART are shaped by a context of meanings. It is important that formal health care providers attend to the dynamic interplay of illness and treatment appraisals. People with HIV may hold negative appraisals of their HIV seropositivity, and/or HIV medications that activate negative feelings and increase distress at the prospect of beginning with ART. By contrast, some people with HIV appraise their serostatus less negatively, for example, they view it as a treatable chronic illness (J. Moskowitz, Wrubel, Hult, Maurer, & Stephens, 2006). This appraisal could be associated with more positive medication appraisals, for example, as life saving. Understanding how these processes inter-relate can help to address appraisal related barriers to HIV management and thus facilitate the successful initiation, adherence, and maintenance of life-saving therapies for those living with HIV. HIV service providers need to take individual differences in illness appraisals into account in helping new clients to cope with their diagnosis, manage their healthcare, collaborate in decision-making about treatment, and prevent future complications from HIV.

This study is limited by the small sample interviewed. The participants were interviewed only once, so there is no information about their subsequent treatment choices, or about their ability to maintain adherence if they chose to begin an ART regimen. Further, the sample is select, in that some participants have already delayed initiating ART for months or even years. Thus, those who volunteered for the study may not express views that are representative of others considering treatment options. We need to compare these participants' illness and medication appraisals with those of people who begin ART as soon as it is medically indicated in order to clarify further how to identify effective interventions.

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