HIV/AIDS Patients' Perspectives on Adhering to Regimens Containing Protease Inhibitors

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OBJECTIVE: To gather qualitative data regarding HIV/AIDS patients' perspectives about HIV-1 protease inhibitors (PIs), and about their experiences taking and adhering to regimens containing PIs.

DESIGN: Six focus groups of persons under care for HIV were conducted between September and November 1996 regarding participants' knowledge, awareness, experiences when taking, and adherence to antiretroviral regimens containing PIs. An identical discussion guide was used to facilitate all six groups. Focus group proceedings were audiotaped, transcribed, coded for themes, and analyzed qualitatively.

SETTING: HIV/AIDS practices of three teaching hospitals and two community health centers.

PATIENTS/PARTICIPANTS: Fifty-six patients with HIV disease: 28 men and 28 women.

MEASUREMENTS AND MAIN RESULTS: Knowledge and positive impressions of PIs were prevalent among this diverse group of persons with HIV, and did not differ by race/ethnicity or gender. Most knew that these were new, potent medications for treating HIV/AIDS. Networks of persons with HIV and medical providers were the most important information sources. Those taking PIs were aware that adherence to the regimen is important, and most were using special strategies to maximize their own adherence, but expressed considerable frustration about the central role these medication regimens had assumed in their life. A subset who did not believe they would adhere to these regimens had declined treatment with them. Motivating factors for taking and adhering to these complex regimens were improving CD4 counts and viral loads and the patient-provider relationship.

CONCLUSIONS: Among those with HIV/AIDS, awareness of PIs and their effectiveness is substantial, owing to the impact of informal networks and medical providers. This early positive "reputation" of PIs may enhance motivation for adherence. Those who are taking PIs invest substantial effort adhering to these complex regimens, but resent the need to make medications the focus of their lives.

KEY WORDS: HIV/AIDS; adherence; compliance; protease inhibitors; antiretroviral therapy.

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there is considerable evidence that these agents will also dramatically improve clinical outcomes, including survival, time to AIDS, and hospitalization rates for patients with HIV disease.⁵⁻¹¹

Four HIV-1 PIs are currently available by prescription in the United States³: saquinavir mesylate (Invirase, Fortovase), indinavir sulfate (Crixivan), zidovudine (Retrovir), and nelfinavir mesylate (Viracept). Although these agents differ in their efficacy and adverse effects, they share important characteristics affecting their use in clinical practice. Viral resistance to these agents occurs rapidly if patients do not maintain therapeutic drug levels. Thus, it has been emphasized that patients' strict adherence to their prescribed PI-containing regimen is critical to maintain a durable clinical and virologic response.¹² Such strict adherence includes avoidance of skipping doses, taking "drug holidays," and other interruptions of treatment.

The complexity of these drug regimens and the critical importance of adherence to them has received a great deal of attention in both the medical literature^{3,4,10-12} and the lay press (Sontag D, Richardson L. Doctors withhold H.I.V. pill regimen from some, failure to follow rigid schedule could hurt others, they fear. *New York Times*. March 2, 1997;1, 31). Only patients who fully understand and accept the level of responsibility and long term commitment necessary to take these regimens consistently should be started on them.^{4,10,11,13} This is essential because all PIs may engender early HIV resistance after even a week of missed medication, irregular use, or incomplete doses.¹⁴⁻¹⁶

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Preliminary findings of this study were presented at the Society of General Internal Medicine annual meeting on May 3, 1997, and the National Conference on Women and HIV on May 6, 1997.

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There is increased optimism among those living with HIV/AIDS and their medical providers because of the availability of HIV-1 protease inhibitors (PIs) and potent combination antiretroviral regimens containing these agents.^{1,2} Protease inhibitors have already substantially affected the clinical care of persons with HIV/AIDS.^{3,4} Although studies of long-term efficacy have not yet been published,

Furthermore, full or partial cross-resistance exists among the PIs; hence, inappropriate use of one PI may limit future therapeutic options.^{3,4,10,11,14-16}

Although adherence is an important consideration in prescribing PIs, there are concerns that it has the potential of being used as a justification for disparities in prescribing practices for patients with HIV/AIDS. It has been observed that some providers judge patients as less likely to be adherent if they are nonwhite, less educated, impoverished, or former injection drug users,¹³ even though the literature suggests that none of these demographic characteristics has had a consistent association with medication adherence.¹⁷

Despite the critical importance of these issues, little data exist regarding patients' adherence to PI-containing regimens. The majority of studies on adherence to HIV medications thus far have focused almost exclusively on zidovudine (AZT).¹⁸⁻²⁵ However, these studies on AZT adherence may not be generalizable to PI-containing regimens, as the efficacy of these regimens is known to be far greater, consist of many more pills, and require more complex dosing strategies than AZT alone (Leland J. The end of AIDS? *Newsweek*. Dec 2, 1996:65-73).

To gain more insight into patients' actual and potential adherence to these regimens, we gathered qualitative information about these issues from a diverse group of patients with HIV/AIDS. The goal of this focus group study was to learn what themes HIV/AIDS patients would identify as important when discussing their antiretroviral therapy. We present here the results of this exploratory study examining HIV/AIDS patients' experiences with and perspectives about taking and adhering to PI-containing regimens.

METHODS

Focus Groups

Eligible subjects for this study included any persons living with HIV/AIDS who met criteria for antiretroviral therapy based on the 1996 recommendations of the International AIDS Society—USA,²⁶ and who were currently receiving ongoing care for their HIV disease at one of five sites in metropolitan areas: Boston Medical Center (formerly Boston City Hospital), Dimock Community Health Center, and Fenway Community Health Center, all in Boston, Massachusetts; and Memorial Hospital of Rhode Island and Rhode Island Hospital, both in the Providence area. The other eligibility criteria were that participants be fluent in English and willing to talk openly in a group setting about their HIV disease and its treatment. Eligible patients were initially approached about focus group participation by their medical provider at the time of a visit or by telephone; if they agreed, they were given information about the location and time of their assigned focus group, and informed consent was obtained. The study was approved by the Human Subjects Committee of each participating insti-

tution. The six study focus groups were held between September and November 1996. At that time, one PI had been available for approximately 1 year, and two others had been available for approximately 8 months.

An expert in focus group methodology moderated the groups using a structured moderator guide developed by the research team. The same moderator led all six groups; this person was not previously known to any of the participants, and she was not a care provider at any of the sites. Focus group composition was stratified by participant gender and metropolitan area (Boston or Providence). In addition, focus groups were largely stratified by mode of acquiring HIV. A brief questionnaire containing items about key demographic and clinical information was completed by each participant prior to beginning the focus group discussion.

Each group engaged in a 2-hour structured discussion of issues regarding treatment of HIV/AIDS with medications, particularly PIs. Following the structured moderator guide, the same topics were raised, in the same order, in each group. The discussion topics in the focus groups and their order were as follows: (1) Whether participants believe that medications to treat HIV are helpful or not, and in what way they are helpful; (2) awareness of reverse transcriptase inhibitors, experiences taking them, understanding of how they work, positive aspects, negative aspects, adherence; (3) awareness of PIs, experiences taking them, understanding of how they work, positive aspects, negative aspects, adherence, and strategies used to enhance adherence; (4) motivating factors for taking and adhering to PI-containing regimens; (5) how participants make decisions about their medications; (6) influence of the provider's recommendation; and (7) information sources regarding HIV/AIDS and its treatment. Discussions regarding experiences taking and adhering to PI-containing regimens were limited to those participants who had taken PIs. Multiple definitions of all terms were provided (e.g., it was made clear that reverse transcriptase inhibitors included nucleoside analogues), and key discussion questions and items of concern were posted on boards for all participants to see.

As each focus group was completed, the facilitator made a complete transcript of the session's proceedings, including spontaneous conversation among the participants prior to and following the formal focus group discussion. This method enabled the facilitator to produce a high-quality transcript and to identify each participant's contribution more accurately than would have been possible using a transcription service.

Data Analysis

Focus group data were analyzed by content analysis of audiotapes and transcripts. Transcript comments were sorted according to each discussion topic. Themes were considered distinct from the focus group "discussion topics" in that themes would come up repeatedly and consistently

re-emerge irrespective of the specific "discussion topic" being discussed at the time. The comments of each focus group participant were extracted along with summaries and highlights of relevant conversation in order to keep the comments in context. Responses were categorized, specific information was extracted, and general themes were identified and summarized. Themes and issues of importance to each individual, underlying motivations, and group dynamics were identified and noted.

Using an iterative method of content analysis employed frequently in qualitative research,²⁷⁻²⁹ we coded transcripts for themes. This is an iterative process in which the reviewer first reads for ideas and allows them to develop into concepts that can be coded. Each of the four members of the research team who served as reviewers identified, copied, cut out, and pooled all examples of material in each of the thematic areas into stacks, then sorting them further by codes. The dominant themes were then compared, qualitatively only, between important subgroups of participants, such as gender, race/ethnicity, and mode of acquiring HIV/AIDS. A final reading of the intact transcripts was done by two of the investigators to confirm the validity of the themes and conclusions.

RESULTS

Participants

There were a total of 56 participants in six focus groups whose demographic characteristics are displayed in Table 1. They were evenly distributed by gender; in terms of race/ethnicity, 50% were white, 29% were African American, and 21% were Latino. In terms of educational attainment, they were fairly evenly distributed between

those with less than a high school education, high school graduates, and those with some college education or more. Participants had an average age of 37.6 years. The mean self-reported CD4 count of the participants was 335 cells/mm³ (range 5 to 640). Participants had known of their HIV infection for an average of 7 years. Women participants were more likely to be nonwhite and have lower educational attainment than the male participants; this difference reflects the differing epidemiology of HIV/AIDS in women, both in New England and nationally.³⁰

Overall, 87% of the participants had taken one or more antiretroviral agents for treatment of their HIV disease; 35% had taken a PI-containing regimen. Although many participants had not yet taken PIs, much of the discussion focused on participants' knowledge of and attitudes about these agents, and other issues that were felt to be related to treatment and adherence with these medications.

Knowledge, Awareness, and Perceptions of Protease Inhibitors

Overall, awareness of PIs was quite high among the focus group participants. Nearly all participants knew of the existence of these new potent medications for treating HIV/AIDS. Here and in subsequent sections we will provide quotations from participants that reflect the perspectives they shared, such as:

I've heard a lot of good stories about them, you know? I haven't heard any bad ones.

and

I hear a lot of people sayin' that they got a new medicine. You know? And you should go on it.

Overall impressions of PIs were quite positive. Many knew someone who had improved dramatically on a three-drug regimen containing a PI, or had themselves already dramatically improved on such a regimen:

I've been taking them for a month and . . . I'm not sayin' it's makin' me Wonder Woman, but I notice the difference already.

I know somebody that was, like . . . I actually thought they were going to die, and um, they were in the hospital on, what do you call those breather machines . . . oxygen machines, all that stuff. After they got out of the hospital, they started taking it . . . and, it's like, they don't even have HIV or anything. They're so active, and I mean, they gained like 30 pounds and . . . just healthy . . . very healthy!

I've got a couple of friends that are takin' the medications, and when they do the test for the viral load, it don't show up.

Thus, the experiences of peers emerged as an important theme explaining why participants were aware of these agents so soon after they became available and why they were so confident that they would work effectively to treat their own HIV/AIDS.

Table 1. Participant Characteristics (n = 56)

Characteristic	n	%
Gender		
Male	28	50
Female	28	50
Race/ethnicity		
African American	16	29
Latino	12	21
White	28	50
Education		
Less than high school	15	26
High school graduate	21	38
Some college or more	20	36
Age in years		
20-29	11	20
30-39	26	47
40 or above	18	33
Probable mode of HIV acquisition		
Injection drug use	36	64
Heterosexual contact	11	20
Male-with-male sex	9	16

Conversely, in five of the six groups, one or more participants stated that they saw someone worsen and die on AZT, and this shaped their impressions of that medication. These same participants pointed out that they were now observing their peers improving on PIs.

One commented:

I always said I'd never take medication. Everybody I knew that took just the AZT, they seemed fine before they started takin' it, and then to me it looked like they got sicker quicker. But now I see with these new meds, they are helpful.

Next, we explored participants' knowledge of how PIs work. Many participants reported that they did not have a complete understanding of PIs' mechanism of action, despite valiant attempts by their providers to explain it and draw diagrams for them. Many, including those with substantial education, said they did not care how they work, so long as they do work; for example,

I've read the literature and had it explained to me, but I just want it to work and I don't care how it works.

The majority of participants, however, seemed to believe what was stated by one participant as:

It does the same thing that the other drugs do in a different way.

Themes identified in this section and subsequent sections are enumerated in Table 2.

Negative Aspects Of Taking Regimens Containing Protease Inhibitors

Most participants were also aware of the negative aspects of taking PIs, especially their many side effects, and the need to focus on taking them exactly as prescribed. Participants on PI-containing regimens expressed much more frustration with the need to stick to a complicated pill-taking regimen than with the medications' side effects. There was concern expressed that taking PI-containing regimens interrupts the normal flow of life and that taking the medications becomes the entire focus of day-to-day existence. Many participants on PI-containing regimens stated that they no longer feel in control of their life—rather, they feel that the medications are in control. Many of those on PI-containing regimens stated that they had altered their lifestyle radically to accommodate the required pill schedule, including altering sleeping and eating patterns. Several participants stated that being on a PI-containing regimen is like having an infant, in that it becomes the focus of all of one's energy and attention.

Being on a PI-containing regimen was described by one participant as becoming a "central organizing principle of life":

Everything is amplified. I'm more aware of, "Oh I ate that cheeseburger. Now I've got to wait another 2 hours before it digests to take my pills." I feel very out of control with the regime that I have to follow. My life is focusing

around that, rather than the other way around. Now it's gotten to a point where I've got a watch that I set every 8 hours to remind me. Because if I'm caught up in the mode of . . . for instance, being at work, if I get caught up in the moment and I forget, you know, it's another possible misstep there. And my partner's also living with it. He's on a different regime than I am, so you can only imagine . . .

This sentiment was shared by nearly all patients taking PI-containing regimens. It was expressed by women as well as men. For example, one woman expressed similar concerns in this way:

I would much rather go to my doctor's office once a week and take a needle, and not have to worry about it for the rest of the week. I could live my life, take care of my kids, go to school, go to work, you know what I mean, without having to worry about "Oops, time to take another pill."

Information Sources About HIV/AIDS Medications

Participants' sources of information about medications to treat their HIV disease were quite varied, from methadone program counsellors to computer Internet chatrooms and Web pages focused on HIV/AIDS treatment options. Not surprisingly, many participants reported that their medical providers were an important source of new information about medications to treat HIV/AIDS. Yet the most important information sources seemed to be based on networking. The networks seemed to be, in part, an outgrowth of key places where HIV patients meet and socialize, including HIV care sites serving specific communities, drug treatment programs, the AIDS Action Committee, and other community-based organizations oriented to specific communities of persons with HIV. The majority of the participants who were gay men and injection drug users appeared to be a part of such networks of HIV-positive people, and benefited from the information they learned from their network's "grapevine." The subset of women who acquired HIV via heterosexual contact rarely reported being a part of a network of persons with HIV. Many stated that they knew no one else with HIV disease. As a result of their isolation from others with HIV, they appeared to have the least access to new information about HIV treatments.

Expressed Interest in Taking Protease Inhibitors

All participants who expressed interest in taking a PI had already discussed this option with their medical provider, and expressed satisfaction with their discussion. Participants who had not been started on a PI after discussing it with their provider had an understanding of when or on what basis their provider planned to recommend starting a PI in the future.

Some participants reported that they had declined treatment with a PI-containing regimen because they did not perceive that they were ready to take them consistently, or because they felt the side effects outweighed the

Table 2. Themes Identified Regarding HIV/AIDS Patients' Perspectives About Regimens Containing Protease Inhibitors

1. Knowledge, awareness, and perceptions of protease inhibitors (PIs)
Awareness of PIs is high and impressions of them are quite positive.
These perceptions are based on the positive experiences of participants and their peers.
Perceptions of PIs are more favorable than those of AZT.
Knowledge does not differ by race/ethnicity, gender, or mode of acquiring HIV.
2. Negative aspects of taking PIs
Taking PI-containing regimens often becomes the central focus of life; this is perceived as the greatest negative aspect of these regimens.
3. Information sources about HIV/AIDS medications
Persons with HIV/AIDS obtain their information about medications from many sources.
Health care providers and informal networks of persons with HIV appear to be the most important information sources.
Gay/bisexual men and those with a history of injection drug use are more likely than others to be part of an informal network of persons with HIV.
Women who acquired HIV via heterosexual contact rarely belong to a network and are often socially isolated from others with HIV.
4. Expressed interest in taking PIs
All participants who were interested in taking PIs had discussed this treatment option with their health care provider.
Some participants, mostly injection drug users, reported they had declined treatment with PI-containing regimens.
Reasons for declining PI treatment included alternative views regarding medication effectiveness and of health locus of control, resilience, and denial.
5. Adherence to PI-containing regimens
Most participants were aware of the need for close adherence to PI-containing regimens and the reasons adherence was important.
Most participants taking PIs were highly motivated to adhere to regimens and utilize personalized strategies to optimize their own adherence.
All those on a PI occasionally missed doses, irrespective of gender, race, or how they acquired HIV.
6. Motivating factors for taking and adhering to PI-containing regimens
Evidence of medication effectiveness (e.g., declining viral loads) and the patient-provider relationship are the most important motivators for taking and adhering to these regimens.

benefits. Many expressed concerns that the medication side effects are similar to drug withdrawal and might trigger substance abuse relapse. Many of these participants, newly in recovery from drug use, espoused an alternative theory that a healthy lifestyle would be most beneficial in keeping them well, and that their body would "let them know" when it was time to start taking these medications to fight HIV. This group of participants asserted that frame of mind is the most important factor influencing a person's health.

The following participant's comment reflects the perspective expressed by a number of these individuals:

My best doctor, best adviser, is my mentality. The way I listen to what my body tells me, which I always done since I was knee high . . . always listened to what my body was sayin'. And I think it all has to do with how people think it, perceive it, and do it. I mean if they're going to let the disease eat at them, it's going to eat at them . . . quickly.

Another participant commented on his decision to decline treatment with a PI as follows:

You know, it might serve the purpose, okay, make your T-cells go up or whatever, or make your viral load get to where it's supposed to, but what about the way you're feelin' overall? The medication does what its supposed to, but is it worth it? Like, for me, it's not worth it. Like, takin' this medication it might help me in the long run, but in the meantime I gotta feel like trash . . . because of all the side effects, the toxicity and stuff. I think it's more

important for quality than quantity of life. This is just what I choose.

This group of patients also reported that they would decide when they were "ready" to take medications both physically and mentally; and when that time came then they would do so consistently and as directed. One participant summed up this perspective in the following way:

I know these medications are good for me. And I know what they can do for me. And when I do decide to take 'em, I'm gonna take 'em in full force like he (another participant) is doin'. But if I started on this medication right now, I'd probably take 'em, like, for a month at the most.

Adherence to Regimens Containing Protease Inhibitors

The majority of focus group participants were aware of the importance of adherence to PI-containing regimens. Participants who were currently taking a PI were all aware of the need for close adherence to the prescribed regimen. For example:

My doctor, she really got detailed. . . . She stressed to me how important it was to take them on time and that if I didn't think that I could do it, then it was no sense in me even startin'.

Most participants had a reasonable understanding of the reasons why adherence is very important with PIs and

were committed to optimizing their own adherence. One said:

They got a very strict schedule of takin' them. And I imagine that's so they don't lose their effectiveness or . . . maybe affect you . . . in a negative way.

Many participants on PIs utilized one or more strategies to enhance their own adherence. Strategies mentioned most frequently were beeper pill cases set to go off every 8 or 12 hours, keeping medications in view, keeping medications in makeup bags, reminders by family members, tightly routinized daily schedules, watches set to go off every 8 or 12 hours, always having the medications with them, 7-day pill cases, and a number of other unusual, but personalized approaches. For example:

I have to show you something. This is what I found. And I think it is the greatest thing since sliced bread. I was at my sister's Tupperware demonstration. And they passed around a basket of these little gadgets, and I looked at this one and thought, "Oh that would be perfect for all my pills."

All those taking PIs occasionally missed or skipped doses. A wide range of reasons for nonadherence were cited:

The last time I skipped a dose was because I completely forgot.

I was out too late. Fell asleep. Woke up and said, "Oh, I didn't take my pills last night."

If you don't want everybody to know, you know, you don't take 'em in front of people. It raises questions.

An important factor that prevented several participants from taking medications exactly as prescribed, despite their reported motivation to do so, was being in an institutional setting, such as a halfway house, homeless shelter, or prison. One said:

Because I'm in a halfway house, and I can't have my own medication on me, I know sometimes I go without taking mine.

Several participants taking PIs did report having long periods of nonadherence, which ranged from a week to a month or more. These were most commonly due to "drug holidays," vacations, or family responsibilities:

Every once in a while I'd have drug holidays, and you do feel like a toxicity's building up, and so on and so forth. That something just tells you to stop. And you stop for, like, a week.

I just had my two grandkids with me for, like, 6 weeks, and I was very overwhelmed with that . . . It just kind of puts my own stuff on a back burner.

Motivating Factors for Taking and Adhering to Regimens Containing Protease Inhibitors

The final theme that emerged involved the factors motivating participants to take and adhere to PI-containing regimens. Evidence of medication effectiveness, such as a declining HIV viral load or an increasing CD4 count,

tended to be the most important factor motivating participants on PIs to take and adhere to their regimen:

So yes, if viral loads are spiraling upwards, it's much more indicative to start a protease inhibitor treatment and stick with it . . . So yeah, the viral load test results are important to me.

I've been HIV for 12 years, and this is the first year I can say that I really feel as though there's something that's probably going to make a difference. I think the AZT and all the other stuff was, like, taking an aspirin when you have a migraine.

Many participants, both men and women, reported that their relationship with their health care provider was also an important motivating factor for taking and adhering to their PI-containing regimen. Participants had difficulty specifying what about the relationship with their provider served as a motivator. It seemed that simply having an ongoing relationship with a provider they trusted was motivating, particularly if this relationship was longstanding:

My provider, her and I have a real good . . . real good relationship. And I trust her. I trust her opinions. I trust whatever she tells me. If she tells me, "I think you should take this," even if I ever have my doubts, I say, "Let me think about it."

I mean my doctor's over here jumpin' with joy. For me, I just ignore those numbers, I don't pay attention to those numbers for myself. But for the first time I saw my doctor really optimistic about something.

Finally, several participants of both genders reported that staying healthy to care for and raise their children was their most important motivating factor.

DISCUSSION

This qualitative examination of HIV/AIDS patients' perspectives on taking and adhering to PI-containing regimens reveals several important themes. For many of those with HIV/AIDS, the positive experience of peers seemed to greatly influence their perspectives about PIs. Peer experience was very important in explaining how much participants knew about these agents and their impressions of how well they work. This positive "reputation" of PI-containing regimens, along with individuals' own positive experience with the medications may make them motivated to adhere to these regimens once they have made the decision to begin them. It may be that this peer influence is already making patients more likely to adhere to difficult PI-containing regimens because they are confident the medications work, given what they have observed in their friends and peers. Importantly, what participants reported observing of their peers taking PI-containing regimens was very different from what they recalled observing when their peers had taken AZT alone. This resulted in very different perceptions of the usefulness of taking PI-containing regimens compared with AZT monotherapy.

Knowledge and awareness of PIs was substantial among this diverse group of participants with HIV/AIDS. Many participants acquired this knowledge through networks of HIV-infected persons to whom they were connected through lifestyle or behavioral connections, such as being openly gay or being a former or current injection drug user. Notably, many participants had acquired early knowledge of PIs as a result of their use of these informal networks of HIV-positive people as a major information source. Women who acquired HIV via heterosexual contact appeared to have the least knowledge about new HIV/AIDS treatment options, in part because of not belonging to such a network. Surprisingly, apart from this one finding, there were no apparent differences in knowledge and awareness of these important new medications by gender, race/ethnicity, or mode of acquiring HIV.

Patients who agreed to be treated with PI-containing regimens appeared to be highly motivated to adhere to these regimens, and had developed special strategies to enhance their adherence. This was particularly good news; not only are patients aware of the need for close adherence to PI-containing regimens, they are going so far as to develop personalized strategies for doing so. At the same time, the need to adhere so closely to the prescribed regimen was perceived as problematic. Specifically, considerable resentment was expressed about the apparent need to make the medication regimen the central focus of their life in order to succeed in being adherent.

Another important theme that emerged was that some participants had decided the medications were not right for them at this time. Many of these were patients who had acquired HIV via injection drug use. Although many of these patients stated that they felt too healthy to take medications at this time, others stated that they simply were exercising their option of delaying medication therapy until they were ready. This self-selection suggests that adherence may be less of a problem than anticipated because patients who cannot, will not, or are not ready to be adherent may avoid PI-containing regimens.

Not surprisingly, the importance and influence of the patient-provider relationship was reported to be a substantial motivator by our focus group participants. Whether patients discuss the option of a PI-containing regimen and whether they remain motivated to continue taking these complex regimens appear to be very much influenced by the quality of their relationship with their medical provider. Notably, the importance of the patient-provider relationship was found in another recent study to be an important predictor of HIV/AIDS patients' acceptance of and adherence to antiretroviral therapy.³¹

This study has several limitations. First, all information regarding patients' experiences taking PI-containing regimens, including their adherence, is based on self-report. Second, we did not include Latino patients who spoke only Spanish; it is possible that the findings reported here may not be generalizable to that group of patients. In addition, there may be a concern about how

representative this group of patients may be because they were of necessity chosen in part based on their willingness to talk openly in a group about their HIV and its treatment. This was a qualitative study, and the data collected are exploratory and thematic in nature. Therefore, we have been careful not to make quantitative comparisons, but rather have reported only qualitative themes that emerged from the data. Also, we have been careful not to make causal inferences from what we have reported here. Rather, we have focused on this research as a method for generating new ideas and hypotheses^{32,33} Finally, this study was performed at a time of rapid change in antiretroviral guidelines; prescribing practices at the time of this study are not identical to current practices. It is certainly possible that patient perspectives regarding antiretroviral agents have also evolved during this period.

In summary, this study appears to validate, at least qualitatively, that HIV patients' willingness to adhere to PI-containing regimens differs from that observed with AZT monotherapy. It is encouraging that those on PI-containing regimens are using a variety of strategies to enhance their adherence. It is equally concerning, however, that such a high level of frustration was voiced about the central role these regimens assume in the lives of those who take them. Therapeutic innovations that simplify these regimens by decreasing the frequency of doses and the number of pills per day may help address this frustration and improve the likelihood of long-term adherence. The themes identified by this study require further examination using research that will quantitatively define and clarify these findings in a larger patient population, and assist in determining appropriate responses to optimize adherence to potent antiretroviral regimens.

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