

# **Motivators and Barriers To Use Of Combination Therapies In Patients With HIV Disease**

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**CAPS Monograph Series,  
occasional paper #5,  
January 1998**

**Center for AIDS Prevention Studies, University of California San  
Francisco**

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## **Table of Contents**

- I. Introduction
- II. Study Design
- III. Key Findings
  - A. Motivators to Initiate Therapy
  - B. Barriers to Initiation of Therapy
  - C. Other Factors That Influence Decision-Making
  - D. Issues and Concerns of Women
- IV. Study Implications

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## **I. Introduction**

The successful two-drug combination therapy in 1994 and protease inhibitors in 1995 set the stage for a new era in treatment of HIV disease, creating a burst of optimism over the prospect that HIV might be a controllable disease. Initial studies of protease containing triple-drug regimens suggested that these combinations could, in some cases, slow clinical progression of the disease and prolong the lives of patients.<sup>1,2</sup> In anecdotal reports, physicians and patients described a kind of "Lazarus" effect in which previously disabled individuals found themselves regaining lost functions, returning to work and planning their futures, instead of preparing for death.

There are still many unknowns about these multi-drug regimens, including their durability of effect and how many individuals for whom they will be effective.<sup>3,4</sup> Nonetheless, the drugs have proven quite effective in clinical trials and are helping many people stay alive longer and experience better quality of life while they are alive.

We thought it important to understand better why people do and do not take advantage of these therapeutic advances. Developing the medications may be only half of the battle; the other half involves making sure that HIV infected individuals have access to the drugs and that they make thoughtful decisions about whether or not to take them. If some of the barriers to taking the drugs can be addressed, they should.

We conducted in-depth qualitative interviews with 114 individuals in the HIV community--75 HIV infected men and women, 18 hotline operators and supervisors, 11 case managers, and 10 physicians and nurse practitioners.

### **We found that individuals are motivated to begin antiretroviral therapy if:**

- they experienced a decline in their health status;
- they saw or heard about improvements in other patients;
- they obtained better research information about the drugs;
- they came to believe that the therapy would prolong their lives;
- their physicians had recommended it; and/or
- they learned how to cope with the treatment regimens and drug side effects.

### **People were deterred from taking advantage of antiretroviral therapy if:**

- they had concerns about the short- and long-term side effects of the drugs;
- their health was good;
- they had concerns about the effectiveness of the drugs;
- they were concerned that the treatment regimens were too demanding;
- they felt that they could manage the disease without drugs;
- they were concerned about developing drug resistant virus;
- they rely on holistic or alternative approaches to managing their disease; and

- their medical provider had not recommended that they begin treatment.

**Based on these findings, we recommend the following:**

- Clinicians need multiple forums in which they can share information with other clinicians and discuss possible approaches to treatment.
- Clinicians and patients need time to discuss whether or not to start antiretrovirals.
- The information needs of people extend beyond how the drugs work to how to cope with the drug regimens and their side effects.
- Other resources used by patients to gain information must be as accurate, comprehensive, and as current as possible.
- Women need special services to assist them in deciding about antiretroviral therapy.
- Spanish speaking patients are not being well-served by the public health system and need more
- Spanish-speaking clinicians and interpreters in order to benefit from antiretroviral therapy.
- Patients and clinicians need access to the best information possible on alternative and holistic remedies to treat HIV.
- Pharmaceutical companies are encouraged to continue drug development so that antiretrovirals can become even more effective and easier to take with fewer side effects.

## **II. Study Design**

In the current study, our goal was to identify those factors that have both deterred patients from initiating therapy or motivated them to opt for the new treatment regimen. We conducted in-depth interviews, either on the telephone or in person, during October, November and December 1997 with 114 individuals in the HIV community. These included 75 HIV-positive men and women, 18 hotline operators and supervisors, 11 case managers and 10 physicians and nurse practitioners. The one-on-one interviews ranged from 30 minutes to more than an hour.

The patients were recruited through posters and flyers circulated in treatment centers, clinics, needle exchange programs and support groups and through referrals from physicians, clinics and case managers. Patients were recruited from a dozen cities and represent diverse ethnic and racial groups, including African-American, Asian, Native American, Hispanic and white. Sixty-four percent of the patients were male and 36 percent female. Thirty-nine percent of patients identified themselves as heterosexual, 49 percent as gay, 9 percent as bisexual and 3 percent as lesbian. More than half of the patients, or 53 percent, had never taken protease inhibitors or combination drug therapy to treat HIV. Thirty-eight percent were taking combination drug therapy at the time of the study. Nine percent had initiated combination drug therapy but had stopped the treatment.

The case managers who participated in the study were drawn from public and private sector AIDS service organizations in seven cities. Most indicated that the majority of

their clients are HIV-positive. Virtually all of the case managers interviewed said their HIV-positive clients generally come from low-income households. Although all the case managers have women clients, the majority of their clients are men, both gay and heterosexual. Their clients come from a broad range of racial and ethnic backgrounds. Seven of the 10 case managers interviewed said most of their HIV-positive clients already had developed symptoms of AIDS or had been diagnosed with full-blown disease.

The physicians in the study were recruited in seven cities through contacts with AIDS service organizations. All treat a significant number of HIV-positive patients, who account for 30 to 100 percent of their caseload. The majority of physicians interviewed described their HIV-positive patients as gay, white men ranging in age from the early 20s to late 40s. Only 10 to 20 percent of their patients are African-American or Hispanic. Between 10 and 75 percent of their patients had developed symptomatic disease.

The AIDS hotline supervisors and operators represent a cross-section of major regional hotlines operated by public sector agencies and AIDS service organizations in eight cities. All of the hotline personnel participated in one of a series of four 90-minute roundtable discussions via telephone conference call.

The hotline operators said their role is to respond to inquiries about sexually transmitted diseases, primarily HIV, and to help HIV-positive individuals link up with organizations in the community that can address their specific needs. The hotline supervisors said there has been a notable decrease in the number of calls from gay men in the community and an increase in calls from heterosexual men and women. Although hotline staff do not ask a caller's race or ethnicity, those hotline personnel interviewed said they believe they are receiving an increased number of calls from people of color. Many of those who call the hotlines do not have private insurance, according to those interviewed. Many hotline personnel said they receive a significant number of calls from people in rural, or non-metropolitan areas, who do not have access to AIDS service organizations.

### **III. Key Findings**

All of the patients interviewed who were not on combination therapy said they were aware of the availability of this treatment option. A large majority of these patients said they were open to the possibility of combination therapy, most often indicating that they would be motivated to start the treatment if:

- they experienced a decline in their health status;
- they saw or heard about improvements in other patients;
- they obtained better research information about the drugs; and/or
- they came to believe that the therapy would prolong their lives.

Patients already on combination therapy cited these same factors as an influence in their decision to begin the treatment. In addition, some of the patients on therapy said they had started treatment because:

- their physicians had recommended it; and/or
- they learned more about the possibility of adjusting the treatment regimen, if necessary.

Among those patients not on combination therapy, the vast majority indicated that they were deterred from the treatment primarily because of:

- concern about possible short- and long-term side-effects;
- the positive state of their health; and
- concern or skepticism about the effectiveness of the drugs.

In addition, a significant number of patients not on the treatment said they were reluctant to initiate therapy because of:

- the demands of the treatment regimen;
- a feeling that the drugs are "too experimental;"
- a concern about taking medications in general;
- a feeling that they could manage the disease without drug therapy;
- a fear of drug resistance;
- a reliance on holistic or alternative treatment approaches; and
- the lack of a recommendation from a medical provider that they begin treatment.

The responses from patients were relatively consistent with reports from physicians and nurse practitioners, who said concern about side-effects and drug effectiveness, as well as the complexity of the regimen, were the key factors that deterred patients from initiating therapy. Physicians and nurse practitioners also said they believed patients shied away from the treatment because of a fear of drug resistance and a positive view of their health status.

Seven out of ten of those patients not on combination therapy said they had not been diagnosed with AIDS and had not had an HIV-related disease. Half of those individuals interviewed who were not on therapy have been HIV-positive for more than five years, although about one in 10 learned they were positive within the last year. More than three-quarters indicated they might opt for combination therapy at some point in the future.

Two-thirds of the patients who were not taking combination therapy said the decision not to begin treatment has not been difficult for them. Those who have struggled with their decisions said they had received conflicting information about the therapy or were subject to pressure, both pro and con, from family members and peers.

More than four in 10 of the patients not on therapy said they believe it is difficult to take these drugs, and another one in five perceive that it is "somewhat" difficult. In fact, two-

thirds of those interviewed said they know of someone who has stopped taking combination therapy. Even so, more than one in five said they do not believe that combination drug therapy would be difficult to take, once they made the decision to start. While the vast majority of those interviewed said they do not have lifestyle factors which would prevent them from undertaking treatment, one in five believe that it would be difficult for them because of their eating habits, school or work environments or "busy" lives.

### **A. Motivators to Initiate Therapy**

Patients were most likely to be motivated to begin therapy when they began to see their health deteriorate, based on changes in T-cell counts and viral load, hospitalization or the emergence of an opportunistic infection. Seeing or hearing word of improvements in other patients and getting access to better information about the drugs also served as strong motivating factors. Some patients also indicated that they began drug treatment because they believed it would prolong their lives. Others said a positive recommendation from their physician was key to starting therapy. Factors mentioned less often by patients included information about possible changes in the drug regimen and resolution of payment issues.

Nearly all of the patients currently on combination therapy said they planned to continue taking the drugs, although some qualified this by saying, "if it continues to work," or "until something better comes along." Patients were motivated to continue on therapy by improvement in their health indicators, such as increased or stabilized T-cell counts, decreases in viral load, weight gain or a general sense of improved health.

*"I'll take them as long as I have to. They make me feel like I'm not sick," said a heterosexual Hispanic female from New York.*

Six in ten of the men and women on combination therapy said the treatment had not been difficult for them, while three in 10 said it has been difficult. A few said taking combination therapy had been only "somewhat" difficult. More than two-thirds of patients reported experiencing some side-effects from the drugs. The group was divided between those who said the regimen schedule was difficult to maintain and those who did not find the regimen difficult.

*"I'm still alive. I wouldn't be here today if it weren't for all the drugs," said a heterosexual white female from Miami.*

*"It's better to take them than not," said another patient, a gay African-American female from New York. "God knows where I would be without them."*

### **Health indicators, including disease progression, changes in T-cell counts and viral**

## **load**

Seven in 10 patients who were not on therapy indicated that they are open to the possibility of treatment "when the time is right." For most of these patients, that time will come when their health begins to deteriorate, as indicated by declining T-cell counts or increases in viral loads (sometimes qualified as "consistent" or "significant" changes in their numbers), the onset of an opportunistic infection or hospitalization.

Disease progression was also frequently mentioned as a reason for starting therapy for those patients interviewed who already had begun the treatment regimen. Eight in 10 said they opted for therapy when there were clear indications of a deterioration in their health. Nine in 10 physicians also cited disease progression as a key factor in a patient's decision to start therapy, and about two-thirds of case managers said this was a strong motivator.

*"I wanted to go herbal, Chinese herbs, but my system was breaking down," said a gay African-American woman from New York who is on combination therapy. "I was getting worse, I got PCP, and they told me I wasn't going to get better."*

*"I was in the hospital. I was willing to try anything at that point. Maybe I was a guinea pig, but I was willing to take anything. Friends said it was a miracle drug," reported a heterosexual African-American woman from Miami."*

## **Seeing improvements in others**

Seeing or hearing about improvements in others also has a strong influence on patients' thinking about combination therapy. Almost half of those interviewed who were not on therapy said they felt encouraged to start treatment based on what they had heard about or witnessed in others about the positive effects of the drugs in HIV-positive individuals. Similarly, for those patients already on therapy, half said hearing reports of improvements in others had encouraged them to obtain treatment.

*"When I first heard about the therapy, I thought, 'Thank God!' I knew that it would work for me and saw that it was working for my friends already," said a gay African-American man from San Francisco who is now on combination therapy.*

*"The new drugs have made a difference in people, physical things," said one gay, African-American man from Washington, D.C. who is not on the therapy. "I have seen the Lazarus syndrome, people getting up out of their death beds. The most dramatic changes are among those who were the sickest. The effect takes a matter of weeks. There are fewer deaths. It gives hope.*

"

Patients reported that news media, support groups, HIV-positive peers and personal experience all served as sources of information about the value of the drugs.

*"I heard about the cocktail on the news," said a heterosexual African-American man from Washington, D.C. "It's working. You hear it on TV and see some people, like Magic Johnson."*

Case managers cited positive reports about the drugs as the number one motivator for patients. About eight of 10 physicians and nurse practitioners also noted that patients were influenced to start therapy based on improvements they saw, or heard about, in others. Hotline personnel reported that some patients were motivated to start combination therapy when they heard that the treatment had brought the virus down to undetectable levels in some HIV-positive individuals.

### **The availability of better research information**

More than half of those patients not on combination therapy said they would start treatment sooner if there were better research information about the effectiveness of the drugs beyond five years, the long-term side-effects and the length of time required on therapy. One third said they would be motivated to begin combination therapy if they knew they would not experience any short- and long-term side-effects. These patients also said they wanted more evidence that these drugs constitute a "cure" for HIV.

*"I'm hoping for the best about combination therapy, but without any long-term data on the results, I'm not certain," said one gay white man from San Francisco who is currently not on treatment. "But overall, I'm hopeful since fewer people are passing away."*

The responses from physicians, nurse practitioners and case managers suggested they feel a strong need for more scientific evidence on the value of the drugs. Most notably, seven out of 10 physicians and nurse practitioners said they believed patients would be motivated to take combination therapy if there were more or better research information on its effectiveness. More than half the case managers said they believed their clients would be influenced to start therapy if more research information were available.

*"The doctor wants me to start taking the drugs, and she gave me some books to read," reported a heterosexual African-American man from Washington, D.C. "She wants me to think about what drugs I want to take and think about commitment. But the things I have to read don't say how long the side-effects will last. Or what happens if you miss timing the drugs? Or what else can you take? Aspirins? Or when do you know if it works? Or how long before you know when to switch (to another combination)?"*

### **A belief that the therapy prolongs life**

Almost half of those patients taking combination therapy, particularly those who have developed AIDS or had opportunistic infections, said they decided to go on treatment because they hoped it would prolong their lives. A few noted that they believed



combination therapy was their last hope and they felt they had "nothing to lose" by trying it.

*"At first, I thought, 'Now I have to take pills for the rest of my life.' But I hope this will prolong my life enough for them to find a cure," said a heterosexual African-American man from New York who is currently on therapy.*

Almost half of the physicians, nurse practitioners and case managers said their patients had been motivated to start therapy because of a belief that it would prolong their lives. On the other hand, only one quarter of patients who were not on the regimen said they believed it might help them live longer.

*"The drugs do give people hope that something can be done to prolong life," said a bisexual Hispanic woman from Los Angeles who has yet to take the drugs.*

### **Perceptions about effective treatments for HIV**

Nearly all patients currently on therapy, regardless of sex, sexual orientation, race or ethnicity, said they believe combination drug therapy, "taking your meds" or using a mix of drug therapy and holistic treatments are the most effective methods to treat HIV. At the same time, about half of those on combination therapy also said that lifestyle or attitude were effective ways to treat HIV. These included changes in diet, exercise and a positive attitude toward the disease. Fewer than one in 10 of those currently on combination therapy cited alternative or holistic approaches as effective treatments for HIV.

### **An understanding that the regimen can be changed, if necessary**

About a third of those currently on combination therapy said they were more inclined to start treatment when they learned more about the ability to try different combinations if the first set of drugs did not work for them. Others on therapy said they became more motivated to begin therapy when they learned that the drug regimen could be altered to fit their lifestyles or were told that the side-effects would not necessarily be permanent.

*"There are so many combinations that you'll always be able to switch if you can't take the side-effects," said one gay African-American man from Washington, D.C. who is on combination therapy.*

Only about one in ten patients not on therapy said the ability to manipulate the regimen would motivate their decision-making, although nearly half cite the regimen as a barrier to their initiating therapy. About one in five case managers said they believed patients were more apt to start therapy if they knew the regimen were somewhat flexible and could be made to fit more easily into people's lives.

### **Physician recommendation**

More than half of patients on therapy said they were prompted to start treatment on the

basis of their physicians' recommendation. However, fewer than two in 10 patients not on the treatment said they would begin combination therapy if their doctors told them they needed to.

*"I was willing to try anything. I trusted my doctor and I saw other people at my doctor's office who said, 'You'll like that,'" reported one gay African-American man from Chicago who is taking combination therapy.*

More than a third of the case managers and about one in four physicians and nurse practitioners said they believed that patients trusted their caregivers to the extent that a positive physician recommendation would prompt them to start therapy.

### **Psychological well-being**

Though not cited by patients themselves, physicians, nurse practitioners and case managers said a patient's psychological well-being often played a role in his or her willingness to start drug therapy. Nearly half of the physicians and nurse practitioners and a majority of the case managers interviewed cited the patient's outlook as a factor in the initiation of therapy. Case managers noted that both extreme positive and negative outlooks could prompt a patient to opt for therapy. For example, some patients who are very positive and optimistic may choose to start therapy because they are confident that the drugs will help them. On the other hand, patients who are depressed or pessimistic about their health, usually because of disease progression, may start drug therapy because they believe it offers them a last chance for prolonging their lives.

## **B. Barriers to Initiation of Therapy**

Patients interviewed who were not on combination therapy were most likely to cite concern about side-effects as a barrier to treatment. Patients also frequently mentioned their positive health status, as well as a concern about the effectiveness of the drugs, as factors that had deterred them from starting treatment. Other factors that often deterred them from treatment were concerns about the demands of the treatment regimen, misgivings about drugs in general or a feeling among patients that they could manage the disease without the drugs. In addition, some patients said they believed the drugs were "too experimental" or indicated that they were afraid of developing a resistance to the current, or future, therapies. Finally, some patients said they relied on holistic or alternative approaches to treat their HIV or were waiting for better treatments to come along. In many instances, patients said their doctors had recommended treatment, though some said their physicians had advised them not to begin treatment yet. The cost of treatment and concerns about loss of privacy were only rarely mentioned by patients as barriers to initiation of therapy.

### **Concern about short- and long-term side-effects**

Concern about side-effects was the most frequently mentioned barrier to initiating combination therapy among HIV-positive patients who had never taken medications to

treat HIV. Eight in 10 of these patients cited concerns about side-effects as a deterrent to therapy, particularly given the absence of symptoms and other positive health indicators.

Frequently, these patients used the word "toxic" in describing drugs for treating HIV, citing this as a reason for not taking the drugs. As many as one in four of these patients also said they won't begin combination therapy yet because they believe the long-term side-effects are unknown and they fear the drugs will make them feel worse or cause damage to their organs, particularly the kidneys or liver. While there was a generalized concern about side-effects among many of these patients, a few said they did not want to experience any side-effects at all or were uncertain about whether the side-effects might diminish or disappear over time.

*"I don't have a good opinion of the meds because of what they are doing to those around me," said a gay, African-American man from Los Angeles who is not on the therapy. "I see my friends getting sick due to the side-effects and that makes me not want to take them. I have seen my friends die while taking the drugs. I feel the drugs will kill me before the virus will. They are all very toxic and worse for the body than the virus."*

*"The drugs are 'working' in some people because they are very sick and have made compromises with the side-effects. It depends on the individual," said a gay Hispanic woman from Miami.*

Those patients interviewed who are currently taking combination therapy also reported that the potential side-effects, fear about toxicities, their inability to tolerate these effects and uncertainty over whether the medications would work for them were the primary obstacles to initiating therapy.

The patients' responses were consistent with reports from physicians and nurse practitioners, case managers and hotline supervisors and operators. Physicians identified side-effects as one of the chief concerns of patients in weighing therapy, along with concerns about the long-term effectiveness of the drugs and the complexity of the regimen. In fact, nine out of 10 physicians said they describe the negative side-effects of combination therapy to patients, particularly gastrointestinal effects such as diarrhea and nausea. Some also inform patients that if they start therapy, they may experience neuropathy, a lack of energy, rashes or kidney problems. Two-thirds of case managers interviewed also said they discussed the possible side-effects with their clients, with specific references to nausea, diarrhea, rashes, possible kidney problems, lack of energy or loss of appetite.

Hotline operators also reported that callers had strong negative perceptions of side-effects. Callers told them they had heard that certain drugs were intolerable and would affect their ability to work at their jobs. These callers were afraid side-effects from the drugs would diminish the quality of their lives and restrict their mobility. Callers who were already on therapy often inquired about specific side-effects they were experiencing, such as loss of sensation in the hands or feet, diarrhea and nausea, weight

gain and "crix belly," the hotline workers reported. As one patient put it, "Introduce a 'foreign' medication into the body and it also kills some good cells."

### **Health indicators, including T-cell counts and viral load**

Among patients not taking combination therapy, more than six in 10 of those interviewed said the positive state of their health was a pivotal factor in not electing therapy. In fact, more than eight in 10 said they were optimistic about the state of their health. These patients said that they "feel healthy," "don't feel sick," or "have had not any opportunistic infections."

*"I'm keeping my options open for when I really need treatment, when the physical symptoms would be more real to me," said one heterosexual white woman from Miami. "If I had my first opportunistic infection, maybe I would have a different outlook."*

*"The way I feel at present, I wouldn't take these drugs, but the door is not closed on the subject," said another patient, a gay white man from San Francisco. "I hope other options are available in the future. I would have to be at a point where I must start (drug therapy) because my health is at a point where no other options are available. I consider therapies the last option."*

Patients indicated that they rely heavily on their T-cell counts as one measure of their health. Nearly four in 10 of the HIV-positive individuals interviewed specifically said they had not started combination therapy because their T-cell counts are too high or have been relatively stable for a long period of time. Occasionally, these individuals indicated that their doctors are in agreement that combination therapy was not necessary yet.

*"My viral load is declining and my T-cells are high and have been for 10 years," reported a gay white man from Seattle. "My doctor says there is no need for the drugs yet. We'll continue to monitor my numbers. I see that as the best idea, too."*

Although patients are more apt to rely on T-cell counts as an indicator of health, a third of those not on combination therapy said they also have considered their viral loads, which are low or stable, to be a factor as well. Still, one in five patients questioned the relevance or accuracy of viral load numbers. A few individuals noted that their viral loads fluctuated widely over a short period of time, and in the case of one individual, over a period of a few hours. In a small number of cases, patients not on combination therapy discounted the value of T-cell counts or viral loads altogether, questioning the validity of these measurements.

*"T-cell and viral load counts don't impact my decisions about drugs. Too many people become obsessed with numbers. I have had tests done within hours of each other that don't agree by a lot. Low T-cells don't mean you're dying," said a heterosexual white woman from Miami.*

Nearly all physicians and nurse practitioners and case managers indicated that they do not try to "persuade" clients to start therapy. The decision to start therapy lies with the

patients and is very much related to disease progression. While most doctors and nurse practitioners interviewed said patients struggle with the decision to start therapy, they said most of their patients opt for the treatment when confronted with signs of disease progression, such as changes in T-cell counts or viral loads or the onset of opportunistic infections. Half of the physicians and nurse practitioners interviewed said the patients' positive perceptions of their current health were a barrier to treatment.

*"My test results show I'm in relatively good health. I haven't taken them so far and am doing well, so why start now? I feel that I can deal with it without the medications. I'm concerned that I will react negatively to the therapies," said a gay Asian man from Seattle.*

### **Uncertainty and/or skepticism about the effectiveness of therapy**

Among those HIV-positive patients interviewed who were not on combination therapy, seven in 10 cited doubts about the effectiveness of the drugs as a reason for not starting therapy. About six in 10 of these patients said they believe the drugs work for most people while three in 10 said that, in their experience, the drugs work for some but not for others. At the same time, however, nearly three-quarters of these patients said they are skeptical about the effectiveness of the combination therapy, questioning whether the drugs would work for them or whether they would continue to work over the long-term. More than one in four in 10 said they expect the drugs would not work for them at some point in the future.

*"At first they thought the drugs could eradicate the virus, but now we know it won't," said a bisexual white woman from Seattle who is not on combination therapy. "They help only 50 percent, and there are side-effects."*

*"As with any medication, it will work for some and not for others," said a heterosexual Hispanic woman from New York. "It's very individual."*

Among those patients who were uncertain about how effective combination therapy would be for them personally, a few said they believe "people are dying on medications" and indicated that they know of people for whom the therapy did not work. A few also said that they believed the "first combination always fails." One individual specifically referred to news reports about an "increasing failure rate." Gay men were somewhat more likely than others to say they are skeptical about the long-term effectiveness of the therapy.

*"People are still dying from AIDS while they are taking these medications," said a gay, African-American man from Los Angeles. "The rate of mortality has slowed down, but the drugs are not necessarily saving lives. It makes me stay where I'm at in not taking meds."*

*"There is a lot of fear about the medications because of the uncertainty. For a while*

*people are doing well, then they start to fail in the long run," said a gay white man from San Francisco is not on therapy.*

Among patients who were taking combination therapy, one in six said they had doubts about whether the medications would prove to be effective for them. This concern had been an obstacle to initiating therapy, these patients said.

Patient beliefs about whether the therapy would be effective for them may reflect in part the reservations of their caregivers. Nine out of 10 physicians and nurse practitioners who were interviewed said they personally were concerned about how well combination therapies work, the long-term efficacy of the drugs and the clinical impact of the drugs on new therapies that might be developed in the future. More than six in 10 of the case managers interviewed expressed similar concerns.

Hotline personnel said they receive calls from a significant number of people who believe protease inhibitors are a cure for HIV and that the drugs work for everyone. To counter this belief, both hotline operators and case managers say they emphasize with patients that individuals respond differently to the drugs. For instance, one hotline operator said he informs patients that "35 percent of people (with HIV) can't even take (the drugs), or if they do, they lose efficacy."

### **The demands of the treatment regimen**

More than half of those patients not taking combination therapy said they were concerned about the impact of the treatment regimen on their lives. These patients indicated that they believed the regimen would force them to alter their schedules or lifestyles. For instance, they noted that they would have to modify their eating habits and adhere to a schedule of set times. Patients often made mention of the fact that there were "too many pills" to take. A few even remarked on the "size of the pills." About one in 10 of these patients said they had not started combination therapy because they know they cannot or will not adhere or are not ready to "commit" to the regimen.

*"It's the side-effects, the neuropathy," said a gay white man from Seattle. "And the inconvenience, the pills all at different times of the day or night, take with food, without food, keep it refrigerated. I could do it, but I'd rather not until I have to."*

Among those patients who were already on therapy, half also indicated that concern about having to adhere to a treatment regimen had been a barrier to treatment. Caregivers also give heavy weight to a patient's ability to adhere to the treatment in deciding whether to recommend the therapy. Eight out of 10 physicians and nurse practitioners said a patient's ability to comply with the regimen is a significant factor in their decision on whether to prescribe combination therapy. Some physicians say mental health disorders, substance abuse problems and addictions are strongly considered when prescribing combination therapy, as these problems could impact a patient's ability to comply with treatment.

Seven out of 10 physicians said they describe the regimen to patients as a drawback to combination therapy. Case managers also were likely to describe the regimen as a negative aspect of combination therapy, including the many pills that need to be taken and the need to follow a complicated schedule. Three in 10 case managers said they told clients that a drawback to combination therapy is the need to "commit" to the regimen or that patients "can't stop taking the drugs" once they begin.

Hotline personnel also frequently used the word "commitment" to describe the decision to start therapy. They reported that some HIV-positive patients did not want to begin a combination therapy drug program because they don't believe they can maintain the regimen and are afraid that it cannot be stopped.

*"Once you start, you will always have to take the pills," said a heterosexual African-American woman from Miami. "They will make me feel sick. I see what they do to some people and this scares me. I hope that if I ever have to take them, they will make me feel better, not worse. I want to live, so if I have to take them, I will."*

### **General attitudes toward medications**

Nearly half of those who are not on combination therapy are influenced in their decisions by attitudes they hold about medications in general, according to reports from patients and case managers. Most frequently, patients said they don't want to take medications that they will need for the rest of their lives. A few individuals also believed that drugs are most beneficial to the sickest patients. One former substance abuser expressed a fear that combination therapy drugs would become addictive. A few patients are convinced that when drugs work, it is because of a belief they will work.

*"If the drugs are 'working' for some people, I think it is because of their mind, body and soul. People believe it is working and that positive attitude is part of why the load goes down, T-cells go up and they feel better. But I wouldn't burst the bubble of people using them. Their belief is part of why it works," said a heterosexual white woman from Miami.*

More than a third of patients already on combination therapy said their attitudes about medications in general had stood in the way of treatment. Similarly, roughly a third of physicians and nurse practitioners said patients' misgivings about drugs in general had been a barrier to initiation of therapy.

### **A feeling that the drugs are too "experimental"**

Nearly half of those not on combination therapy said they have reservations about what they perceive to be the experimental nature of the drugs used to treat HIV, most often citing a lack of research data or saying that the drugs are "not well-researched." People also said they believed the drugs "haven't been around long enough," were approved by the FDA too quickly or have been given to the HIV community too early. Generally, those who identify themselves as heterosexual, especially those of Hispanic background, are much

more likely than gay men to view combination therapy as "too experimental." A few people specifically stated that they "don't want to be guinea pigs" or don't want to take "experimental drugs."

*"There is so little known about the drugs and what the long-term effects will be regarding one's health, drug resistance, side-effects," said one heterosexual Hispanic woman from Seattle. "After AZT's fiasco, I won't be a guinea pig."*

*"(When drug therapy was recommended), I thought, 'I'm going to be a guinea pig.' There's not enough information and a lot of bad press on AZT. The drugs are toxic. I don't want to be experimented on," said one heterosexual African-American woman from Miami.*

*"So little is known about the drugs," commented another patient, a gay white man from San Francisco. "It's all experimental, and they are testing on people as they go along."*

Four in 10 physicians said perceptions among patients that the drugs are still experimental had been an obstacle to treatment. However, less than one in five of the case managers cited this as a barrier. The "experimental" nature of the drugs was only mentioned by one in 10 of patients already on combination therapy.

#### **The ability to manage the disease without medication and beliefs about HIV**

Eight in 10 patients not on combination therapy said they believed changes in lifestyle or attitude were the most effective form of treatment for HIV. A good diet was cited by more than half of these patients as the most effective way to treat the disease. Also named as effective treatments were good rest, exercise, a "positive lifestyle," spiritual growth, a positive attitude, reduced stress, vitamins, control over one's life and reduced consumption of alcohol and recreational drugs.

Four in 10 of those not on combination therapy hold beliefs about HIV and their abilities to manage the disease that impact their decision to start therapy. Some patients said they believe drugs may not be necessary to treat HIV, with some patients believing that drugs are only needed five to 10 years after infection. Fully one quarter of those interviewed also expressed the view that HIV drugs may cause more damage to their bodies than the virus itself, and one individual said she believes HIV may not be the only cause of AIDS. There are also some patients who express a positive conviction that HIV is "not a death sentence" or "won't be the cause of my death," a belief that minimizes their perceived need for medication.

*"I have a strong distrust about the disease and the medications themselves, as well as those entities pushing these costly and toxic drugs on HIV-positive people," said one bisexual, African-American man from Washington, D.C.*

*"Being HIV-positive doesn't prey on my mind. If you take care of yourself, you can live a*



*long life. It's like having diabetes. You have to change your way of living," said a gay white man from New York.*

### **Fear of resistance and concern about drug failure**

About four in 10 of the individuals not on combination therapy said they feared they would become resistant to the drugs, which would no longer work for them. One in five expressed a concern that once they start combination therapy, they would not be able to stop because they would be subject to resistance. A few patients also said they believe that resistance always occurs with combination therapy drugs or that they would be worse off if they stopped taking the drugs because the disease would progress more rapidly.

Among those not on combination therapy, slightly more than half said they were concerned the drugs would fail at some point in the future. A quarter of these patients said they don't know whether the drugs might fail, often commenting that it "depends on the individual." Notably, gay white men are far more likely to indicate a concern about future drug failure. The majority of Hispanic patients interviewed said they don't know whether the drugs might fail.

About three in 10 patients who were on combination therapy said they hesitated about starting the drugs because of concerns about building a resistance to the current therapies, as well as future treatments that might be developed. While the majority of these patients said they were not concerned that the drugs might fail, the gay white men among them were concerned, with more than half expressing this fear.

*"I waited three years due to a lack of need, but concern about resistance also came into play," said a gay white man from San Francisco who is now on therapy. "It's better to take as few drugs as possible for as long as possible to avoid resistance and leave my options open."*

Almost two-thirds of physicians and nurse practitioners also said they believed fear of resistance played a role in patients' reluctance to initiate therapy. However, fewer than one in 10 case managers cited fear of resistance as an obstacle to treatment, although one in four managers said they do tell clients that taking a combination drug therapy could affect their ability to take antiretroviral drugs in the future.

### **Use of alternative or holistic remedies**

Four in ten patients not on therapy said they believe holistic or alternative approaches are the most effective ways to treat HIV. Acupuncture and herbal remedies were among the most frequently mentioned approaches to therapy among those patients not on treatment. Other alternative or holistic treatments believed to be effective are creative visualization, meditation, homeopathy, massage, biofeedback, acidophilus, blue-green algae, flower essences and marijuana. A few of these patients attributed increases in T-cells or viral load reductions to these alternative approaches.

*"I want to control what happens in my body," said a gay Hispanic woman from Miami. "Acupuncture, Chinese herbs and biofeedback is working for me. My viral load is undetectable and my T-cells are 800."*

Most patients not taking combination therapy said they would not object to the treatment "when it becomes necessary." Still, only one third said that some form of drug treatment, including combination drug therapy, is one of the most effective methods of treating HIV. Others said effective treatment of HIV includes using medications "as needed" or using a mix of drug therapy and holistic treatments. Only a few said they believed in exclusive use of holistic or alternative remedies and would reject drug therapies out of hand.

*"It gets to be tricky. If effective is defined as reducing (viral) load and feeling better, then protease inhibitors are effective," said a gay, African-American man from Washington, D.C. who is not on combination therapy. "But drugs are only short-term remedies. A holistic approach, the mental, physical and spiritual, is the most effective in the long run."*

Among those patients currently taking the drugs, fewer than one in 10 said use of holistic or alternative remedies had been a factor in their decision to start therapy. About a third of physicians, and roughly one in five case managers, also said they believed patients' reliance on alternative or holistic remedies was an obstacle to treatment with combination therapy.

*"The alternative medicine craze is hurting people and exploiting people's hopes," said one physician from Dallas. "I'm troubled by things I'm hearing from some patients that the AIDS virus doesn't exist or that the medicines are a hoax. Patients hear that information coming from certain groups in the San Francisco Bay Area, and it carries a particular air of credibility because of where it's coming from."*

### **Recommendation of medical providers**

A significant number of patients not on combination therapy, or about three-quarters, reported that their doctors had recommended that they begin treatment. On the other hand, one in four said their doctors had not recommended that they initiate therapy yet. Two out of 10 of these patients specifically said they have been influenced in their decisions not to start combination therapy as a result of interactions with their caregivers.

Often these patients say their doctors have withheld a recommendation to start therapy based on the patients' T-cell counts. Some patients also said they believe their doctors have not yet recommended therapy because the physicians had an optimistic view of the patients' health.

More than four in 10 of these patients said that when therapy was recommended, their initial reaction was that it would not be a good move; one in four said they had questions and reservations about the therapy. One in five patients said when they first heard about

combination therapy, they thought it would be a "good thing," but half of them added, "not yet."

### **A desire to wait for better treatments**

About one in five of those not on combination therapy indicated that they are "waiting for the future" in the hope that better treatments will be developed. Some said they believe that the next generation of drugs will be more effective and easier to take, and others said they are "leaving their options open" for the future. About one in 10 patients not on therapy also said they are trying to remain free of drugs for the time when they will really need them.

*"I want to do what it takes to stay healthy," said a gay white man from San Diego. "The advances have been great, and I feel that they will develop better drugs in the future. I've heard there are other drugs that are better, and I want those. I'll wait until better drugs come on the market."*

About a third of physicians and nurse practitioners said they believe that patients have not opted for combination drug therapy because they are waiting for improved treatments that might become available. Hotline personnel also said they believe there is a group of people who are waiting for drugs that are more easily tolerated, have fewer long-term side-effects and are cheaper or less complicated to take. These patients tend to view themselves as healthy enough to wait for better options.

### **Cost issues**

Patients not on combination therapy rarely cited cost as a barrier to treatment. In fact, only one patient from a state where ADAP has reportedly been closed to patients indicated that she wanted to start combination therapy but was unable to find a program that would pay for it.

*"I've found the combination I want, but ADAP won't pay," said one heterosexual African-American woman from Miami. "I just heard about the pharmaceutical companies' compassionate use program, so I'll ask my doctor to write to them when he gets back from vacation."*

Two others who were interviewed said that if they decided to start, they did not know who would pay or were concerned that they earned too much to qualify for assistance but not enough to afford the drugs. Nine out of ten patients not on therapy said they knew where to obtain the drugs if, and when, they made the decision to start therapy.

*"Medicaid and Medicare are for the poor, but not for the "average Joe" like myself," said one patient, a bisexual African-American man from Washington, D.C. "I don't make enough to pay for them, but I make too much to qualify for government assistance."*

While two in 10 patients on therapy said coverage for cost of the drugs was a factor in deciding to start therapy, they were expressing concern that they might get cut off from programs once they had begun therapy.

While patients reported relatively little concern about issues of cost, their caregivers frequently perceived the cost of treatment to be an obstacle. Nearly half of the case managers and more than two-thirds of physicians and nurse practitioners cited cost as a barrier to initiation of therapy.

Hotline operators and supervisors also reported frequently receiving questions about cost of treatment and payment mechanisms. They reported that callers were unaware of programs for which they might qualify and said some patients believed they did not qualify for a drug assistance program because they earned too much, were too poor or were undocumented. Hotline operators also said they spoke to people who had drug prescriptions in hand but had not had them filled because they had changed jobs and were waiting for their insurance plans to activate.

### **Privacy considerations**

Concerns about privacy were mentioned by one in 10 patients who were not on combination therapy as a factor influencing their decisions not to initiate therapy. These patients worried that their HIV status would be revealed or that they would have to answer questions from family, co-workers and others if they began taking medications.

*"Three times a day to take pills is a hassle. To follow the regimen isn't easy to do publicly. People look at you if you take pills in public," said a heterosexual African-American man from Miami.*

*"My 9-year-old son would see me taking all these medications, and I'm not ready yet to tell him I'm sick," said a heterosexual Hispanic woman from New York.*

Privacy issues were rarely mentioned as a barrier to therapy by physicians and nurse practitioners or case managers. However, hotline personnel reported that callers were often reluctant to initiate drug therapy because they were afraid to file a claim with a private insurance company. These callers were concerned that employers would learn of their condition once they started ordering drugs. They feared discrimination, loss of their jobs, loss of benefits or inability to receive new benefits. The hotline personnel also reported concern among some heterosexual and bisexual men that their families would learn their HIV status and reject them based on the assumption that "only gay men get HIV."

### **C. Other Factors That Influence Decision-making**

It is clear from the study that patients are hungry for information about new drugs and

must make decisions about treatment in the face of sometimes conflicting reports about drug effectiveness, side-effects and other aspects of treatment. Some rely on their caregivers for guidance, while others are distrustful of the medical profession and look for direction from other sources, such as members of a support group or publications geared to HIV-positive individuals. Ultimately, however, it is the patient who decides whether, and when, to start treatment.

*"It's hard to know what is reliable and unreliable," said one bisexual African-American man from New York. "We (HIV-positive people) share information because the doctors don't tell us the same things. You use your own judgment."*

*"My doctor and I have looked at a few options, but since I don't have an interest (in drug therapy), we don't spend a lot of time on it. He sees it as being my decision," said another patient, a gay white man from Seattle.*

### **The role of caregivers, case managers and others**

Most of the patients who are on combination therapy said it was their physicians who first suggested this form of treatment. In one of the strongest differences noted between men and women, men were twice as likely as women to be influenced by information received from their physicians in deciding on treatment. Overall, the men interviewed said the most reliable information about treatment came from their doctors, followed by peers who are HIV-positive. The study also found that men were more likely than women to rely on an extended HIV information and resource network, including pharmacists, Internet sites and publications from groups such as Project Inform, Positively Aware, Poz, Beta News and the federal Centers for Disease Control and Prevention.

Most of the men and women on therapy said their doctors usually spend enough time during office visits in discussing their condition. Yet several patients noted that they were not satisfied with the time they spent with their physicians and actively sought out other physicians who were more attentive. In the case of one woman, an African-American patient who is on public assistance, the decision to initiate therapy was directly related to finding a physician at a public health facility "who spent time with me, getting to know me, rather than seeing different doctors every time I went and who spent five minutes asking the same questions as the last doctor and two minutes about me."

Among those patients not on combination therapy, eight in 10 said their health care providers spent enough time with them and answered their questions. Those men and women who said they believed their doctors were "too busy" or "didn't spend enough time with them" were frequently patients at public health clinics. A few patients also said they actively sought out doctors who they felt met their needs, most often looking for those physicians who were specialists in HIV treatment.

*"At the clinic in the hospital, there was always a different (doctor)," said one heterosexual African-American man from Washington, D.C. "They never asked about my HIV and it was on my records. They only treated me for what I was there for. I asked to*

*be referred to a specialist because I wanted to know more."*

*"I'm not unhappy with the doctor but with the rushed environment," said a heterosexual, African-American woman from Miami. "But I'm pretty dogmatic. I insist on answers, and I write down my questions."*

About four in 10 of those not currently on therapy said their doctors described the benefits of treatment as decreased viral load and increased T-cell counts. Less frequently, patients said they had been told by their doctors that combination drug therapy would make them "feel better," help them live longer, have a positive effect on their emotional well-being, combat the virus, rebuild their immune systems or result in fewer opportunistic infections.

Nearly three in 10 patients not on therapy said their doctors had not told them anything specific about the benefits of combination drug therapy. Among these patients, however, a majority indicated that they and their doctors had agreed that combination drug therapy was not yet necessary. A few said they had told their physicians they were opposed to drug therapy and would not discuss it with them.

While half of those on therapy said they had no trouble understanding the "jargon" or information they received about HIV and drug treatments, four in 10 indicated that they don't always understand what the doctors are saying to them or what they are reading. Often, however, patients said they ask for clarification in "laymen's language" when they don't understand what physicians tell them. A number of patients commented that they had become confused with the variety of acronyms and different names for drugs.

Among those patients who are taking combination therapy, six in 10 said their doctors described the benefits as decreased viral load and increased T-cell counts. About a third said their doctors told them that combination therapy would help them live longer or make them "feel better." The majority of patients on therapy, or six in 10, said they had no trouble understanding the "jargon" they encounter in visits with their doctors or in information received from other sources. Those patients on therapy are somewhat less likely than those not on therapy to indicate that they don't always understand the information they are being given. Nevertheless, three in 10 said they don't always understand the information and while many ask for clarification, a few said they simply "trust their doctors."

Physicians said they believed they played the most influential role in patients' decisions to initiate combination drug therapies. Only one physician interviewed said that case managers had an influence on patients' decisions, whereas case managers were far more likely to view themselves as being involved in patient decision-making. Physicians also indicated that nurse practitioners, patients' partners and spouses, as well as friends and HIV-positive peers, had a strong influence in patients' decisions to start therapy. Physicians indicated that while they might recommend treatment, they did not pressure patients and ultimately left the decision to them.

*"I don't believe in persuading patients (to go on combination therapy)," said one physician from Dallas. "I give them information to read, news articles, AIDS-care pamphlets. If you pressure them, it won't work. It's up to them to decide and usually they will come around."*

*"The decision (to begin combination therapy) lies primarily with the patient," said another physician from Seattle. "But I have dissuaded some patients from starting if it isn't their decision, but that of some other influence."*

When discussing the benefits of combination therapy with their patients, physicians most frequently said they emphasize the treatment will:

- reduce the chances for opportunistic infections;
- decrease viral load counts;
- strengthen or protect the immune system;
- increase patients' energy levels;
- increase T-cell counts;
- help patients feel better emotionally;
- help patients live longer;
- help patients stay healthy;
- help patients gain weight; and
- prevent hospitalization.

In discussing drawbacks of combination therapy, physicians most often mention:

- the side-effects;
- the demands of the regimen;
- the cost of medication;
- drug toxicities; and
- a lack of long-term knowledge about drug effectiveness.

Physicians were apt to believe that their HIV-positive patients had a relatively good understanding of the meaning of their T-cell counts and viral loads; the differences between monotherapy and combination therapies; the general purposes and effects of protease inhibitors; and the importance of strict compliance with drug regimens. On the other hand, physicians said they believed patients had a relatively poor understanding of the general purpose of nucleoside analogs; their personal level of tolerance for various antiretroviral drugs; and the relevance of p24 antigens.

Case managers generally agreed with physicians on those areas in which patients had a good or poor understanding. The one difference was that case managers were more apt to believe that patients had a poor understanding of the general purpose and effects of protease inhibitors.

Case managers indicated that doctors, in addition to the patients themselves, play the

most important role in the decision to initiate drug therapy. Case managers also believe they have some influence on the decision and that clients' friends who are HIV-positive have a role in decision-making. Only one of the case managers interviewed said that he did not discuss the benefits or drawbacks of combination therapy with his clients, deferring instead to their physicians. Virtually all case managers said they provide their clients with printed information about combination therapy that is prepared by pharmaceutical companies and AIDS service organizations.

"Clients are looking for accurate, updated, consistent, statistical information on new and improved drugs. It gives them more to grasp onto, a more positive outlook. It encourages them because it means they understand what the positive effects will be and the proper time to go on the drugs," said one case manager from New York.

When discussing HIV treatments with clients who have not started drug therapy, case managers said they describe a variety of benefits but most frequently report telling clients that combination therapy may:

- decrease viral load and increase T-cell counts;
- result in increased energy levels;
- protect the immune system;
- help clients live longer;
- help clients stay healthy; and
- not necessarily cause side-effects.

When discussing drawbacks of combination therapy with patients, case managers are most likely to emphasize:

- side-effects;
- the regimen
- the need to commit to therapy once it is begun;
- the possibility of drug resistance; and
- the cost of medication.

One case manager in Miami said that the "the more educated (clients are) about combination drug therapies, the more power they have to choose what is best for them."

*"I give both sides of the coin (about combination therapy), and it's the client's choice," said another case manager from New York. "They take a little bit from everybody and then make up their own minds. I don't know what will happen in the future, and I couldn't live with myself if there were bad effects (from the drugs)."*

Another case manager expressed similar misgivings about offering a recommendation to clients to initiate therapy.



*"I tend to direct my clients to their doctors for their medical questions," said the case manager from San Francisco. "I feel that I should play as neutral a role as possible. If we had more effective treatments, I would feel more comfortable encouraging them to start."*

Hotline personnel were sharply critical of the care being provided to HIV-positive individuals by physicians and other caregivers. Often, they say, it becomes their job to "debrief" patients after a visit with physicians because physicians fail to give patients the information they need. The hotline personnel said they believed patients were not given adequate explanations of the meaning of laboratory tests and that few doctors spent enough time telling patients what to anticipate with combination therapy, including possible side-effects. Many times they reported receiving calls from patients seeking to confirm a doctor's recommendation to start therapy. In fact, hotline supervisors said that some doctors give out hotline numbers to patients to get explanations about drug therapies or answer patient questions.

According to supervisors, patients are "nervous and feel pressured to get on the treatments." Hotline supervisors generally agreed that doctors do not appreciate the enormity of the decision for patients in initiating therapy. They said some doctors discouraged patients from starting the treatment by failing to explain how a triple combination drug regimen could fit the lifestyle or schedule of a patient. As a result, supervisors and operators say, some patients don't believe the regimen will work for them and neglect to fill their prescriptions.

Overall, there are strong perceptions among hotline personnel that some HIV-positive people are not receiving adequate medical care because:

- Many HIV-positive individuals are receiving treatment from their general practitioners who do not have expertise in treating HIV. One operator who has been working on an AIDS hotline for more than a decade said that even HIV experts have made it clear that general practitioners and family practice physicians should not prescribe protease inhibitors because the protocol is too complex.
- Patients who only speak Spanish are frequently being treated by physicians who do not speak the language. Because Hispanics have a cultural tendency to implicitly trust physicians, these patients do not question what information they can glean from their physicians.
- The public health system is not equipped to deal with the ongoing needs of HIV-positive individuals and is not adequately serving some patients, particularly African-American and Latino patients. Hotline personnel also said they sensed a strong distrust of public health workers among African-American patients. They said patients often were intimidated by the system and were discouraged from receiving care by long waits for a brief visit with a physician, sometimes as little as two minutes. One operator said that there is a sense that doctors at public health clinics put restrictions on who can receive combination therapy. The hotline

workers said they strongly believed that once patients entered the system, they were likely to be prescribed medications.

Hotline staff said they emphasize to callers the need for the patient and the doctor "to have open lines of communication," "to understand each other" and for patients to feel secure enough to talk about everything. Operators and supervisors said they frequently counseled callers to find a new doctor to treat their HIV if this atmosphere of positive communication did not exist or if they felt other important health issues were at stake.

### **Information sources**

Although doctors are most often cited as reliable sources of information about HIV therapy by those patients who are not on treatment, they are named as reliable sources by less than half of these patients. Those not on combination therapy cited other HIV-positive individuals as reliable sources of information nearly as often as they mention doctors. While a substantial majority of African-Americans do view doctors as reliable information sources, gay men were more likely to point to other HIV-positive individuals as reliable information sources.

*"The doctors at my HMO don't know as much about HIV as I do, so I often don't feel a need to talk with them," said a bisexual Hispanic woman from Los Angeles.*

One in five patients not on therapy said they consider support groups as a credible source of information about HIV and treatments. Other frequently mentioned sources of reliable information on HIV therapy include publications such as Beta, Poz and Positively Aware; HIV seminars, fairs and workshops; and medical journals and reports on treatment studies.

Among those patients not on combination therapy, most notably among the gay men interviewed, the mainstream media is most often cited as an unreliable source of information about HIV therapies.

*"There is hype in the media (about the benefits of combination therapy), which only explains one side to the issue. They are giving a skewed side to the drug issue," said one heterosexual African-American female patient from Seattle.*

Although drug companies are named as unreliable sources of information as frequently as the mainstream media, both are mentioned by fewer than one in five of those patients interviewed. Other sources considered unreliable by patients not on therapy include other HIV-positive people, doctors, the general public, herbal remedy companies, Project Inform, nurse practitioners and the FDA. One in ten patients not on therapy said they could not think of any unreliable sources, perceiving all information as useful, and one in ten said they did not know who to trust.

In general, hotline personnel said patients appear to rely on a variety of different sources

for information and referral. Those organizations repeatedly cited as credible sources were Project Inform, Beta News, Poz and Bay Windows.

As for information provided by pharmaceutical companies, hotline staff said they believe it needs to be considered with "caution." Yet hotline staff said pharmaceutical ads, particularly those appearing at bus stops, shelters, on radio and TV and in magazines are a credible information source on drug therapies. One operator also noted that a company-sponsored "food fair" in South Florida had been an effective way to bring people together to learn about protease inhibitors.

Most hotline supervisors said their organizations develop their own materials for in-house use and to send to callers. Some operators and supervisors said patients remained confused by the multiple general and brand drug names and had a hard time remembering which drugs they were taking or which drugs had been recommended to them. The hotline personnel said those materials that worked best were simple fact sheets on viral loads and protease inhibitors in general.

#### **D. Issues and Concerns of Women**

HIV-positive women generally express concern about the lack of information on the effects of combination therapy in women. More than one-third of women interviewed said they believe there is a lack of research about HIV drug therapies involving women and indicated that this research gap had contributed to their decision not to initiate treatment. Women are also somewhat more apt than men to express concern about long-term side-effects of the medications, particularly citing apprehension, or the lack of research, about the drugs and child-bearing.

*"I heard about protease inhibitors very early, but there's no research on women's issues," said a gay Hispanic woman from Miami.*

*"There is confusion about my viral load. It's been fluctuating. The question is, should I go on therapy or not? I chose not to due to the lack of information on how women react to the medications. I would rather take alternative, natural methods," said a heterosexual white woman from Vancouver, Washington.*

While men tend to rely on specialized print publications for information about HIV treatment, women were less likely to look to the print media for information. Rather, women said face-to-face communications with doctors, support group members and other HIV-positive individuals, were their most reliable sources of information. Importantly, women identify support groups as reliable sources of information as often as they mentioned their doctors but note that finding support groups for women is difficult. Women also were twice as likely as men to say they began combination therapy because they trusted the information provided by their physicians.

Women also reported getting different information from physicians than men. Fewer than two in 10 of those women not on therapy said their doctors described a decrease a viral load as one of the benefits of combination therapy. By contrast, two-thirds of gay men not on therapy said their doctors described this as a benefit of treatment. Women not on therapy most often said their doctors told them the benefits of therapy would be an increase in T cells and a sense of "feeling better."

Some hotline operators reported receiving more calls from women than from men, sometimes from partners or spouses of HIV-positive men. These operators agreed that while there was a lot of material generally available on the pros and cons of protease inhibitors, there was little research information available on combination therapies as they relate to women. Hotline personnel did say that they believed women were better at researching and getting answers about HIV treatment, often sought emotional support "more honestly" and sooner than men did, but had fewer support groups to rely upon than men.

#### **IV. Study Implications**

HIV-positive individuals face an enormously complex set of issues in deciding whether to elect, or reject, combination therapy. The study suggests that patients are taking a thoughtful approach to the issue, relying on advice from their physicians, the experience of other HIV-positive individuals and a variety of other information sources in making what is an important personal choice. Because of the nature of HIV disease, which may progress over a period of many years, patients have the benefit of time in making this choice. In the process, it is critical that they have access to expert clinicians and other reliable resources in the HIV community to help them make an informed decision.

Clinicians need a forum in which they can share information with other clinicians and discuss possible approaches to treatment. Many of the physicians and patients interviewed are approaching antiretroviral therapy with caution. Some clinicians and patients are concerned that the experience with new drugs is so limited that their effects are not known. All HIV clinicians and patients need access to expert clinicians so that they can make maximally informed decisions. Increasing the ways that clinicians can share their experiences in using antiretroviral medications can only help them and others use them in a more informed way. Telephone hot- and warm-lines, telephone conference calls, and conferences are needed to insure that clinicians have access to and are giving the best advice to their patients.

Clinicians and patients need time to discuss whether or not to start antiretrovirals. Many clinicians and patients reported that they did not have time to engage in complete discussions about the medications and how to use them. Given the importance of their use, strategies need to be devised to insure that patients with HIV have sufficient access to information to get their questions answered and concerns addressed.

The information needs of people extend beyond how the drugs work to how to cope with

the drug regimens and their side effects. Individuals have a lot of information on how the drugs work to reduce the impact of HIV infection. Individuals have many concerns about the regimens and side effects and whether or not they will be able to manage taking the drugs and dealing with those side effects. Clinicians and hotline operators need to share clinical experiences in this arena, and patients need good information about how others have coped with these demanding regimens.

Other resources used by patients to gain information must be as accurate, comprehensive, and current as possible. Hotline operators need to have access to continuing education so that they can provide callers with the best information available on the drugs. Regional hotlines, which are now operated independently, also should develop outlets for sharing information and consider developing cooperative working relationships. In addition, groups that maintain HIV web sites also have a responsibility to keep their sites well-maintained and current, indicating when an entry was most recently updated.

Women need special services to assist them in deciding about antiretroviral therapy. Women were often reluctant to initiate combination therapy because they believed there was too little research on the impact of the drugs on women and childbearing. Clearly, there is a need for more scientific research in this arena. The study also suggests that women rely heavily on face-to-face communications to obtain information about combination therapy, yet they found it difficult to locate support groups. This is a gap that needs to be addressed in the HIV community. In addition, women are not finding a voice in existing publications about HIV and could benefit from a newsletter devoted strictly to women's issues and the impact of antiretroviral therapy on women. The study also suggests that Spanish-speaking patients are not being well-served, particularly by the public health system. These patients could benefit from policies aimed at increasing the availability of Spanish-speaking clinicians and interpreters in the HIV community.

Patients and clinicians need access to the best information possible on alternative and holistic remedies to treat HIV. The medical community could benefit from more scientific research on the impact of these remedies on HIV-positive patients. Clinicians also should be aware of these approaches and the existing medical literature on them and be respectful of these alternatives.

Pharmaceuticals need to be encouraged to continue drug development so that antiretrovirals can become even more effective and easier to take with fewer side effects.

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**This research monograph was funded by a grant from Glaxo-Wellcome.**