Talking to other health professionals, I am often struck by the way in which poor adherence is accepted as something that is “natural,” an unfortunate fact of life that no one likes but that you just have to accept. I believe, however, that adherence is achievable: it takes a large amount of work and there are no short cuts but there are many things that health providers can do to assist adherence.

I am a primary care physician practicing in Sydney, Australia. My practice is composed almost exclusively of well-educated, seropositive, gay men with effective social support systems. Of the approximately 500 seropositive patients I treat, about half of them were diagnosed prior to 1990 and one quarter diagnosed after 1995. Almost all were diagnosed early in the course of illness; few presented with an opportunistic illness. This article describes the approach I have taken to facilitate adherence in this particular population at three critical points in the process: before initiating treatment; immediately after initiating treatment; and at every point during therapy.

Building a Foundation for Adherence

What I do not do at any time is simply give out information sheets about treatments. Information giving is necessary but, in itself, it is not sufficient to ensure the behavior changes necessary for high levels of adherence. It is not enough simply to tell individuals what they should do.

Before a patient begins therapy, I spend a minimum of two hours with that individ-

ual making sure that he or she understands three things: why he or she needs to begin treatment, that he or she can do it, and how he or she can do it. This task—as well as others I discuss here—need not be the exclusive domain of doctors and could just as easily be done by other health staff: nurse practitioners, physician assistants, pharmacists, or counselors. (Other tasks could also be accomplished by community groups and peer support.) But someone must make this commitment.

In my practice, I am the one who conducts this orientation. First, I go through my beliefs about treatments. I am very clear that I believe the treatments work and that taking them makes a difference. I don't think that any health provider can expect patients to care about taking drugs properly if the health provider is not able to impart the belief that taking the drugs is important. When I have asked patients why they will begin therapy with me when they would not with another physician, I hear the same response again and again: “When Dr. X said it was up to me—that I could take them if I wanted—I never got the idea it was important, I never felt like it was really going to make a difference.”

I spend time ensuring that each individual understands why he or she needs to take the drugs with a high degree of adherence, offering what I call HIV 101 and the rules of HIV therapy. I begin by explaining HIV, how it reproduces, what mutations are, what resistance is, and what viral load is and why it is important. I begin with the knowledge an individual patient brings, build on it, and individualize my approach. At the end of HIV 101, patients have to understand how HIV reproduces and why resistance is a problem with this virus. If patients don’t understand these things, I believe it is unlikely they will adhere.
In Geneva this past summer, it was not unusual to hear criticism of the World AIDS Conference’s focus on adherence. Several sessions considered a broad range of topics related to the psychosocial issues faced by people trying to sustain difficult antiviral treatment regimens. But many believed that adherence was taking precedence over a host of other HIV-related psychosocial concerns, including those faced by people in developing countries, where treatment remains too inaccessible for adherence to even begin to be an issue.

It is clear nevertheless that adherence remains a central concern—not only in the world of HIV disease, but also throughout medicine. To the extent that medications are accessible, the challenges of complex regimens have significant effects on the quality of life of people with HIV disease (not to mention the ability to sustain treatment and therefore health).

The Role of Providers

Much of the adherence literature focuses on the role of clients themselves in maintaining medication adherence. But, it is clear that providers, starting with medical staff and including mental health and social service professionals, can play an important part in ensuring that clients have the knowledge and skills to apply to the challenge of taking their medications regularly.

This issue of FOCUS deals with this aspect of care: what can providers do to prepare and support their clients taking medications? Cassy Workman, an Australian physician who presented on this topic at the World AIDS conference, is firm about the obligation of medical providers to facilitate an ongoing process of education and problem-solving. Her goal is to individualize therapy so her patients have the best chance of adhering to regimens. Tim Teeter, who works with disadvantaged clients, sets similar goals for his efforts with homeless people with HIV.

The issue of adherence is important for another reason. Because it so clearly straddles medicine and mental health, it may offer lessons to providers in both areas about the complexity of each field. In particular, by applying some of Workman’s principles, medical providers may better understand ways of incorporating quality-of-life issues and mental health into medical practice.

From this, I proceed to my three rules of HIV therapy:

• Never give the virus an even break. (Keep drug levels up and HIV reproduction down)
• Give HIV an inch and it will take a combo. (Let it reproduce and it will mutate, let it mutate and it will develop resistance)
• Keep options, don’t throw them away. (Let resistance develop and you’ve wasted an option).

The Capacity to Adhere

The second task is to help individuals understand that they can attain a high degree of adherence. Different drug combinations require different things from different patients. The only way to respond to these requirements and achieve high rates of adherence is to individualize regimens for each patient, which requires truly understanding the patient.

To individualize a regimen, I need to know the earliest time and the latest time the patient gets up and goes to bed, whether he or she eats as soon as getting up, and what he or she normally eats. Does all of this change on weekends? Does the individual live with other people? Has the individual disclosed his or her serostatus to those people? Does the individual feel the need to hide medications? Where does the individual keep treatments at his or her partner’s house? Does the individual come home from work before going out, does he or she go out straight from work? Does he or she regularly travel for work? Does the individual drink alcohol, and how much and how often? Does he or she smoke or use recreational drugs? How often does the individual wake up somewhere he or she did not plan to be?

I never assume anything and try to individualize everything. If I do not fit a combination to my patients in this way, I am asking them not only to take treatments and not forget to take them, but also to change their lives around. That is a lot to ask.

An example clarifies this process. A new patient, I’ll call him Sam, came to see me: he said, “I just can’t take these treatments the right way.” Sam was an occasional...
injection drug user with what could best be described as a chaotic lifestyle. He had seen a hospital-based specialist prior to coming to me. This doctor had prescribed didanosine (ddI), stavudine (d4T), and indinavir, one of the most difficult and demanding regimens for patients to take. Luckily, Sam took the combination only for a day and when he just could not adhere, stopped before a resistant strain could emerge. When I talked to Sam, I discovered that no matter how chaotic his life became, he always ate twice a day and he always ate at home. Switching to nelfinavir, ritonavir, d4T, and lamivudine (3TC), twice a day at the times when he eats, Sam has not missed a dose in nine months.

Medication side effects have an impact on adherence, and almost all antiviral drugs we currently use have significant side effects. Anticipating these side effects and how to handle them gives patients the belief and the capacity to respond to them without missing doses. If diarrhea is a possible side effect of a drug I prescribe, I outline a treatment plan in advance in case it emerges: I give the patient prescriptions for the drugs he or she might need to overcome this side effect—I don’t leave it to him or her to have to come back to my office to treat the diarrhea. I do everything I can to help patients feel that they are in control. That includes making them aware that there are other regimens we can choose if the side effects are severe or if there is some other reason an individual cannot manage this combination.

Anticipating Obstacles

Some physicians prescribe a couple of standard combinations, attempting to get all of their patients to fit into these combinations. I don’t believe that this works. Currently, we are using 18 different combinations in my practice because what is right for one individual is not right for the next. When a physician individualizes therapy, it shows patients that they can incorporate their medications into their lives rather than having their lives ruled by their medications.

As I point out to patients, there are dozens of things that they do everyday, often many times every day. They get up, they get to work or school on time, they remember what time their favorite programs are on television, they get dressed. I tell them that they can remember to take their drugs as well, that the trick is to come up with ways to help them do this.

To begin, I give every patient written instructions about their combination: what it is, what it looks like, when to take it, whether it is necessary to eat or not to eat with it. The next thing I do is to try to minimize failure. Too often I hear doctors say, “But everyone is going to miss doses.” I try to anticipate when a person is likely to miss a dose based on his or her individual characteristics and to create safety nets before this happens. I suggest a variety of approaches including: using beepers, storing drugs at friends’ homes and at work, getting reminder calls, getting their computer to remind them, and timing doses with meals. I tell patients that they may still miss doses but that they need to deal with each and every one of these episodes as a problem-solving exercise and not as a guilt-producing opportunity. I suggest that if an individual misses a dose once, it is likely that those same circumstances (or very similar ones) will arise again. I suggest that they think “laterally,” encouraging them to create a different safety net every time they miss a dose so they won’t miss it again.

I don’t expect my patients to fail. I don’t think taking drugs is impossible for patients. I don’t put patients on drugs until I have come up with a combination that they believe they can succeed in taking. I consider all of these things before a patient begins treatment.

Sustaining Adherence

It is unreasonable to expect patients to make major changes to their lives and continue to do so in a void. So I challenge the practice of instructing patients starting treatment to return in three months. In my practice, we book an appoint-
ment for the patient one week after beginning treatment, with the understanding that if all is going well the patient can cancel the appointment and talk to me by telephone instead. A visit at the end of the second week is non-negotiable. At this point, we measure viral load and review all the problems the patient may be having. I make sure that he or she is taking the combination in the right way and that there are no problems that we did not foresee.

I expect viral load testing to demonstrate some improvement very quickly. If there is not at least a half log drop in viral load in the first two weeks, then I consider changing therapies. I believe that measuring viral load at this point and getting the results back to patients within a week is one of the biggest single steps I take that makes a difference. Seeing a viral load drop from 600,000 to 15,000 after 14 days provides an incredible boost to adherence. While patients may believe that the drugs are going to work, they also need to be shown that they are working.

I routinely see my patients every six to eight weeks. If a combination is going to fail or if they are going to develop side effects, I want to know about it as soon as they do; I want the best chance of success with another regimen, and this occurs when you switch at the lowest possible viral load.

At every consultation I ask them about their experience taking their regimens. I used to ask them if they have missed any doses and if so, how we can stop it next time. But, I found that I would get one-dimensional answers: “once” or “a couple of times.” Now, I ask “In what situations have you found it difficult to take your drugs since I last saw you?” I get a very different type of answer: patients start to tell me of the situations that have been difficult, when they have missed doses and when they think they might in the future. Most of my patients come in and tell me what they have changed before I ask: they are working it out by themselves.

Recently, one of my patients, I’ll call him Terry, started off his consultation with the following story: “I found I had problems on pay day. We all go out for a few drinks after work, and while I always mean to go home after, it just doesn’t happen. We always end up going out to dinner somewhere. So, I have to make a decision about going home to get my ritonavir or going out to dinner, and I want to go out to dinner. But I’ve worked it out. The ATM machine where I get out the money for dinner is next to where my friend works. He’s got a fridge at work, and I’m storing extra doses there.”

**Conclusion**

All of this individualized attention takes a lot of time, time that may be difficult to find in any practice. Again, it is important to note that delivering this level of service need not fall on the shoulders of the physician alone: nurses, physicians assistants, and counselors can undertake many of the necessary tasks. Perhaps more important is that while all of this effort takes time, it saves time too. Terry, the patient I described above, would probably have ended up missing doses once a week. He would have developed resistance and it would have taken more time to find a new combination that would work. The process to ensure an individualized regimen and support for patients in adhering saves time in the end—and it potentially saves lives.
Adherence: Working with Homeless Populations
Tim Teeter, BSN, MA

The factors that complicate medication adherence among homeless people are similar in some respects to the factors facing other people with HIV disease—dealing with adverse side effects, handling complex daily dosing schedules—but these challenges are often complicated by concurrent substance abuse and mental illness, and require different approaches in a population that has neither the financial nor social resources of more stable clients. This article presents strategies for working with homeless people, not only to increase treatment adherence, but also—and more importantly—to help clients prioritize regular health care. The approaches in this article are informed by work with clients of the San Francisco AIDS Foundation (SFAF), which last year provided services to more than 2,300 clients, many of whom fit the profile mentioned above.

The Tiered Approach

While there are astonishing stories of people who successfully adhere to treatment despite homelessness or marginal housing, experience suggests that it is premature to begin HIV treatment discussions with clients without also helping them to begin to meet their basic needs. Through focus groups and program evaluation interviews, many clients at SFAF report that they are not able to address regular medical care until their lives begin to stabilize. While many homeless people have difficulty establishing regular medical care with a consistent health care provider, without this stabilizing link, adherence to HIV medications is not possible.

The connection with the client determines all future work toward adherence. Supportive case management is a tool to facilitate this connection and to assist the client to stabilize his or her life and address basic needs such as housing and food, while assuring mental health, substance abuse or domestic violence crises are also addressed. For many clients, the next tier of case management focuses on establishing mental health and substance abuse treatment. Medical care fits here as well: the case manager plays a vital role in encouraging regular health care visits, contacting health care providers, monitoring the relationship between providers and clients, and arranging transportation to and from health care visits. As basic physical and health care needs begin to be addressed, the client’s level of trust in the case manager or treatment advocate will increase, and meaningful conversations about HIV treatment can begin.

Initiating Treatment Conversations

Unfortunately, not all primary health care providers have the time to provide sufficient HIV treatment education to their patients. But the knowledgeable case manager or treatment advocate must make the time for these discussions. Experience shows that personal, one-on-one conversations may provide the best learning forum for the client. A discussion about HIV treatment may involve defining HIV infection for the client. Begin by finding out what having HIV means to the client. What are the client’s beliefs about HIV disease? To


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See also the Clearinghouse section in two past issues of FOCUS: February 1998 and August 1997.
whom has the client disclosed serostatus? Be prepared to help the client work through anger, guilt, and denial. Medical and technical jargon can be overwhelming for clients, so use language and explanations that match a client’s level of understanding. Similarly, do not assume that a client can (or cannot) read; ensure that any written materials match the client’s reading level.

Case managers must be knowledgeable about HIV. When they are unable to answer all of a client’s questions, case managers should research the information and get back to the client with answers. During this process, case managers should discuss the role and importance of adherence. It may also be helpful for case managers to provide incentives for clients to return regularly, both for education and support for the client, and for regular monitoring contact for the case manager. Successful approaches include: hosting regular lunches for clients as a forum to discuss treatment issues; having a registered dietitian conduct monthly nutrition clinics; and running a weekly drop-in treatment discussion group and providing snacks or nutritional supplements to clients who attend. In all of this, a client’s attention span may be short, so information must be brief and easily understood.

When Clients Start HIV Treatment

To successfully promote adherence, it is essential to have a thorough understanding of a client’s daily routines, or to know that there is no regular pattern to the day and what to do when this situation exists. Taking medications more than twice a day adds greatly to the challenge. Among the three classes of drugs currently available to treat HIV, many drugs can be taken twice daily (all the nucleoside reverse transcriptase inhibitors; delavirdine; nevirapine; nelfinavir; combination saquinavir/ritonavir). The newest non-nucleoside drug, efavirenz, may be taken once daily.

Describe to clients common adverse side effects of each possible medication. This is an important step in helping clients make informed choices. Some side effects may be diminished with food, so work with the client to ensure food is available.

Medication storage and ease of administration is critically important, especially for clients who are homeless. Medications requiring refrigeration, such as the capsule form of ritonavir, are not usually options. Medication sets (“medisets”) allow clients to lay out a week’s supply of medications at a time, and are particularly useful when they are the type that have removable cassettes for each day. An inexpensive watch with an alarm may help remind clients to take the second dose of the day. Before starting treatment, clients may wish to practice taking placebos for a week. Filling a mediset with a week’s supply of candy—using different colors or brands to represent different medications—is a good way to predict how well a client will adhere to a regimen.

The most debilitating side effects may occur during the first two weeks of treatment. In preparing for this period, case managers can work with clients to define the best ways to ensure success by addressing housing, nutrition and stress-reduction needs. Ensure that housing will be stable for two weeks. Develop strategies for dealing with diarrhea, such as supplying the client with adult diapers, if needed. Discuss ways to ensure that substance use does not interfere with adherence. Encourage the client to nap when tired or not feeling well, and to drink water or juice frequently to ensure adequate hydration. Above all, be available to the client during the introductory period and to provide ongoing support.

Conclusion

Spending adequate time with clients is the key to working with HIV-infected homeless people. Homelessness is isolating, so basic needs must be addressed before discussing treatment for HIV. For clients who decide to initiate treatment, knowing their daily routines, informing them of potential adverse side effects, and working through problems with them can increase the probability of adherence.

Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:

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Common Adherence Issues

A review of the literature details the range of variables involved in medication adherence and suggests that the overlap among these variables—for example socioeconomic status, psychiatric stress, social relationships, and health care access—requires multifaceted approaches.

The authors review the literature on adherence to medications for HIV and for two other conditions: chronic illness, because HIV has a median incubation period of 10 years or more, and mental illness, because psychiatric diagnoses are common in people with HIV. They identify correlations between adherence and a variety of factors, including demographic variables, psychosocial characteristics, medication characteristics, and health care delivery.

Since non-adherence may result from confusion about correct dosage or about the need to take medications continually, including during asymptomatic phases, it is important for providers to educate people with HIV about their diagnoses and treatments. According to one study, subjects who learned the names of their medications had higher levels of adherence than subjects who did not. Regular communication between providers and patients is also important. A study of hypertensive subjects found that adherence increased proportionally with the number of times a subject discussed hypertension with a doctor.

Education alone, however, may not improve the ability to remember to take medications on time. To respond to this, providers need to help patients integrate treatment regimens into daily schedules, using devices such as timed pill dispensers and alarm clocks, and reminders from other people.

For many people, the cost of treatment and related expenses contribute to non-adherence. In a study of diabetic patients whose insulin costs were subsidized, 50 percent of subjects who discontinued treatment did so because they could not afford transportation to a pharmacy. Another study found that severely immunocompromised HIV-infected individuals were more likely than others to miss scheduled doctor visits. According to the same study, providing on-site child care services greatly improved attendance rates.

Among people with HIV, psychiatric problems often affect adherence to treatment regimens. According to one study, HIV-infected people who adhered to their treatment regimens at least 80 percent of the time had significantly less depression than people with lower rates of adherence. In another study, 52 percent of subjects diagnosed with psychiatric illness achieved an 80 percent rate of adherence to zidovudine (ZDV; AZT), compared with 81 percent of patients without psychiatric diagnoses. Research suggests that psychiatric intervention is an effective way of increasing treatment adherence for HIV-infected individuals.

Adherence, Substance Abuse, and HIV

A study of a hospital-based methadone maintenance program found that on-site dispensing of HIV medications, whether or not it is combined with medication management (individualized assessment and problem solving), does not produce significant long-term increases in HIV treatment adherence. On-site dispensing, however, did improve adherence during the course of the intervention, and clinic attendance increased among participants undergoing the medical management intervention.

The first phase of the San Francisco study evaluated on-site dispensing of zidovudine (ZDV) to a group of 13 male and 12 female HIV-infected hospital patients. The mean age of the sample was 41 years, and all subjects had been prescribed ZDV for at least two months. Ten patients were African American, eight were White, five were Latino, and two were Asian American.

Subjects met every weekday with a nurse to receive all three daily doses of ZDV—one to be taken under the nurse's supervision, and the other two to be self-administered at the appropriate times. Daily interaction with the nurse provided a critical environment for participants to express concerns and receive non-judgmental support. The meetings also enabled the nurse and the
participants to examine progress and obstacles related to adherence. In comparison to a control group of regular care patients, participants in the study showed slightly higher adherence rates during the course of the intervention. One month after the intervention, however, there were no significant differences in adherence levels between the two groups.

The study’s second phase evaluated the effectiveness of combining medication management with on-site dispensing to improve long-term adherence. The sample included six men and six women with a mean age of 42 years. All subjects had been prescribed HIV medications before the study began. Two patients were African American, six were White, two were Latino, one was Native American, and one was of mixed ethnic background.

The combined intervention consisted of nine interdependent medical management strategies, ranging from individual assessments and tailored regimens to teaching self-monitoring and building motivation. Participants had weekly one-on-one contact sessions with a provider, who was also available for unscheduled meetings. One month after completing the intervention, participants reported self-improvements in filling their prescriptions, systematizing their medications, and strengthening their motivation to maintain adherence.

**Inconsistencies in Physician Care**


A Canadian study found considerable differences in the ways physicians treat patients infected with HIV. In addition, some treatment practices and beliefs differed significantly from government guidelines for care.

The evaluation consisted of a 51-item, self-administered survey mailed to 659 physicians participating in a program that offers free HIV treatments to all HIV-infected people in British Columbia. Thirty-eight percent of physicians completed the initial survey; an additional 27 percent completed another survey in which they specified their demographic characteristics and experiences with HIV-infected patients. Seventy-nine percent of the original respondents were male, and 40 percent were younger than 40 years. Ninety-one percent of responding physicians had previous experience treating HIV-infected patients, and 72 percent were treating HIV-infected patients at the time of the survey.

Responses regarding non-HIV vaccines generally correlated with therapeutic guidelines. Eighty-one percent of respondents endorsed annual influenza vaccinations, and 79 percent endorsed one-time only hepatitis B vaccination. For other general disease prevention measures, however, levels of agreement with standards of care were lower: 51 percent endorsed twice-yearly gynecological exams, 48 percent endorsed annual tuberculosis skin tests, and 65 percent believed that HIV seropositive patients should rest at least once. Ninety-two percent of physicians agreed that HIV-infected patients should undergo CD4+ cell counts.

While the mean knowledge score was 62 percent for preventive care, scores were lower in advanced disease management: 52 percent for managing antiviral therapy, 40 percent for opportunistic infection prophylaxis, and 29 percent for opportunistic infection treatment. Compared to the rest of the sample, younger physicians had a greater understanding of preventive measures, and physicians who had medical specialty training were more familiar with the treatment of opportunistic infections.

**Next Month**

As prevention interventions increasingly target seropositive people, "partner counseling and referral services" (PCRS), formally known as partner management and partner notification, have received increased attention. HIV policy makers are developing approaches to help providers implement PCRS in ways that support clients, protect confidentiality, and serve prevention goals. In the February issue of *FOCUS*, Catherine Baker, Drew Johnson, and Harold Rasmussen, officials at the California State Office of AIDS, outline the concepts and strategies behind PCRS.

Also in the February issue, Sandy Schwarcz, MD, a policy maker at the San Francisco AIDS Office, describes a new form of antibody testing—the detuned assay—that distinguishes between recently infected people and those infected more than four months prior to the test. She defines the assay’s technique and its treatment and prevention implications, including its role in partner counseling and referral.
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