

Retention *in*
HIV care:

A Guide to
Patient-Centered Strategies

May 2011



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2011

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The human immunodeficiency virus (HIV) is a sexually transmitted and blood borne retrovirus that causes immune deterioration, chronic disease, and early mortality. More than one million people are currently living with HIV infection in the United States. An estimated 21% of people living with HIV (PLWH) have not been diagnosed (Campsmith, 2010) and, despite effective treatment, up to one third of those who have been diagnosed are not receiving routine HIV care (Fleming et al., 2002). This is unfortunate, as patients who keep regular clinic visits live longer and have healthier lives than those who do not. The maximum benefits of antiretroviral therapy are derived when PLWH are diagnosed and receive care early in the course of the disease. In addition to the obvious personal health benefits for individual patients, PLWH who are engaged in care are less likely to transmit the infection to others (Marks et al., 2005).

For newly diagnosed patients who are receiving HIV care, mortality is twice as high for those who miss a clinic visit within the first year of diagnosis (Mugavero, Lin, Willig, et al., 2009). Appointment non-adherence has been associated with virologic failure (failure to reach undetectable levels), clinical disease progression (including AIDS-defining illnesses), and death (Giordano et al., 2007). Clearly, retention in care depends on successfully connecting to an HIV clinic and being actively engaged in care, but this is not an all or nothing process, as many patients cycle in and out of treatment.

Individual and structural barriers can keep patients from fully engaging in care. Individual barriers may include:

- Healthcare beliefs (such as not perceiving the need for care)
- Not liking the care provider
- Not feeling well enough to come to clinic
- Feeling well (healthy) and not understanding the need for regular HIV care even when feeling well
- Forgetting clinic appointments
- Substance abuse and mental health problems
- Insufficient financial resources and/or lack of insurance
- Housing issues
- Fears related to treatment
- Competing time demands such as work and other appointments
- Limited access to transportation
- Family responsibilities and/or the need to care for others that may supersede self-care

Structural barriers may include:

- Inconvenient clinic hours, especially for patients who work
- Clinics that are not located on easily accessible public transportation lines
- Homophobia, racism, discrimination, and stigma
- Cycling in and out of prison
- A long wait time from making an appointment to the actual clinic visit, especially for first clinic appointments
- Culturally insensitive treatment
- Language barriers

Linkages to care and retention in care will become even more important as the number of new patients in need of HIV treatment increases, partly in response to the Centers for Disease Control and Prevention HIV Testing Recommendations that advocate opt-out testing (CDC, 2006) and partly in response to the National HIV/AIDS Strategies (NHAS; Office of National AIDS Policy, 2010). Retention in care can be improved through the use of a variety of tactics, such as:

- Providing comprehensive and easy-to-access services, including case management
- Decreasing structural barriers at clinics, including expanded appointment times for working patients, one-stop care, and transportation vouchers
- Creating a clinic environment that is friendly and welcoming to patients
- Providing basic HIV education
- Teaching patients the skills that will help them stay in care

The Clinic Environment

A warm and welcoming clinic environment requires teamwork. Everyone, including the receptionist who greets patients at the front desk, the medical assistant who takes vital signs, the clinician who provides medical care, the social worker or case manager who helps patients navigate the clinic system, and, in effect, anyone who has patient contact, has an important role in helping patients feel cared about and cared for.

There are many ways to create a clinic culture that is inviting. In fact, it can be as simple as:

- Greeting patients by name
- Saying, “Thanks for coming in today. It’s good to see you.”
- Treating each patient as an important individual

Tailor Messages to the Patient

Every patient is different and you need to adjust your approaches and messages to each one. It may help to consider the following groups of patients.

New patients need to feel welcome and to learn about the importance of establishing routine care. Things you can say to new patients:

- “Welcome to our clinic. If I can do anything to help you, please let me know.”
- “It is very important to keep your appointments. If you can’t come in, please let me know and I will help you schedule a new appointment.”
- “People with HIV who come to their appointments do better than those who don’t. I look forward to seeing you on a regular basis.”
- “It is important for you to keep your appointments so we can work together to keep you healthy.”
- “If you come to your appointments regularly, we have a better chance of managing your HIV so that you don’t get sick.”
- “It is important that I see you regularly to ensure that there are no problems with your health or your medications.”

Inconsistent attenders who do not regularly show up for appointments can frustrate providers and clinic staff. It is important to provide education and support to these patients. Try some of these messages:

- “We have good evidence that people with HIV who come to their appointments do better than those who don’t. When you miss your appointments, we can’t work together to keep you healthy.”
- “You deserve the best care possible, but when you miss appointments I can’t monitor your labs and adjust your treatment if there are problems.”
- “You have an important role in keeping yourself healthy. When you don’t come in, it is more difficult to act as partners in your care.”

It is easy to ignore **established patients** who consistently keep their clinic appointments, but they deserve reinforcement for being conscientious.

Give them positive messages:

- “Welcome back. How are you doing?”
- “Thanks for keeping your appointment. It is good to see you again.”
- “You do such a good job of keeping your appointments. It makes it easier for us to work together to keep you healthy.”
- “You’re doing well and I know it is—in part—because you’ve been coming in so regularly.”
- “We are a team, and when it comes to your health, you’re the most important player.”

Focus on the Patient’s Strengths

Strengths-based approaches emphasize the patient’s skills, abilities, and self-efficacy; they minimize problems, deficits, and helplessness. Focusing on strengths improves the provider-patient relationship, teaches the patient to advocate for him/herself, decreases denial, and limits resistance to care. When patients understand their strengths, they are better able to set personal goals and develop plans to reach those goals. Make use of both formal (substance abuse/mental health treatment, case management, transportation support, housing assistance, etc.) and “natural” or informal resources already in the patient’s life (job, family, friends, personal motivation). Strengths-based care uses the following strategies:

Emphasize strengths and base goals on past successes

- “How have you solved this problem in the past?”
- “What skills and resources do you use to solve other problems in your life?”

De-emphasize the patient’s account of things s/he’s done wrong

- “We all make mistakes. That’s how we learn. The important thing is that you’re here today.”
- “Sometimes mistakes provide a learning opportunity. What can you do differently next time?”

Use affirmations to acknowledge personal effort

- “By coming to your appointments, you’re helping to create a healthier life for yourself. You can feel proud of this.”
- “I know that you are a smart, resourceful person with the ability to overcome problems related to your care.”

Reframe negative and erroneous statements into positive/neutral and more appropriate assertions

- “I can never keep my appointments. I mess up everything I do.”
 - ◇ “You’re here today, and that’s a great start.”
 - ◇ “We can work together to develop a system to help you get to the clinic.”
- “I didn’t come to my last appointment because I felt good. There’s no point in coming when I don’t feel sick.”
 - ◇ “It’s very important to come in even when you feel well.”
 - ◇ “Keeping your appointments can help you stay healthy.”

Patients are resilient. People constantly adapt and evolve; they are capable of affecting their environments and circumstances, not simply reacting to them. Despite their problems, the patients you work with are survivors, each with unique strengths and skills. Offer hope:

- Help patients create personal meaning that incorporates optimism about the future.
- Let the patient know you believe in him/her, even when s/he doesn’t yet share that confidence.

The Importance of Education



Patients need to know about their health problems and develop the skills necessary to engage in care. Often we expect patients to do things, but they don’t understand why or they don’t have the skills to meet our expectations. It will help if your patients know the basics about HIV infection and how being engaged in care can make a difference in disease progression. They will also need to develop skills in the following areas: Getting Organized, Communicating with Providers, and Problem Solving. (See Teaching Tools.)

Clinicians are often too busy to provide education in the depth necessary to make real differences in their patients' lives, so it is important to get case managers, social workers, nurses, peer navigators, patient educators, and other clinic staff involved in the teaching process. You may want to consider this sequence of events:

- Assess the patient's learning needs to determine the areas that require focused education.
 - ◊ Clinicians will often be the first to recognize a problem. When you see a need for education, determine (a) if the problem can be quickly managed (in which case, it should be addressed immediately with a brief message or piece of information) or (b) if it needs more in-depth teaching (in which case, it is appropriate to refer the patient to a staff member who knows how to provide the needed education). Clinicians can help facilitate this process by making statements such as, "I would like for you to spend some time talking to our health educator. He can help you learn how to solve problems like the one you just described."
 - ◊ Staff members who have been assigned the task of teaching patients about the skills that will help them stay in care should initiate education with a more thorough assessment of the problem area(s). (See Teaching Tools.)
- Develop a plan to deliver the education. Teaching can be delivered individually in one-on-one sessions or in small groups. If the patient is willing, it may help to include significant others in education sessions.
- Allow sufficient time to cover the identified needs; more than one session may be required.
- Follow up after teaching. Plan a session to determine if the patient has additional questions, learning needs, and/or misconceptions that need to be corrected. If you have taught a skill to the patient, ask for a demonstration of the learning. For instance, if you taught a patient to use a calendar, ask her to show you where she has entered her next appointment on her calendar.

Practical Tips

- Motivation is a complex topic and beyond the scope of this pocket guide, but we know that people are often motivated by self-serving (personal gain) reasons and by altruistic (socially conscious) reasons. Providers can



use knowledge of these motivators to strengthen retention in care messages. Remember that different motivators work for different people at different times depending on the context of the individual's situation.

- ◇ To reinforce the self-serving motivator, use statements such as:
 - ◆ “Coming to all of your clinic visits will help you stay healthy.”
 - ◆ “I’m sorry this drug is causing side effects, but we can work together to help you feel better.”
- ◇ To reinforce the altruistic motivator, use statements such as:
 - ◆ “Your family/partner needs you to stay as healthy as possible.”
 - ◆ “It will be easier to contribute to your job/family when you feel well.”
- Be culturally appropriate:
 - ◇ Honor differences in languages, social customs, spiritual traditions, and health/illness beliefs
 - ◇ Use materials that address culture in an appropriate manner
 - ◇ Use easy-to-understand language
 - ◇ Provide translation services
- Offer referral to ancillary services that can address specific patient needs such as substance abuse, mental health, transportation, and housing
- See newly diagnosed patients as soon as possible after a positive HIV test to emphasize the need to engage in care and to stay in care
- Use a system of reminder calls (personal calls are preferable to automated calls)
- Follow up with patients who have missed a clinic appointment, and reschedule as soon as possible



Remember . . .

Health care providers **can** help patients develop skills to enhance retention in HIV care. It is worth the effort. Help your patients by:

- Acknowledging that change occurs slowly and that every small step is a success
- Bearing in mind that it can be difficult (but certainly not impossible) to change long-standing behaviors
- Using affirmations and empathy to demonstrate sincere caring and increase patient trust
- Encouraging the patient when problems occur and celebrating successes as they happen



Teaching Tools

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Teaching Tools: Relating the Basics of HIV Infection to Retention in Care

Assessment. Ask questions specific to HIV biology and treatment to determine if there are gaps in the patient's information. Sample questions:

- "Tell me what you understand about your lab work."
- "What is a good viral load?"
- "What does it mean when your CD4 cell count goes below 200?"

At the least, the patient needs to have a working knowledge of the following information.


Information for the Patient

CD4+ T lymphocytes are white blood cells that are responsible for initiating and maintaining the immune responses that help you fight off infections.

- HIV targets these cells and kills them. Your body can make new cells to replace the cells that have died, but over time HIV kills more cells than your body can replace.
- The lower your CD4+ T cell count, the more impaired your immune system and the greater the likelihood you will develop an opportunistic disease and/or a life-threatening condition.
- One goal of therapy is to keep your CD4+ T cell count high.

The viral load is a measure of how many viruses can be found in your blood.

- An undetectable viral load indicates that the virus cannot be found in your blood by the lab tests that are currently available. It does **not** mean that the virus is not there; it is, however, an indication that the viral load is too small to detect.
- The lower the viral load, the better your clinical outcome AND the lower your risk of transmitting HIV to a sexual or drug-using partner.
- Another goal of therapy is for you to have an undetectable viral load.



Basics of treatment:

- The better you adhere to your treatment, the better chance you have of staying healthy.
- If you have side effects to your medications, you need to talk to your care provider. Side effects make it harder to take your medications as prescribed, but your provider can help you deal with side effects to help you stay on your treatment.

Staying in care can make a difference in your health:

- Patients who attend clinic appointments regularly are more likely to maintain healthy lab values.
- Patients who attend clinic appointments regularly are more likely to get the help they need to deal with problems as they emerge.
- Patients who attend clinic appointments regularly are more likely to adhere to their medications.

Teaching Tools: Organization Skills

Assessment. Ask questions specific to how the patient usually stays organized. Sample questions:

- “How do you usually remember things?”
- “What are your biggest problems when it comes to keeping your clinic appointments?”
- “What helps you remember your clinic appointments?”
- “Tell me how you keep track of your important paperwork. How is that system working for you?”

If the assessment reveals that the patient has problems getting organized, the following information may be useful. *Note: Have the patient practice/ demonstrate using a calendar or file folder during the teaching session.*

Information for the Patient

Most patients use a calendar to keep track of important dates and appointments. You need to decide what kind of calendar works best for you – a small pocket-sized calendar? the calendar on your cell phone? Remember that calendars work best if you have them with you most of the time. Use your calendar effectively:

- Put all clinic appointments in your calendar as soon as you make them
- Use extra pages in your calendar to take notes and list questions
- If you use a paper calendar, carry a pen or pencil so you can write things down as they occur

In addition to your calendar, you can be better organized by:

- Deciding which activities are most important and doing them first
 - ◇ Make a list of things to do and number them in order of importance.
 - ◇ Check off each item as you complete it.
- Keeping health information in one place.
 - ◇ A multi-pocket file folder works well for this.
 - ◇ Make tabs for lab work, appointments, educational materials, documents you need for social services, and other important papers.
 - ◇ Make it a habit of taking your folder to clinic visits in case you need any paperwork.



Teaching Tools: Communication Skills

Assessment. Ask questions specific to how comfortable the patient feels discussing concerns with his/her care provider. Sample questions:

- “When you have questions about your health care, how do you get them answered?”
- “Are you comfortable talking to your care provider? If not, please tell me about that.”
- “Have you had questions that you were too embarrassed or uncomfortable to ask your provider? What do you do when you have those kinds of questions?”

If the assessment reveals communication problems, the following information may be useful. *Note: One of the best ways to teach communication skills is to do role-plays with the patient.*

Information for the Patient


Your providers want to hear your questions and concerns, so it is important for you to talk to them. Tell them how you are doing and about any problems you are having, especially when you develop new symptoms or problems taking your medications. Here are some ideas on how to communicate better with your provider. They are easy to remember if you think **ABCC**:

Ask Questions. You need to know about your treatment and your provider is the best person to teach you about your care. You might have questions like these:

- “How long do I have to take this new medication?”
- “What does my CD4 count mean?”
- “Why do I need another blood test?”

Be Prepared. It isn’t always easy to remember the things you need to talk about, so plan ahead for your clinic visit.

- Write questions down (use your calendar, a notebook, or a section of your file folder) and bring them to appointments.
- Keep a list of all of your medications and bring the list to your appointments.
- Bring a list of problems, new symptoms, and other things you want to talk about to your appointments.



Communicate Concerns. It is not unusual for people with HIV to worry about their care, and it helps to discuss these things with your provider. For instance, you may have some of the following concerns:

- “I am afraid of the side effects of these medications.”
- “Sometimes I feel so tired and sad.”
- “My job makes it hard to keep my clinic appointments.”

Clarify. Sometimes your provider will say things that you don’t understand. When that happens, some patients are intimidated. They may think, “I don’t understand what my doctor is saying, but I don’t want to seem stupid, so I just smile and nod, even if I have no idea what she wants me to do.” A better way to handle this would be to say:

- “Can you find another way to explain that to me?”
- “So are you saying . . . (and restate what s/he just said in your own words).”
- “I still don’t understand why I need to take all of these pills.”
- “What do you mean when you say that I need an assay? I never heard of that.”

Teaching Tools: Problem Solving Skills

Assessment. Ask questions specific to how the patient usually solves problems. Sample questions:

- “What problems most affect your ability to keep your clinic appointments? How have you resolved those problems in the past?”
- “Tell me about a time when you were able to figure out what to do about a problem.”
- “Tell me about a time when you just couldn’t find a solution to a problem.”
- “Remember the last time you missed an appointment? What was going on then?”

If the assessment reveals that the patient needs help with problem solving, the following information may be useful. *Note: Trust patients to create their own unique solutions. You may have ideas or suggestions, but the answers people come up with for themselves enhance their sense of self-efficacy and are usually those that will work best for them.*

Information for the Patient

It is not unusual for people with HIV infection to have problems keeping their appointments – sometimes life just gets hectic. It helps to have a system for thinking about ways to solve your problems. We call this system the **3 Os**:

The first step is to state your problem clearly. For instance: “I can’t come to my appointment because I don’t have anyone to take care of my baby.”

Once you know what the problem is, you can work your way through the **3 Os**:

Options: Think of different ways to solve the problem.

- “I could ask my mother to watch the baby.”
- “I could ask my neighbor to watch the baby.”
- “I could take the baby to the appointment with me.”

Outcomes: What are the expected outcomes to each option?

- “If I ask my mother, she will watch the baby but I will get a lecture about how it is my responsibility.”
- “If I ask my neighbor, she might watch the baby but I will have to babysit her kids in exchange.”
- “If I take the baby with me, she might cry and fuss but she might also sleep through the appointment.”

Order: Decide what to do first.

- Of all the ways to solve the problem, which would work best for you? Which is the easiest or least risky?
- If that option doesn’t work, what is your next best choice?

Let’s look at another problem. Remember to state your problem clearly. For instance: “I’m afraid to tell my boss that I need time off to go see the doctor.” Once you know what the problem is, work your way through the

3 Os:

Options: Think of different ways to solve the problem.

- “I could call in sick on the days that I have an appointment.”
- “I could ask someone to cover for me and just leave for a couple of hours.”
- “I could tell my boss why I need to be gone and see what happens.”

Outcomes: What are the expected outcomes to each option?

- “If I call in sick, I will have to take the whole day off and it will use up my sick leave pretty quickly.”
- “If I ask someone to cover for me I wouldn’t have to use my sick leave, but they might start asking questions about my health and if the boss finds out I might get fired.”
- “If I tell my boss he might be sympathetic, but he could also find a way to fire me.”

Order: Decide what to do first.

- Of all the ways to solve the problem, which would work best for you? Which is the easiest or least risky?
- If that option doesn’t work, what is your next best choice?

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Resources

Mountain Plains AIDS Education and Training Center (MPAETC)

<http://www.mpaetc.org>

AETC National Resource Center

<http://www.aids-ed.org>

AIDS InfoNet

<http://www.aidsinfonet.org>

Centers for Disease Control and Prevention, HIV/AIDS page

<http://www.cdc.gov/hiv/default.htm>

Health Resources and Services Administration (HRSA) TARGET Center

<http://www.careacttarget.org>

National HIV/AIDS Clinicians' Clinical Consultation Center

<http://www.nccc.ucsf.edu>

National Institutes of Mental Health Office on AIDS

<http://www.nimh.nih.gov/about/organization/od/office-on-aids-oa.shtml>

National Library of Medicine – HIV/AIDS Information

<http://sis.nlm.nih.gov/hiv.html>



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