

IN THE KNOW
HIV INFO

Optimizing Entry Into and Retention in HIV Care and ART Adherence for PLWHA

A Train-the-Trainer Manual for Extending
Peer Educators' Role to Patient Navigation



This training manual is funded through an unrestricted educational grant from Janssen Pharmaceuticals.

Acknowledgements

We wish to acknowledge and express our gratitude to Moisés Agosto-Rosario (National Minority AIDS Council, Washington, DC, USA) and Angela Knudson (International Association of Physicians in AIDS Care, Washington, DC, USA) for authoring this document. The following staff members of the International Association of Physicians in AIDS Care, also in Washington, DC, USA, were engaged in the document's development: Benjamin Young, MD, PhD; and José M. Zuniga, PhD, MPH.

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Description of the Training Program

The purpose of this training program is to address the need for peer educators to actively engage with people living with HIV/AIDS (PLWHA) in enhancing entry into HIV care, promoting antiretroviral therapy (ART) adherence, and facilitating long-term retention in HIV care. The curriculum consists of an intensive one-day course that is based on recently published global guidelines outlining evidence-based interventions to improve entry into and retention in HIV care, as well as ART adherence for PLWHA.¹

Peer educators are already engaged with PLWHA in many communities. This training program aims to hone their knowledge and skills in HIV care, as well as provide them with the tools necessary to assist PLWHA in navigating the complexities of HIV care in the extended role of patient navigator. The training program's format will be a combination of didactic sessions and interactive group exercises, including case studies to translate knowledge gained into courses of action driven by the guidelines.

This training program is made possible thanks to a collaborative effort between the International Association of Physicians on AIDS Care (IAPAC) and the National Minority AIDS Council (NMAC), with the support of an unrestricted educational grant from Janssen Pharmaceuticals. This training program is part of *In the Know*, IAPAC's series of patient education and empowerment activities.

Goals and Objectives

The goal of this train-the-trainer activity is to train and certify peer educators on evidence-based interventions to assist PLWHA to optimally adhere to ART and remain engaged in HIV care in a variety of clinical settings. Once participants complete the activity, they will receive Certificates of Completion, and will be encouraged to train other peer educators in their respective communities.

At the conclusion of the activity, participants will be able to:

- Define barriers that prevent optimal engagement in HIV care;
- Outline strategies to improve timely linkage to and retention in care as an effective means of assuring successful ART initiation and optimal adherence;
- Integrate evidence-based education and counseling interventions that will help PLWHA engage in HIV care and achieve HIV treatment success; and
- Understand the challenges faced by special populations and evidence-based interventions to provide patient-centered care in a variety of settings.

Notes for the Trainer

This manual is designed to enhance a peer educator's role within their community by engaging with PLWHA around entry into and retention in HIV care and ART adherence. While each section is deemed as important, it is ultimately the trainers' decision how best to adapt the training materials to fit into the context of their community. The curriculum is designed to build upon peer educators' existing knowledge and experiences.

Manual Design: The manual's format consists of eight sections covering key topic areas designed to give trainees a comprehensive view of their role as a peer educator working with PLWHA to achieve successful entry into and retention in HIV care and optimal ART adherence. Each section is allotted a suggested duration, and in addition to didactic materials in the form of PowerPoint slide decks, interactive exercises are included with full instructions for the trainer to utilize in planning and conducting a training program. The manual will allow participants to capture their thoughts and record their responses and observations within the workbook.

Duration: Each section includes the approximate time it will take to cover the information.

Learning Objectives: Learning objectives are listed so that trainers know what knowledge and skills participants should gain after completing each section.

Materials Needed: In addition to this manual, trainers will need a flip chart, markers, and the Certificate of Completion that will be presented to each participant that completes the training course. Finally, trainers will need the five PowerPoint slide decks meant to help them present the material, including:

1. ART 101: What You Need to Know
2. Adherence and HIV Treatment
3. Drug Resistance and HIV Treatment
4. State of HIV Care in the United States
5. Guidelines for Improving Entry into and Retention in Care and Antiretroviral Adherence for Persons with HIV

Work for the Trainer to do in Advance: Trainers should review each section and the five PowerPoint slide decks listed above and adapt the materials as needed for their audience.

Step-by-Step Instructions: This training should be as participant-focused as possible, and trainers should draw upon the wealth of experiences peer educators bring to the session. In addition, trainers should strive toward creating a learning environment that is interactive, encouraging the exchange of information and ideas as a skills-building exercise.

SECTION 1

The New Paradigm and the Role of Peer Educators

PEER EDUCATION: THE CURRENT TO THE EXTENDED ROLE FOR TREATMENT NAVIGATION

Trainer Instructions: This section focuses primarily on the definition, importance, qualifications, current role, and advantages of peer education programs. It sets the stage for the purpose of this training program.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 10 minutes

Learning Objectives:

- Define peer education
- Discuss the advantages of peer education programs
- Identify the current role of peer educators

What is Peer Education?

Peer education is the sharing of knowledge by someone who is either directly a part of the same social group as the individual with whom the knowledge is being shared, or who is of the same age, gender, sexual orientation, race and ethnicity, occupation, socio-economic, and/or health status. But, most importantly, they inspire trust. In relation to HIV education, peer education is a less formal and more intimate approach to education that helps people who are unfamiliar with, or dislike a formal way of learning, to be presented with knowledge by their peers. This educational intervention occurs at various levels, depending upon where the person finds herself/himself within the continuum of HIV diagnosis to HIV care. For instance, the peer education process

has helped many individuals deal with the first emotional reaction at the time of diagnosis by learning from a person who has experienced it or can relate to the experience firsthand.

A peer educator's success depends upon the sharing of mutual experiences, but equally upon the peer educator's level of knowledge and her/his ability to translate knowledge into course of action that can be easily communicated to and readily implemented by an individual. Individuals who wish to become peer educators must be trained in and continuously updated on various subject matter ensuring that the information they share in the course of their peer education work is both accurate and reliable. Peer education also can be a very effective way of reaching marginalized groups. For example, peer education programs have been found to work well in prison settings, where authority figures are often distrusted.^{2,3}

Advantages of Peer Education Programs

- **People trust those in a similar situation:** PLWHA have the opportunity to discuss their personal circumstances in a safe environment with someone who relates to their situation.
- **Improved adherence:** Peer educators can support PLWHAs' adherence to care and treatment because they may have a deeper understanding of what the client is experiencing.
- **Community participation:** Peer educators can play a role in community mobilization, decreasing stigma, and increasing support for PLWHA.
- **Empowerment of individuals:** Peer educators can increase PLWHAs' confidence that they can make good decisions and take action. Peer education programs can help both peer educators and PLWHA make positive changes in their behavior in order to take care of their personal health and that of their families.

- **Job opportunities:** Training and work experience may improve peer educators' job opportunities in the formal economic sector.
- **Improved service quality:** Peer educators can help to improve the overall quality and effectiveness of healthcare programs by giving feedback to the clinic about the needs of PLWHA and the community.
- **Task shifting and saved time:** Peer educators can help free up the time of doctors, nurses, and social workers by providing basic education and counseling at the clinic.
- **Increased access:** Peer educators can gain access to groups that are otherwise difficult to reach and encourage them to seek prevention, care, and treatment services. Similarly, peer educators can follow up with clients who have missed appointments, since they are often from the same communities.⁴

Current Role of Peer Educators

Understanding the meaning of peer education and its advantages will allow us to define criteria and build a profile that will help develop the roles and responsibilities of peer educators based on the context of the communities in which they live.

The primary role of a peer educator is to help a person to define her/his concerns and seek solutions through the mutual sharing of information and experiences.

A peer educator should have certain personal characteristics as well as qualifications or skills in order to be effective in the role of a peer educator.

The following are standard personal characteristics of a peer educator:

- A person of principles and integrity who "practices what they preach" and is seen as a role model by others.
- A person able to empathize and understand the emotions, thoughts, feelings, and language of others, therefore connecting and relating more effectively.
- A person who not only communicates with their peers about a desired risk reduction practice but also demonstrates it in her/his own life.
- A person who has the ability to influence community norms.
- A person who inspires and encourages her/his peers to adopt health-seeking behaviors through

sharing common weaknesses, strengths, and experiences.

- A person who is sensitive, open minded, a good listener, and a strong communicator.

Following are some of the skills and qualifications needed to be a peer educator:

- Should be a peer (i.e., a peer educator who is a sex worker may be more comfortable with other sex workers).
- Should speak the language and know the cultural norms and values of the group/community.
- Should have training in group facilitation or peer education in order to communicate clearly and effectively.
- Should be knowledgeable of the subject.
- Should know where to refer peers to organizations where accurate information can be found.
- Should increase one's knowledge of the subject or related healthcare matters (e.g., sexually transmitted infections, reproductive health).
- Should have solid/good interpersonal skills.
- Should have leadership and strong motivational skills.
- Should be non-judgmental and open minded.

TRAINER INSTRUCTIONS

Interactive Exercise I: Peer Educator Job Description

Duration: 20 minutes

Step 1: Start by asking participants to brainstorm around what a peer educator does as part of the multidisciplinary HIV care team. Record responses on a flip chart.

Step 2: Pass out copies of the peer educator job description (*Handout 1*)⁵ to each participant. Review the job description and ask if there are any questions.

Step 3: Review how peer educators will be supported and supervised by program partners, for example, healthcare workers or non-governmental organizations (NGOs). You may also want to discuss any peer educator incentives (stipend, transport allowance, uniform, etc.) during this step.

Step 4: Discuss with participants that an important part of being a peer educator is sharing relevant information that may assist in better communication with PLWHA. Ask participants to break into groups to discuss the following two questions for about 10 minutes (you may want to write these on a flip chart):

- What have been your experiences in initiating dialogue with PLWHA?
- Has sharing personal information, such as HIV status (negative or positive), affected your ability to relate with PLWHA?

Step 5: Bring the large group back together and discuss shared experiences across the groups in relation to peer educator/PLWHA best practices.

Step 6: Allow time for participants to ask questions about the roles and responsibilities of being a peer educator.⁵

INTERACTIVE EXERCISE I

Peer Educator Job Description

Example of a Peer Educator Job Description (*adapt to the local context*):

- Spend at least 2-3 days per week working at the health facility and 1-2 days per week working in the community.
- Participate as an active member of the multidisciplinary care team, including attending multidisciplinary team meetings.
- Conduct group education sessions, in coordination with other members of the multidisciplinary care team.
- Conduct one-on-one counseling sessions with clients, caregivers, and treatment supporters on the following topics:
 - HIV basics
 - Understanding care and treatment
 - Adherence to care and treatment
 - Disclosure, stigma
 - Positive living and positive prevention
 - Ongoing psychosocial support
 - Biomedical prevention
 - Others topics as decided by the program
- Help clients with referrals within the health facility, including walking them to the referral point, explaining why the referral was made and what services will be given at the referral point, and making sure the client is seen in a timely manner at the referral point.
- Act as a link between clients and the multidisciplinary care team, including presenting common concerns of clients and adherence challenges faced by clients in multidisciplinary team meetings.
- Implement family-focused care by asking all clients about family members and encouraging them to come for HIV testing and counseling, care, and treatment.
- Work as part of the multidisciplinary care team to identify and follow-up with clients who do not return to the clinic for appointments, CD4 or other tests and results, and medication refills (this includes making follow-up phone calls and home visits according to the facility protocol).⁵

EXTENDED ROLE FOR PATIENT NAVIGATION

Trainer Instructions: This section focuses primarily on the definition, goals, and importance of patient navigation.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 10 minutes

Learning Objectives:

- Define patient navigation and its shift from peer education
- Review the goals of patient navigation
- Discuss why patient navigation is important

The introduction of pre-exposure prophylaxis (PrEP), treatment as prevention (TasP), and the implementation of the National HIV/AIDS Strategy (NHAS) and the Patient Accountability and Affordable Care Act (Affordable Care Act) challenge us to reconfigure the way we develop and implement HIV educational programs in the context of this new paradigm. Even though peer educators will still be indispensable, their roles and responsibilities will need to change and evolve to patient navigation. With other diseases, such as cancer, diabetes, and even in some HIV programs, there are individuals who work as patient navigators. Most models of patient navigation come from the cancer and diabetes community. The closest thing we have to patient navigation is case management. If patient navigation is the future in the context of the Affordable Care Act, we must start to transition from peer educator to patient navigator.

What is Patient Navigation?

Patient navigation is a process by which an individual—a patient navigator—guides patients with a suspicious finding, through and around barriers in the complex care system to help ensure timely diagnosis and treatment. Barriers to quality care fall into a number of categories:

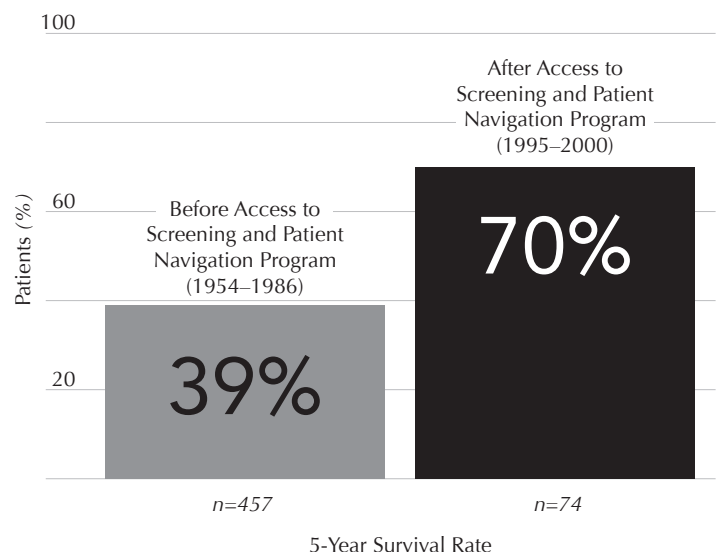
- Financial/economic
- Language/cultural
- Communication
- Healthcare system complexities
- Transportation
- Bias based on culture/race/age
- Fear, discrimination, stigma

Patient navigation helps ensure that patients receive culturally competent care that is also:

- Confidential
- Respectful
- Compassionate
- Mindful of the patient's safety

Harold P. Freeman, MD, founder and national champion of the patient navigation movement in the United States, established the nation's first patient navigation program in 1990 at Harlem Hospital Center to help improve access to cancer screening and address the delays in clinical follow-up and barriers to cancer care that poor people encountered. The pilot program compared five-year survival rates of breast cancer patients who were navigated and those who were not, and found an improvement in the navigated patients. Figure 1 shows the positive effects this program had on patients.⁶

FIGURE 1: Harlem Hospital Center — Improved Access to Screening and Patient Navigation



The Patient Navigator

A patient navigator is essentially a problem solver and a highly resourceful individual. A navigator can be:

- A trained healthcare professional (e.g., social worker, nurse)
- A lay individual who can coordinate the needed healthcare services

The navigator is trained to anticipate, address, and overcome barriers to care, and to guide patients through the healthcare system during a very difficult time.

Patient navigators can help improve the quality of care patients receive, and patient navigation programs may help extend or even save patients' lives. With the help of a patient navigator, patients are:

- Guided through the complexities of treatment
- Assisted in filling out insurance paperwork or finding transportation to medical appointments
- Aided in identifying local resources
- Given ideas about communicating effectively with healthcare professionals
- Encouraged and supported emotionally

The result is that patients with suspicious findings have a greater chance of receiving a quick and timely diagnosis and any necessary treatments. In addition, services may be better coordinated and more consistent, resulting in improved outcomes.

It is important to define clear boundaries and properly define the role and functions of a patient navigator. Navigators who are not healthcare professionals should NEVER:

- Provide physical assessments, diagnoses, or treatments
- Order care, treatments, or medications
- Attend to or become involved in any direct patient care (e.g., changing dressings, providing direct financial assistance, picking up patients for appointments)
- Provide physical, occupational, or speech therapy
- Offer opinions about any aspect of healthcare delivered within or external to the organizations
- Provide recommendations or opinions about doctors or healthcare organizations.⁷

Goals of Patient Navigation

The goals of patient navigation are to:

- Save lives—ensure that all patients who have a suspicious finding encounter resolution through

more timely diagnosis and treatment.

- Eliminate barriers to care—make sure that patients attend follow-up appointments and are aware of and can access needed services.
- Ensure timely delivery of services—assist patients in moving through the healthcare system as needed in a timely manner.

Too often the positive gains made in being diagnosed early are lost because of a lack of clinical follow-up by the patient. Patient navigators, while collaborating with other members of the care team (e.g., doctors, nurses, social workers), guide patients through the healthcare system and help to prevent and eliminate barriers to quality care and treatment.⁸

Why Is Patient Navigation Important?

Many patients—especially the poor and those who are marginally linked to the healthcare system—have trouble getting adequate care because of barriers, including:

- Need for financial help, social support, or transportation
- Lack of information
- Gaps in care

These barriers may cause patients to miss follow-up appointments or delay care until they are very sick. It is vital that patients receive continuous care from screening through diagnosis and treatment to ensure the best quality outcomes.

Patient navigation is important because it:

- More accurately identifies barriers to care
- Improves sharing of resources
- Enhances continuity of care, which may result in improved outcomes
- Improves quality of services
- Increases patient satisfaction

Patient navigators are trained in these necessary skills and have the appropriate qualities—enthusiasm, an openness to learning, connectedness to the community and its culture, and the dedication to act as compassionate, effective guides in bridging the gaps to help patients, their caregivers, and their families.⁹

TRAINER INSTRUCTIONS

Interactive Exercise II: Patient Navigator Job Description

Duration: 20 minutes

Now that the participants have learned and discussed the roles, responsibilities, and qualifications of a peer educator and the importance of patient navigation, have trainees adapt the peer educator job description (*Handout 1*) to a patient navigator position in a community health center that only includes the following:

- Personal characteristics
- Qualifications and skills
- Roles and responsibilities

Step 1: Ask participants to break into groups and adapt the peer educator job description (*Handout 1*) to a patient navigator position (*Handout 2*). They should also review how patient navigators would be supported and supervised by program partners, for example, healthcare workers or NGOs. They should brainstorm what a patient navigator would do as part of the multidisciplinary HIV care team.

Step 2: Bring the large group back together and discuss personal characteristics, qualifications and skills, and roles and responsibilities for patient navigators. Record responses on a flip chart.

Step 3: Allow time for participants to ask questions about the roles and responsibilities of being a patient navigator.

INTERACTIVE EXERCISE II

Patient Navigator Job Description

Patient Navigator Job Description

Personal Characteristics:

Qualifications and Skills:

Roles and Responsibilities:

SECTION 2

Cascade of Engagement in HIV Care

Trainer Instructions: This section focuses primarily on the definition and the importance of an HIV treatment cascade and how it's being used.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 15 minutes

Learning Objectives:

- Define the HIV treatment cascade
- Discuss why the HIV treatment cascade is important
- Explain how the HIV treatment cascade is being used

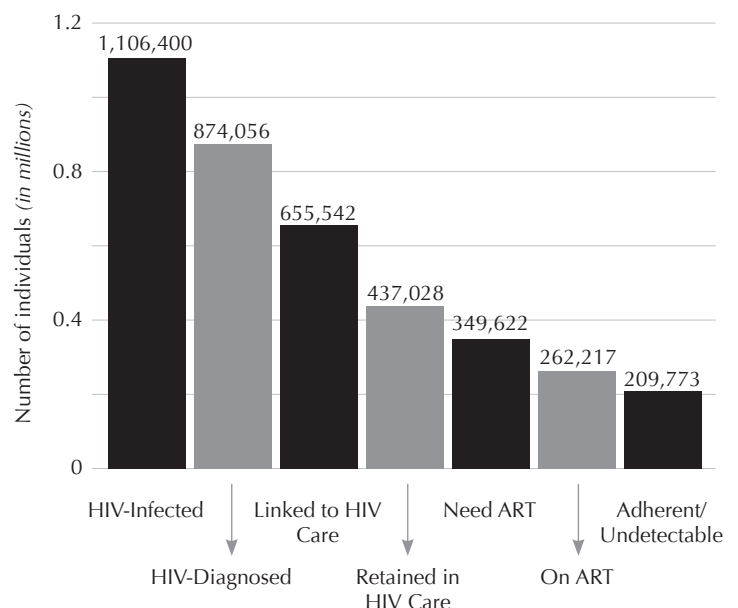
New scientific and clinical discoveries have given us the opportunity to see, for the first time in the epidemic, an evidence-based pathway that tells us that the possibility to contain the epidemic by decreasing the incidence of infections is possible. With the advent of treatment as prevention (the provision to and use of ART by PLWHA to reduce morbidity and mortality as well as the risk of onward HIV transmission through durable viral suppression, or TasP) and pre-exposure prophylaxis (the use of oral ART or topical microbicides by HIV-uninfected individuals before and after potential sexual exposure to HIV to reduce the risk of acquisition of the virus, or PrEP), there is new promise to curb the HIV epidemic. Challenges will exist when translating these biobehavioral interventions into an environment that does not offer the same control settings that were part of clinical trials design.

In an ideal world, we could end the HIV epidemic. Achieving this lofty goal would necessitate everyone infected knowing their status, having uninterrupted access to care and treatment, and reaching undetect-

able levels of HIV virus in their blood stream. It would also require overcoming all the psychosocial and socioeconomic barriers that jeopardize treatment success, including HIV-related discrimination, isolation, and stigma that PLWHA continue to face more than 30 years into the HIV epidemic.¹⁰

In the real world, ending the HIV epidemic presents us with many challenges, most of which can be addressed. Doing so, however, requires creativity, dedication, commitment, accountability, financial resources, and political will. While many of those have guided the US response to the HIV epidemic over the past 30 years, the reality we face when we look at the actual state of the HIV epidemic reveals significant gaps, laid out in stark relief by what is known as the “Gardner Cascade,” a visual tool that makes it easy to understand the current state of engagement

FIGURE 2: Number of PLWHA Engaged in Selected Stages of the Continuum of HIV Care—United States



by PLWHA in the continuum from HIV diagnosis through to HIV treatment success (defined as optimal adherence and viral suppression [otherwise known as undetectable levels of virus in the blood stream]).

What is the HIV Treatment Cascade?

The HIV treatment cascade, shown in Figure 2, was first described by Edward M. Gardner, MD, and his colleagues, who reviewed HIV care engagement statistics nationwide and developed estimates of how many PLWHA in the United States are engaged at various steps in the continuum of care, from diagnosis through to viral suppression. Their analysis, published in March 2011, found that along each step of the cascade (i.e., diagnosis, linkage to HIV care, retention in care, ART initiation, ART adherence), a significant number of PLWHA “fall off,” and only a very small percentage actually achieve viral suppression.¹¹

In late 2011, the US Centers for Disease Control and Prevention (CDC) conducted its own analysis of HIV care data, viral load and CD4 laboratory reports, and other published data to develop national estimates of the number of PLWHA at each step of

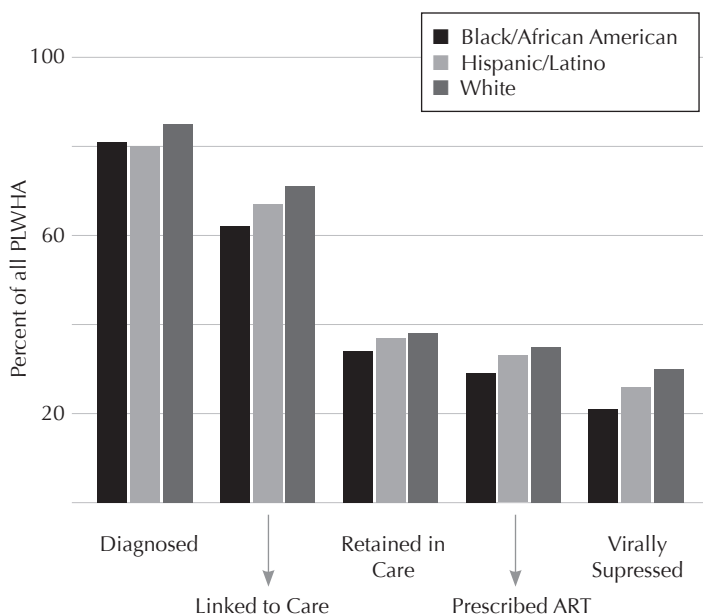
the treatment cascade. Their findings, published in the CDC’s *Morbidity and Mortality Weekly Report (MMWR)*, were similar to those of Dr. Gardner and his colleagues. For every 100 PLWHA in the United States, the CDC estimated that:

- 80 are aware of their HIV status
- 62 have been linked to HIV care
- 41 are retained in HIV care
- 36 receive ART
- 28 are able to adhere to their ART and achieve undetectable viral loads

In short, the CDC found that only 28% of the more than 1 million PLWHA in the United States, are getting the full benefits of the continuum of care and treatment they need to manage HIV disease and achieve HIV treatment success. Put another way, nearly three out of four Americans living with HIV/AIDS have failed to successfully navigate the treatment cascade.¹²

Subsequently, in July 2012, the CDC released updated numbers, showing that only one-quarter of the 1.1 million Americans living with HIV/AIDS had their virus under control. The CDC’s comprehensive analysis also provided a first-ever look at HIV care engagement by race/ethnicity, age, risk group, and gender. Figure 3 reveals that African-American PLWHA are least likely to be in ongoing care or to have their virus under control.¹³

FIGURE 3: The Stages of Care in the United States by Race/Ethnicity



African-American PLWHA are least likely to be in ongoing care or to have their virus under control.

Why is the HIV Treatment Cascade Important?

The HIV treatment cascade provides a way to examine critical questions, including: How many individuals living with HIV are getting tested and diagnosed? Of those, how many are linked to care? Of those, how many are retained in care? Among that group of individuals, how many receive ART? Of those, how many are adhering to their treatment plan and achieve viral suppression? By closely examining these separate steps, policymakers and service providers are able to pinpoint where gaps may exist in connecting PLWHA to sustained, quality care. Knowing where the drop-offs points are most pronounced (and for which populations) helps national, state, and local policymakers as well as service providers to implement system-specific improvements and service enhancements that better support individuals as they move from one step in the continuum to the next.

- Lowering the amount of virus in the body can keep a person with HIV healthy for a longer period of time.
- Keeping the virus under control (namely, an “undetectable viral load”) greatly lowers the chances of transmitting HIV to others.
- More than 18,000 people die of AIDS-related complications each year. The number of HIV-positive individuals who progress to AIDS has decreased over time because of ART. Without ART, most persons living with HIV develop AIDS within 10 years of infection, resulting in substantial morbidity and premature death.

At the federal level, government agencies use the HIV treatment cascade to inform discussions concerning how best to prioritize and target resources. For example, it points to the importance of continu-

At the state and local levels, program planners also apply the treatment cascade by using local data to assess where resources are needed. For example, the Los Angeles County Department of Public Health produced a program brief summarizing data on the spectrum of engagement in care and treatment for all persons infected with HIV in Los Angeles County. Similar analyses have been conducted in San Francisco, Chicago, Washington, DC, and other communities, enabling them to take steps to improve engagement at each step in the continuum of HIV care. Ensuring success at each step in the HIV treatment cascade will move us closer to allowing every PLWHA to achieve the benefits of HIV treatment, care, and support.

TRAINER INSTRUCTIONS

Interactive Exercise III: HIV Treatment Cascade

Duration: 20 minutes

Step 1: Now that the participants learned and discussed the HIV treatment cascade, divide them into groups and distribute *Handout 3*, and have them discuss among themselves the three questions in *Handout 3* from their point of view and in the context of the community they serve.

Step 2: After the discussion, have participants complete the second half of the handout by identifying (following the cascade), where and how to apply peer educator and/or patient navigator interventions. Responses should be limited to one sentence or less.

Step 3: Allow time for participants to ask questions about the roles and responsibilities of being a patient navigator.

INTERACTIVE EXERCISE III

HIV Treatment Cascade

1. What is the HIV treatment cascade?
2. Why is the HIV treatment cascade important?
3. How is the HIV treatment cascade being used?

After answering and discussing these questions, identify where in the HIV treatment cascade a peer educator and/or a patient navigator applies interventions and how: (Please limit your response to one sentence or less)



After answering where and how to apply interventions as a peer educator and/or a patient navigator, discuss your answers as a group.

Recommended Community Exercise: Build an HIV treatment cascade for your community. Following publication of the macro-level Gardner Cascade model, the CDC developed a micro-level model that is more demographically focused, based on gender, race, and age. It has been strongly recommended that at the state and local level, where numbers are available, health officials build their own cascade to map out the epidemic's profile at a state, county, or local level.

SECTION 3

ART 101: What You Need to Know

Trainer Instructions: This section focuses on the basics of ART and what peer educators must know in order to assist PLWHA in achieving treatment success. For this section, refer to the set of slides titled *ART 101: What You Need to Know*. Guide the participants through the discussion using the following outline of the presentation. Inform participants that the following slides/information presented here may reflect questions they will be asked by PLWHA, and the sample language below provides guidance on ways to answer the questions.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 20 minutes

Learning Objectives:

- Define the goals of ART
- Discuss the tools to achieve ART goals
- Define ART success

Talking Points for Trainer:

- The goals of ART are to improve quality of life, and allow for people to live longer and healthier lives.
- By taking ART, CD4 counts increase, which allows the immune systems to continue to do its job of protecting against opportunistic infections (OIs).
- There are many ART options, and consulting with a doctor is the most effective way to find what options work best.



ART 101:

An ART regimen geared toward treatment success usually consists of at least three drugs from two different "classes" of antiretroviral (ARV) drugs. There are now six classes of ARV drugs, each works somewhat differently at stopping HIV from multiplying:

- NRTIs (nucleoside reverse transcriptase inhibitor)
- NNRTIs (non-nucleoside reverse transcriptase inhibitors)
- PIs (protease inhibitors)
- Integrase inhibitors
- CCR5 antagonists
- Fusion inhibitors

Antiretroviral goals:

- Improving your quality of life
- Extending, enhancing your life
- Reducing your chance of developing opportunistic infections (OIs)
- Restoring and/or preserving your immune system
- Maximizing and sustaining a suppression in the amount of HIV in your blood (your "viral load")

Tools to achieve ART goals:

- Selection of potent ARV regimen
- Preservation of future treatment options
- Rational sequencing of ARV regimens
- Maximizing adherence
- Use of resistance testing

Defining ART success:

- Within about two weeks after starting ART, your viral load will decrease dramatically
- Within two to six months, you will probably be told that your HIV is “undetectable”
- Undetectable means that even though you are still HIV positive, your viral load is so low that tests are not sensitive enough to detect it in your blood
- Your CD4 count will increase, and your immune system can recover and do its job
- With more CD4 cells, there is less of a chance of developing an OI, such as thrush
- If you take all your ARV drugs on time, your chances of remaining undetectable are EXCELLENT

What if I am detectable?

- If you are on your third, fourth, or fifth ARV regimen, reaching undetectable status is sometimes difficult
- Fortunately, many recent studies show there is a benefit to keeping your viral load as low as you can, even if it is detectable

Constructing ARV regimens:

- 25 individual ARV drugs and 9 co-formulated ARV drugs are currently FDA-approved in the United States
- Theoretically thousands of ARV regimens can be constructed/prescribed
- ART success can be improved by:
 - Selecting an appropriate ARV regimen
 - Preserving future treatment options

- Maximizing adherence
- Testing for drug resistance

FDCs and STRs:

- Fixed-dose combination (FDC): Two or more drugs contained in a single dosage form, such as a capsule or tablet
- Single-tablet regimen (STR): An FDC capsule or tablet containing all drugs that comprise an ARV regimen
- By reducing the number of pills a person takes each day, FDC drugs can help improve adherence to HIV treatment

Recommendation to the trainer: After each presentation, allocate time for Q & A, discussion, comments and feedback. You can also take Q & A after each slide but be mindful that it may consume your time and divert the group from the learning objectives of the presentation.

SECTION 4

Adherence and HIV Treatment

Trainer Instructions: This section focuses on the basics of ART adherence. For this section, use the set of slides titled *Adherence and HIV Treatment*. Guide the participants through the discussion using the following outline of the presentation. Inform participants that the following slides/information presented here may reflect questions they will be asked by PLWHA, and the sample language below provides guidance on ways to answer the questions.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 10 minutes

Learning Objectives:

- Review HIV treatment goals
- Define the importance of adherence
- Discuss the consequences of poor adherence, including resistance
- List strategies and tools to improve and maintain good adherence to HIV drugs

Talking Points for Trainer:

- ART can decrease viral loads to undetectable levels and increase CD4 counts, but only if taken as prescribed.
- Adherence means taking pills in the prescribed doses at the correct time.
- Missing or not taking doses of pills can lead to HIV drug resistance.
- There are strategies and tools to help promote ART adherence.
- This presentation is not designed to replace discussion with a healthcare provider or offer specific medical advice. It can however be a starting point for discussions about HIV treatment adherence.



The goals of HIV treatment are to:

- Decrease the amount of HIV in your blood (your “viral load”), slowing HIV’s progression
- Increase the number of CD4 cells in your blood (your “CD4 count”), protecting you from opportunistic infections

How do HIV drugs work?

- HIV drugs work by slowing the virus’ ability to make billions of copies of itself
- HIV drugs can reduce your viral load to such a low level it cannot be detected by laboratory tests (which is referred to as an “undetectable” level)
- To get the most benefit from HIV treatment you must take your HIV drugs properly, which is known as “adherence”

How do I take my HIV drugs properly?

- Adherence to your HIV treatment involves:
 - Taking all the medicines that make up your HIV drug combination in the correct quantities
 - Taking your HIV drugs at the right time
 - Following healthcare provider, pharmacist, or label instructions about food intake

- Checking for interactions with other drugs, both prescribed and over-the-counter

Why is it so important to adhere?

- Taking your HIV drugs properly means that the levels of those drugs will be high enough to effectively fight HIV
- That means HIV cannot reproduce at its usual pace, making copies that are “resistant” to the HIV drugs you are taking
- “Resistance” is bad because it means the virus can overcome the HIV drugs you are taking and they will stop working

So resistance is bad, right?

- The consequences include:
 - An increase in your viral load to detectable levels
 - A decrease in your CD4 count
- Your healthcare provider will likely switch you to alternative HIV drugs (ones that work against drug-resistant HIV but may have more side effects or pose other challenges)

How many doses can I miss?

- You will receive the best results from your HIV treatment by taking all or almost all of the doses of your HIV drugs properly
- Ask your healthcare provider what you should do if you miss a dose; this varies depending on the HIV drugs you are taking
- Typically if you have missed a dose and remember within a few hours it is okay to take your HIV drugs
- If it has been more than a few hours, it may be too late for that particular dose
- Never take a double dose of your HIV drugs to make up for one you may have missed

What can I do to better adhere?

- Be involved in decisions about your HIV treatment – an active member of your HIV care team
- Seek assistance with mental health and substance abuse issues
- Ask your healthcare provider about avoiding or managing side effects that can be barriers to adherence

There are also some practical tools to help you adhere to your HIV drugs, including:

- Keeping track of your HIV drug intake on a calendar or day-minder
- Pill boxes (check with your pharmacist to make sure the HIV drugs are suitable for storing out of their original container)
- Alarms on your cell phone, watch, or computer

Where can I go for help?

- If you are having ongoing difficulties taking your HIV drugs, talk to your healthcare provider
- For general support, visit a local AIDS service organization or health clinic
- You can also visit patient-friendly websites
 - www.thebody.com
 - www.poz.com
- You can recommend your healthcare provider visit professionally oriented websites
 - www.iapac.org
 - www.nursesinaidscare.org

Recommendation to the trainer: After each presentation, allocate time for Q & A, discussion, comments and feedback. You can also take Q & A after each slide but be mindful that it may consume your time and divert the group from the learning objectives of the presentation.

SECTION 5

Drug Resistance and HIV Treatment

Trainer Instructions: This section focuses on the basics of HIV drug resistance - which is an outcome of poor or non-adherence. For this section, use the set of slides titled *Drug Resistance and HIV Treatment*. Guide the participants through the discussion using the following outline of the presentation. Inform participants that the following slides/information presented here may reflect questions they will be asked by PLWHA, and the sample language below provides guidance on ways to answer the questions.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 10 minutes

Learning Objectives:

- Identify HIV drug resistance
- Discuss resistance testing
- Review strategies to avoid resistance
- Review strategies to manage resistance

Talking Points for Trainer:

- Among the goals of ART are a sustained decrease in viral load to undetectable levels, and an increase in CD4 counts.
- Poor or non-adherence to ART can lead to HIV drug resistance, which contributes to HIV treatment failure.
- HIV drug resistance can be avoided by good adherence, and managing any barriers to good adherence (e.g., side effects).
- Resistance can be transmitted, thus safer sex and harm reduction strategies are important.
- If resistance develops, there are available HIV treatment options to manage drug-resistant HIV.
- This presentation is not designed to replace discussion with a healthcare provider or offer specific medical advice. It can however be a starting point for discussions about HIV drug resistance.



What is resistance?

- HIV makes billions of new copies daily
- These copies are not always identical; the tiny differences are known as “mutations”
- Some of these mutations are in parts of the virus that are targeted by ARV drugs, which means the new copies are less easily controlled by the drugs (aka “drug-resistant” virus copies)

What is cross-resistance?

- If resistance develops to one ARV drug, this may mean that the virus is also resistant to other, similar drugs you have not taken, which is called “cross-resistance”

- Cross-resistance can affect all available ARV drugs, but it is not inevitable
- Your healthcare provider will select an ARV drug that is likely to be the most effective against your virus if resistance does develop

What does resistance mean for me?

- The consequences of developing resistance include:
 - An increase in your viral load to detectable levels
 - A decrease in your CD4 count
 - Your healthcare provider will likely switch you to alternative ARV drugs (ones that work against drug-resistant HIV but may have more side effects or pose other challenges)
 - Maintaining your first combination of ARV drugs is highly recommended to keep your future treatment options open.

How is resistance determined?

- Blood tests:
 - Genotypic
 - Phenotypic
- These tests are used when a person is first diagnosed HIV positive to determine whether she/he has acquired resistant-virus
- And as a routine part of HIV clinical management, performed when HIV treatment is started and when it is changed

How do I avoid resistance?

- Take your HIV treatment in the prescribed doses at the correct time, in the correct amount, and in the correct way
- Talk to your healthcare provider if you find yourselves struggling with taking your HIV treatment, including:

- Pill burden
- Side effects
- Alcohol, substance abuse
- Depression

How is resistance managed?

- If you develop resistance to one or more of your current ARV drugs, your healthcare provider will likely change your HIV treatment regimen
- Selection of a new HIV treatment regimen will be based on the results of a resistance test
- There are HIV drug options available for drug-resistant HIV

Can I transmit resistance?

- Drug-resistant HIV can be sexually transmitted, as well as through contact with HIV-infected blood (for example through injection drug use), or from an HIV-positive mother to her baby
- If you have a detectable viral load (and drug-resistant virus), there is a risk you could transmit resistance
- Practice safer sex, and if you are an injection drug user, use clean needles/syringes

Recommendation to the trainer: After each presentation, allocate time for Q & A, discussion, comments and feedback. You can also take Q & A after each slide but be mindful that it may consume your time and divert the group from the learning objectives of the presentation.

SECTION 6

State of HIV Care in the United States

Trainer Instructions: This section focuses on the basics of entry into and retention in HIV care. For this section, use the set of slides titled *State of HIV Care in the United States*. Guide the participants through the discussion using the following outline of the presentation.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 20 minutes

Learning Objectives:

- Discuss the importance of timely entry into and retention in HIV care
- Define how discrimination, isolation, and stigma can represent barriers to optimal engagement in HIV care

Talking Points for Trainer:

- Timely entry into and retention in HIV care is absolutely critical. Delayed entry can lead to progression to AIDS, onset of OIs, and hastened death.
- Remaining in care is important, and failure to remain engaged in HIV care can place PLWHA at an increased risk of acquiring HIV drug resistance and achieving poor health outcomes.
- Discrimination, stigma, and isolation are barriers to HIV status disclosure and engagement in HIV care. An environment conducive to taking an HIV test, disclosing status, and living positively with an HIV diagnosis is important to effective HIV treatment and prevention.



Entry into care:

- Failure to initiate timely HIV care after diagnosis is common
 - 75% of newly diagnosed link to care within 6-12 months
- Delayed entry into care is associated with:
 - Greater likelihood of progression to AIDS
- Among individuals initially diagnosed in 2009, one-third were diagnosed with AIDS, so they are presenting late
 - Greater risk of HIV transmission
- Percentage of newly diagnosed individuals receiving HIV care within after diagnosis:
 - St. Louis: 73% after 1 year
 - New York City: 64% after 3 months
 - Antiretroviral Treatment and Access Study: 60% within 6 months

Retention in care:

- Successful HIV treatment requires sustained retention in care
- 50% of HIV-positive individuals are not engaged in regular HIV care
 - Do not have sustained access to ART and other services

- Are at increased risk of HIV drug resistance
- Experience poor health outcomes, including death
- Contribute to HIV transmission in the community

“The Challenge”:

- Between 45-55% of individuals fail to receive HIV care during any year
- About one third of individuals fail to access care for 3 consecutive years in some communities
- 25-44% of HIV-positive individuals are entirely lost to follow up in some settings

Cascade of engagement in care:

- According to the Gardner Cascade, of HIV-positive individuals:
 - 79% are aware of their status
 - 25% aren't linked to care within 1 year of diagnosis
 - 60% are not receiving regular care
 - 19% have undetectable HIV viral loads

Linkage to and retention in care:

- Percentage of all HIV-positive individuals engaged in stages of HIV care (2010)
 - 80% know their status
 - 62% linked to care
 - 41% stay in care
 - 36% receive treatment
 - 28% have undetectable viral loads

Geography of the US HIV epidemic:

- Highest number of new cases in the South, and the Northeast
- Majority of cases in cities
 - Baton Rouge, LA
 - Miami, FL
 - Jackson, MS

- Baltimore, MD
- New Orleans, LA
- Columbia, SC
- Washington, DC

Racial and ethnic inequalities:

- People of color have higher rates of HIV infection
 - African Americans:
 - 14% of the population
 - 44% of new cases
 - 44% of HIV population
 - Hispanics/Latinos:
 - 16% of the population
 - 20% of new cases
 - 19% of HIV population

Discrimination, isolation, stigma:

- US PLWHA are concerned about disclosing their status due to:
 - Social discrimination – 90%
 - Impact on ability to establish future relationships – 57%
 - Risk of losing employment – 36%
 - Risk of losing family and friends – 32%
 - Risk of losing health insurance – 30%
 - Impact on current relationship – 29%
- US PLWHA also face unique obstacles to their engagement in HIV care, including:
 - Discrimination (sexual orientation) – 16%
 - Social isolation – 42%
 - Stigma (of any kind) – 42%

Recommendation to the trainer: After each presentation, allocate time for Q & A, discussion, comments and feedback. You can also take Q & A after each slide but be mindful that it may consume your time and divert the group from the learning objectives of the presentation.

SECTION 7

Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV

Trainer Instructions: This section focuses on a set of recently published global guidelines that outline evidenced-based interventions to improve entry into and retention in HIV care, as well as ART adherence for PLWHA. For this section, use the set of slides titled *Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV*. Guide the participants through the discussion using the summary table found on the following pages.

Please present the information in this section that is most relevant to your audience, and avoid reading word for word.

Duration: 20 minutes

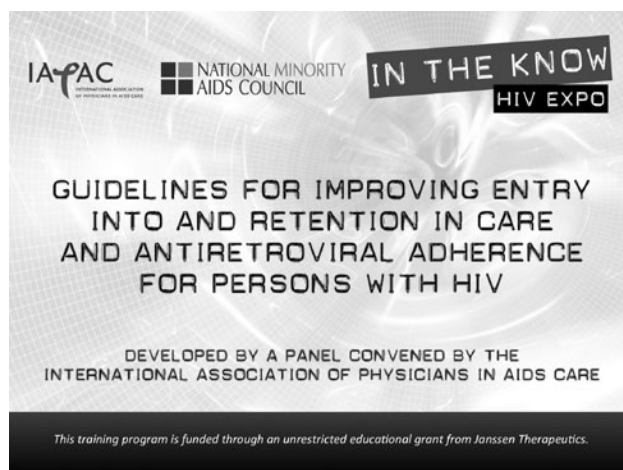
Learning Objectives:

- Recognize the importance of the guidelines to improve entry into and retention in HIV care, as well as ART adherence, for PLWHA
- Understand the roles other healthcare

professionals play in implementing the guidelines' recommendations

Talking Points for Trainer:

- This section will highlight information on guidelines published June 5, 2012, by the *Annals of Internal Medicine*.
- Timely entry into and retention in HIV care are essential to the provision of effective ART, delayed onset of AIDS, and a healthy life living with HIV that is virologically suppressed.
- Of persons who know their HIV status in the United States, only 69% were linked to care and only 59% were retained in care. Achieving a high level of ART adherence is among the key determinants of successful HIV treatment.
- These guidelines are evidence-based recommendations to help providers optimize entry into and retention in care and support ART adherence for PLWHA.



What these guidelines address:

- Entry and retention in HIV care
- Monitoring ART adherence
- Interventions to improve ART adherence
- Adherence tools for patients
- Education and counseling interventions
- Health system and service delivery interventions
- Special populations

SUMMARY TABLE OF RECOMMENDATIONS

Entry Into and Retention in HIV Medical Care

1. Systematic monitoring of successful entry into HIV care is recommended for all individuals diagnosed with HIV (II A).
2. Systematic monitoring of retention in HIV care is recommended for all patients (II A).
3. Brief, strengths-based case management for individuals with a new HIV diagnosis is recommended (II B).
4. Intensive outreach for individuals not engaged in medical care within 6 months of a new HIV diagnosis may be considered (III C).
5. Use of peer or paraprofessional patient navigators may be considered (III C).

Monitoring ART Adherence

6. Self-reported adherence should be obtained routinely in all patients (II A).
7. Pharmacy refill data are recommended for adherence monitoring when medication refills are not automatically sent to patients (II B).
8. Drug concentrations in biological samples are not routinely recommended (III C).
9. Pill counts performed by staff or patients are not routinely recommended (III C).
10. Electronic drug monitors are not routinely recommended for clinical use (I C).

Antiretroviral Strategies

11. Among regimens of similar efficacy and tolerability, once-daily regimens are recommended for treatment-naïve patients beginning ART (II B).
12. Switching treatment-experienced patients receiving complex or poorly tolerated regimens to once-daily regimens is recommended, given regimens with equivalent efficacy (III B).
13. Among regimens of equal efficacy and safety, fixed-dose combinations are recommended to decrease pill burden (III B).

Adherence Tools for Patients

14. Reminder devices and use of communication technologies with an interactive component are recommended (I B).
15. Education and counseling using specific adherence-related tools is recommended (I A).

Education and Counseling Interventions

16. Individual one-on-one ART education is recommended (II A).
17. Providing one-on-one adherence support to patients through 1 or more adherence counseling approaches is recommended (II A).
18. Group education and group counseling are recommended; however, the type of group format, content, and implementation cannot be specified on the basis of the currently available evidence (II C).
19. Multidisciplinary education and counseling intervention approaches are recommended (III B).
20. Offering peer support may be considered (III C).

Health System and Service Delivery Interventions

21. Using nurse- or community counsellor-based care has adherence and biological outcomes similar to those of doctor- or clinic counsellor-based care and is recommended in under-resourced settings (II B).
22. Interventions providing case management services and resources to address food insecurity, housing, and transportation needs are recommended (III B).
23. Integration of medication management services into pharmacy systems may be considered (III C).
24. DAART is not recommended for routine clinical care settings (I A).

Pregnant Women

25. Targeted PMTCT treatment (including HIV testing and serostatus awareness) improves adherence to ART for PMTCT and is recommended compared with an untargeted approach (treatment without HIV testing) in high-HIV-prevalence settings (III B).
26. Labor ward-based PMTCT adherence services are recommended for women who are not receiving ART before labor (II B).

Substance Use Disorders

27. Offering buprenorphine or methadone to opioid-dependent patients is recommended (II A).
28. DAART is recommended for individuals with substance use disorders (I B).

SUMMARY TABLE OF RECOMMENDATIONS *(continued)*

Substance Use Disorders *(continued)*

29. Integration of DAART into methadone maintenance treatment for opioid-dependent patients is recommended (II B).

Mental Health

30. Screening, management, and treatment for depression and other mental illnesses in combination with adherence counseling are recommended (II A).

Incarceration

31. DAART is recommended during incarceration (III B) and may be considered upon release to the community (II C).

Homeless and Marginally Housed Individuals

32. Case management is recommended to mitigate multiple adherence barriers in the homeless (III B).

Homeless and Marginally Housed Individuals *(continued)*

33. Pillbox organizers are recommended for persons who are homeless (II A).

Children and Adolescents

34. Intensive youth-focused case management is recommended for adolescents and young adults living with HIV to improve entry into and retention in care (IV B).
35. Pediatric- and adolescent-focused therapeutic support interventions using problem-solving approaches and addressing psychosocial context are recommended (III B).
36. Pill-swallowing training is recommended and may be particularly helpful for younger patients (IV B).
37. DAART improves short-term treatment outcomes and may be considered in pediatric and adolescent patients (IV C).

ART = antiretroviral therapy; DAART = directly administered antiretroviral therapy; PMTCT = prevention of mother-to-child transmission.

Grading Scales for Quality of the Body of Evidence and Strength of Recommendations

Quality of the Body of Evidence	Interpretation
Excellent (I)	Randomized, controlled trial evidence without important limitations; overwhelming evidence from observational studies
High (II)	Randomized, controlled trial evidence with important limitations; strong evidence from observational studies
Medium (III)	Randomized, controlled trial evidence with critical limitations; observational study evidence without important limitations
Low (IV)	Observational study evidence with important or critical limitations

Strength of Recommendation	Interpretation
Strong (A)	Almost all patients should receive the recommended course of action.
Moderate (B)	Most patients should receive the recommended course of action. However, other choices may be appropriate for some patients.
Optional (C)	There may be consideration for this recommendation on the basis of individual patient circumstances. Not recommended routinely.

Recommendation to the trainer: After each presentation, allocate time for Q & A, discussion, comments and feedback. You can also take Q & A after each slide but be mindful that it may consume your time and divert the group from the learning objectives of the presentation.

SECTION 8

Role of Peer Educators (and Patient Navigators) in Implementing the Entry Into and Retention in Care and Antiretroviral Adherence Guidelines

Trainer Instructions: This section focuses primarily on guideline recommendations either specific to or related to the role peer educators or patient navigators can play within the HIV care team. Have participants break into groups, and instruct them to read the recommendations, and refer to the summary paragraph below each recommendation to better understand the science behind each one.

Duration: 20 minutes

Learning Objectives:

- Understand a peer educator's role in implementing the recommendations

Have participants break into groups to review and discuss each recommendation in this section in the context of the following questions:

1. How does this recommendation help you define or modify your role as a peer educator in the community?
2. How would you implement the recommendation in your work environment?
3. How will this recommendation be applied under challenging circumstances? For example, working with the homeless/marginally housed or people with a history of substance use?

Recommendation 3

Brief, strengths-based case management for individuals with a new HIV diagnosis is recommended (II B).

The Antiretroviral Treatment and Access Study evaluated entry into and retention in care as part of a multisite randomized control study in several US care sites comparing strengths-based case management

sessions (up to five in a 90-day period) with passive referrals for local care among patients with recently diagnosed HIV infection. Trained social workers helped clients to identify their internal strengths and assets to facilitate successful linkage to HIV medical care. A significantly higher proportion of the case-managed participants visited an HIV clinician at least once within six months (78% vs. 60%) and at least twice within 12 months (64% vs. 49%). However, availability of resources may impede implementation in a given jurisdiction or service area.

Recommendation 4

Intensive outreach for individuals not engaged in medical care within 6 months of a new HIV diagnosis may be considered (III C).

In a sample of 104 individuals in whom HIV was diagnosed within six months before enrolling in the US Special Projects of National Significance Outreach Initiative, 92% attended medical appointments within six months of enrollment. At study baseline, 14% of individuals had undetectable HIV-1 RNA, which increased to 45% after 12 months of follow-up. This observational demonstration project used a variety of approaches, focusing on individuals considered underserved by the healthcare system (such as women, youth, and people with a history of substance use or mental illness).

Recommendation 5

Use of peer or paraprofessional patient navigators may be considered (III C).

Patient navigation has been described as a model of care coordination and is largely based on peer-based programs established for patients with cancer. Patient navigators are trained to help HIV-infected patients facilitate interactions with healthcare. In an analysis of four patient-navigation interventions from the US Special Projects of National Significance Out-

reach Initiative, involving more than 1,100 patients who were inconsistently engaged in care, the proportion with at least two visits in the previous six months increased from 64% at baseline to 87% at 6 months and 79% at 12 months in the intervention group. In addition, the proportion of patients with undetectable HIV-1 RNA was 50% greater at 12 months than at baseline.

Recommendation 15

Education and counseling using specific adherence-related tools is recommended (I A).

The available literature suggests that some tools may be more beneficial to patient adherence when combined with education or counseling. Seven studies evaluated a particular adherence tool (pill organizer, dose planner, reminder alarm device, or EDM) as distinguished from general one-on-one education and counseling. All but one demonstrated an effect on adherence, and three of the six that investigated effects on biological markers found significant positive effects. Three studies that used EDMs with counseling about missed doses showed improvement in adherence, and two showed improvement in biological markers. A factorial-design randomized, controlled trial (RCT) and another RCT showed the inferiority of using a reminder device without counseling and suggested that tools may be most successful when offered as part of a comprehensive support package.

Recommendation 16

Individual one-on-one ART education is recommended (II A).

Of the 14 interventions with ART education components, 10 had favorable effects on adherence outcomes, two had initial effects that deteriorated over time, and two showed no benefit on adherence; only one study demonstrated clear benefit on biological markers, six did not evaluate biomarkers, and seven showed no biomarker benefit. Among effective interventions, education was not the only component; most interventions also included counseling or skills-building, along with activities to promote adult learning. Group-delivered education is addressed in recommendation 18.

Recommendation 17

Providing one-on-one adherence support to patients through one or more adherence counseling approaches is recommended (II A).

Strategies to support adherence that involve one-on-one discussions targeting enhancement of facilitators and easing of barriers are recommended. Twenty-seven interventions in the evidence base used individual adherence counseling; of the 25 evaluating adherence, 16 established positive effects, three demonstrated as-treated or post hoc effects, three demonstrated early effects that deteriorated over time, and three demonstrated no benefit. Of the 17 that included biological outcomes, 12 demonstrated no benefit and five demonstrated positive effects. Although most interventions are delivered in person, there are also successful examples of telephone-based counseling or mixed in-person and telephone-based models and home visits. Further, expanding one-on-one counseling to include serodiscordant partners has demonstrated some benefit on adherence, although not on HIV-1 RNA, whereas inclusion of “caregivers” with ART-naïve patients had mixed results (no benefit in 1 study and support for effects on adherence and HIV-1 RNA overall but not over time in another). The evidence base suggests the utility of providing some form of discussion-based support to individuals receiving ART and provides a wide array of potentially effective specific interventions that should be carefully matched to clinic population needs and resources.

Recommendation 18

Group education and group counseling are recommended; however, the type of group format, content, and implementation cannot be specified on the basis of the currently available evidence (II C).

The evidence base included seven studies of group-based education and counseling programs targeting general clinic populations. Although some studies have demonstrated significant improvements in ART adherence, HIV-1 RNA, or CD4 cell counts and one study demonstrated effects in specific subsets of participants, other studies showed no significant improvements in adherence. Notably, studies targeted diverse patient groups and used a wide range of interventions, so the evidence does not clearly converge to support one particular approach to offering group education and counseling. Characterizing these

interventions as “group” interventions designates their main modality, but several interventions also used an individual component or support for group members.

Recommendation 19

Multidisciplinary education and counseling intervention approaches are recommended (III B).

Use of multidisciplinary teams is distinct from multiple team members duplicating efforts or content addressing adherence; multidisciplinary team members have clearly delineated roles and cover content specific to their particular area of expertise. A health-team approach in which 109 ART-naïve patients met with a pharmacist, dietitian, and social worker for targeted education and counseling before ART initiation did not produce significant effects on pharmacy refill-based adherence at 12 months but did significantly affect HIV-1 RNA outcomes. Another intervention using nurses and pharmacists targeted multiple factors (such as diet, work, social support, tools, and skills-building); significant effects on adherence were reported, but HIV-1 RNA and CD4 cell count did not change significantly.

Recommendation 20

Offering peer support may be considered (III C).

Nine studies were reviewed and showed mixed outcomes. One reported null findings from a peer-based psycho-educational group, and eight studies examining interventions involving treatment partners or peers, or both, demonstrated some success. The evidence base exhibits diverse results for use of peers. Several interventions (e.g., including treatment partners to supervise or directly administer ART, peers to provide social support) showed improvement in adherence or biological markers or both. Combination of use of peers and intervention in these studies limits the ability to draw conclusion on the specific effect of peers versus the interventions they delivered.

Recommendation 21

Using nurse- or community counselor-based care has adherence and biological outcomes similar to those of doctor- or clinic counselor-based care and is recommended in underresourced settings (II B).

Two RCTs showed noninferiority of nursing ART care to doctor-based care. One trial found a nurse-peer model was not inferior to the traditional doctor-

counselor model in adherence, HIV-1 RNA, and CD4 outcomes. Another RCT also demonstrated noninferiority of CD4 and HIV-1 RNA outcomes with nurses rather than doctors caring for people receiving ART. A cohort analysis with a notable limitation (the exposed cohort differed from control cohort) showed that a system of providing ART through volunteers (trained and supervised by a clinical officer) in a rural community was not inferior, in the short term, to a clinic-based standard of care.

Recommendation 22

Interventions providing case management services and resources to address food insecurity, housing, and transportation needs are recommended (III B).

Research with US homeless populations has shown mixed results, but HIV-1 RNA levels improved in an as-treated analysis of a housing provision intervention. Case management is discussed in Recommendation 32. Cohort studies with comparator groups evaluated outcomes of interventions for food-insecure patients and showed that ART adherence, retention in care, and clinical outcomes can be enhanced with food supplementation programs. Addressing transportation issues in the context of case management and a home visit also may decrease missed appointments, especially among women with mental health or substance use disorders.

Recommendation 30

Screening, management, and treatment for depression and other mental illnesses in combination with adherence counseling are recommended (II A).

Randomized, controlled trials indicate that cognitive-behavioral therapy for depression and psychosocial stress improves ART adherence when conducted in tandem with ART adherence counseling. Combined mental health and ART adherence counseling interventions have shown significant reductions in depressive symptoms, improved ART adherence, and improved treatment outcomes in RCTs. In contrast, an RCT of a stress management intervention with no ART adherence counseling reduced psychological distress but did not improve ART adherence or treatment outcomes. Evidence further indicates that pharmacologic treatment of depression is beneficial for ART adherence and treatment outcomes.

Recommendation 32

Case management is recommended to mitigate multiple adherence barriers in the homeless (III B).

Case management includes referral to mental health and substance use treatment and housing (or housing vouchers), as appropriate, and can facilitate continuity when individuals are transitioning into and out of incarceration. However, referrals require the availability of infrastructure and resources, which differ dramatically among communities. One observational study showed that case management was associated with improved adherence and CD4 cell counts in a marginally housed population.

Recommendation 34

Intensive youth-focused case management is recommended for adolescents and young adults living with HIV to improve entry into and retention in care (IV B).

Among 174 HIV-infected youth, appointment attendance improved significantly after introduction of individualized case management focusing on increasing self-efficacy and developing group activities to improve support networks. In a cohort study of 61 young gay men who were newly diagnosed or in intermittent care, intensive case management, including initially weekly and then monthly meetings, also improved attendance to medical visits, and more intervention visits were associated with increased likelihood of ART prescription.

SECTION 9

Practical Application of Entry Into and Retention in Care and Antiretroviral Adherence Guidelines

Trainer Instructions: The purpose of this section is to give participants the opportunity to apply knowledge gained about the guidelines to improve entry into and retention in HIV care, as well as ART adherence for PLWHA, in a client-based approach. This will require engaging in individual client analysis, discussing with peers the applicability of various guidelines-recommended interventions, and learning how to develop a course of action collectively.

Divide the participants into groups of 5-10 people. Have each group appoint a note taker. Each group will be assigned one of the training topic areas (*Handouts 4-9*), first from case study session 1 (topics 1-3), then from case study session 2 (topics 4-6) if time permits. Groups will have 30 minutes to answer questions for their assigned training topic and as a group they will decide what to do for their patient. After 30 minutes of smaller group discussion, the trainer/facilitator reads case study training topic 1, and each group assigned that training topic would share their course of action. Then the same process will be repeated for training topics 2 and 3. If time permits, continue on to case study session 2 (topics 4-6).

Duration: 1 hour for each case study session (2 hours total)

Learning Objectives:

- Understand a peer educator's role in implementing the guidelines through interactive case studies.

Training Topics:

- Training Topic 1: Initiation of and retention in HIV care
- Training Topic 2: Promoting ART adherence and avoiding drug resistance
- Training Topic 3: Enhancing provider-patient communication and dialogue
- Training Topic 4: Understanding the nexus between HIV clinical and psychosocial management
- Training Topic 5: Managing side effects and toxicities associated with ART
- Training Topic 6: Delivering HIV health promotion messages related to lifestyle interventions

INTERACTIVE EXERCISE IV

Training Topic 1: Initiation of and Retention in HIV Care

Case Study 1 is a 23-year-old African-American female. She received a diagnosis of HIV at 19 years old. She has declined to initiate treatment to date, but she is now beginning to consider ART. She will be getting married in the near future and may want to start a family “at some point in the next few years.” She currently takes birth control pills to prevent pregnancy, and her partner uses condoms.

Give your patient a name:

Add other relevant patient characteristics:

Describe the top 3 concerns that you immediately think of when meeting this patient for the first time.

1.

2.

3.

Please list the questions that you would ask this patient to determine her readiness for initiating ART and her potential to adhere to her ARV regimen.

1.

2.

3.

4.

5.

Please list your “best practices” for peer educator-patient communication regarding:

ART Initiation:

Adherence:

Family Planning:

Health Promotion:

What specific tools and resources do you think this patient would benefit from in order to achieve greater adherence?

INTERACTIVE EXERCISE IV

Training Topic 2: Promoting ART Adherence and Avoiding Drug Resistance

Case Study 2 is a 57-year-old gay Latino man with history of hepatitis C virus (HCV) infection and is recently diagnosed HIV positive. He has a history of diabetes and hypertension; he is a former tobacco smoker. His current CD4 count is 225 cells/mm³, and HIV RNA level is 175,000 copies/ml. He has high cholesterol and his weight is 255 pounds.

Give your patient a name:

Add other relevant patient characteristics:

Describe the top 3 concerns that you immediately think of when meeting this patient for the first time.

1.

2.

3.

Please list the questions that you would ask this patient to determine his readiness for initiating ART and his potential to adhere to his ARV regimen.

1.

2.

3.

4.

5.

Please list your “best practices” for peer educator-patient communication regarding:

ART Initiation:

Adherence:

Co-morbidities:

Health Promotion:

What specific tools and resources do you think this patient would benefit from in order to achieve greater adherence?

INTERACTIVE EXERCISE IV

Training Topic 3: Enhancing Provider-Patient Communication and Dialogue

Case Study 3 is a 29-year-old pregnant African-American woman and is diagnosed HIV positive during routine pre-natal care. She is not yet linked to HIV care, but is clinically eligible for ART. She has no prior medical history, is treatment-naïve and has not disclosed her status to her partner or family.

Give your patient a name:

Add other relevant patient characteristics:

Describe the top 3 concerns that you immediately think of when meeting this patient for the first time.

1.

2.

3.

Please list the questions that you would ask this patient to determine her readiness for initiating ART and her potential to adhere to her ARV regimen.

1.

2.

3.

4.

5.

Please list your “best practices” for peer educator-patient communication regarding:

ART Initiation:

Adherence:

PMTCT:

Disclosure, Stigma:

Health Promotion:

What specific tools and resources do you think this patient would benefit from in order to achieve greater adherence?

INTERACTIVE EXERCISE IV

Training Topic 4: Understanding the Nexus between HIV Clinical and Psychosocial Management

Case Study 4 is a 35-year-old heterosexual Latino woman who presents for care. She has had multiple previous HIV care providers. The patient reports feeling isolated and without family or social support; she has a depressed mood and a high level of stress about her finances and relationship issues. The patient has three children, all HIV negative. She reports feeling fatigued and has lost 15 pounds. She is currently experiencing virologic failure on her second ARV regimen.

Give your patient a name:

Add other relevant patient characteristics:

Describe the top 3 concerns that you immediately think of when meeting this patient for the first time.

1.

2.

3.

Please list the questions that you would ask this patient to determine her readiness for switching and adhering to a new ARV regimen.

1.

2.

3.

4.

5.

Please list your “best practices” for peer educator-patient communication regarding:

Patient-Provider Communication:

Adherence:

Mental Health:

Side Effects:

What specific tools and resources do you think this patient would benefit from in order to achieve greater adherence?

INTERACTIVE EXERCISE IV

Training Topic 5: Managing Side Effects and Toxicities Associated with ART

Case Study 5 is an 18-year-old Caucasian gay man, has suppressed HIV RNA on a new second-line ARV regimen, reports having had difficulty adhering to his first ARV regimen because of side effects, and had virologic failure with drug resistant HIV. He has a history of bipolar disorder. He is alternately homeless and marginally housed, based on his ability to secure an odd job.

Give your patient a name:

Add other relevant patient characteristics:

Describe the top 3 concerns that you immediately think of when meeting this patient for the first time.

1.

2.

3.

Please list the questions that you would ask this patient to determine his potential to continue adhering to his ARV regimen.

1.

2.

3.

4.

5.

Please list your “best practices” for peer educator-patient communication regarding:

Adherence:

Side Effects:

Mental Health:

Quality of Life:

What specific tools and resources do you think this patient would benefit from in order to achieve greater adherence?

INTERACTIVE EXERCISE IV

Training Topic 6: Delivering HIV Health Promotion Messages Related to Lifestyle Interventions

Case Study 6 is a 47-year-old incarcerated Asian man, with a history of injection heroin use and is poorly linked to HIV medical services. He has had multiple previous ARV regimens and has not been consistently taking his ART prior to incarceration, but has been engaged in education and counseling in prison. His current CD4 count is 175 cells/mm³, and his HIV RNA level is 35,000 copies/mL.

Give your patient a name:

Add other relevant patient characteristics:

Describe the top 3 concerns that you immediately think of when meeting this patient for the first time.

1.

2.

3.

Please list the questions that you would ask this patient to determine his potential to adhere to his ARV regimen.

1.

2.

3.

4.

5.

Please list your “best practices” for peer educator-patient communication regarding:

Substance Use:

Adherence:

Engagement in Care:

Health Promotion:

What specific tools and resources do you think this patient would benefit from in order to achieve greater adherence?

SECTION 10

Conclusion

Trainer Instructions: This completes the train-the-trainer activity. Ask if there are any additional questions about the information presented.

Congratulate participants, and present them with their individualized Certificates of Completion, which acknowledges their dedication to ensure PLWHA are successfully linked to and engaged in HIV care, including helping to promote ART adherence.

Next Steps

By completing this training, peer educators have been provided with the knowledge and tools they need to implement the recommendations discussed, and go on to train and certify other peer educators in their respective communities. However, the field of HIV medicine evolves quickly, thus peer educators must participate in ongoing continuing education opportunities.

Inform participants that all information and training materials are available on the IAPAC and NMAC websites (www.iapac.org/www.nmac.org), where additional capacity-building activities are also regularly posted.

Glossary of Key Terms

Following are key terms as described in the 7th Edition of the *AIDSinfo Glossary of HIV/AIDS-Related Terms*.¹⁴

Acquired Immunodeficiency Syndrome (AIDS): A disease of the immune system due to infection with HIV. HIV destroys the CD4 T lymphocytes (CD4 cells) of the immune system, leaving the body vulnerable to life-threatening infections and cancers. AIDS is the most advanced state of HIV infection.

Adherence: Taking medications exactly as prescribed. Poor adherence to an HIV treatment regimen increases the risk for developing drug-resistant HIV and virologic failure.

Antiretroviral (ARV): A drug used to prevent a retrovirus, such as HIV, from replicating. The term primarily refers to antiretroviral (ARV) drugs or regimens.

Antiretroviral Therapy (ART): The recommended treatment for HIV infection. Antiretroviral therapy (ART) involves using a combination of three or more antiretroviral (ARV) drugs from at least two different HIV drug classes to prevent HIV from replicating.

CD4 Count: A laboratory test that measures the number of CD4 T lymphocytes (CD4 cells) in a sample of blood. In people with HIV, the CD4 count is the most important laboratory indicator of immune function and the strongest predictor of HIV progression. The CD4 count is one of the factors used to determine when to start antiretroviral therapy (ART). The CD4 count is also used to monitor response to ART.

Drug Class: A group of drugs that share common properties, which may include a similar mechanism of action, chemical structure, or approved use. Antiretroviral (ARV) drugs are classified into six drug classes on the basis of how each interferes with the HIV life cycle. These six classes include the nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), integrase inhibitors, CCR5 antagonists, and fusion inhibitors.

Drug Resistance: When a bacteria, virus, or other microorganism mutates (changes form) and becomes insensitive to (resistant to) a drug that was previously effective. Drug resistance can be a cause of HIV treatment failure.

Human Immunodeficiency Virus (HIV): The virus that causes AIDS, which is the most advanced stage of HIV infection. HIV is a retrovirus that occurs as two types: HIV-1 and HIV-2. Both types are transmitted through direct contact with HIV-infected body fluids, such as blood, semen, and genital secretions, or from an HIV-infected mother to her child during pregnancy, birth, or breastfeeding (through breast milk).

People Living with HIV/AIDS (PLWHA): Infants, children, adolescents, and adults infected with HIV/AIDS.

Pre-Exposure Prophylaxis (PrEP): Administration of antiretroviral (ARV) drugs before potential HIV exposure in order to reduce the risk of HIV infection. Clinical trials are underway to determine if pre-exposure prophylaxis (PrEP) is a safe and effective way to reduce HIV transmission in people at high risk for HIV infection.

Standard of Care: Treatment that experts agree is appropriate, accepted, and widely used for a given disease or condition.

Treatment as Prevention (TasP): The provision to and use of ART by PLWHA to reduce morbidity and mortality as well as the risk of onward HIV transmission through durable viral suppression.

Treatment Failure: When an antiretroviral (ARV) regimen is unable to control HIV infection. Treatment failure can be clinical failure, immunologic failure, virologic failure, or any combination of the three. Factors that can contribute to treatment failure include drug resistance, drug toxicity, or poor treatment adherence.

Treatment-Experienced: When a person with HIV is currently taking or has previously taken antiretroviral (ARV) drugs.

Treatment-Naïve: When a person with HIV has never taken antiretroviral (ARV) drugs.

Undetectable Viral Load: When the amount of HIV in the blood is too low to be detected with a viral load (HIV RNA) test. Antiretroviral (ARV) drugs may reduce a person's viral load to an undetectable level; however, that does not mean the person is cured. Some HIV, in the form of latent HIV reservoirs, remain inside cells and in body tissues.

Viral Load (VL): The amount of HIV in a sample of blood. Viral load (VL) is reported as the number of HIV RNA copies per milliliter of blood. An important goal of antiretroviral therapy (ART) is to suppress a person's VL to an undetectable level—a level too low for the virus to be detected by a VL test.

Virologic Failure: A type of HIV treatment failure. Virologic failure occurs when antiretroviral therapy (ART) fails to suppress and sustain a person's viral load to less than 200 copies/mL. Factors that can contribute to virologic failure include drug resistance, drug toxicity, and poor treatment adherence.

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Notes

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