

What Support Services Providers Should Know About HIV Clinical Guidelines: Improving Health Outcomes Series*

New York State Department of Health AIDS Institute

TOPIC: Primary Care for People Living with HIV

BACKGROUND

The role of the primary care provider is to serve as a patient's first point of contact with the health care system. The primary care provider is concerned with a wide range of factors that affect a person's health. The components of primary care include: medical history and physical examinations; laboratory assessments and diagnostic testing; health maintenance and preventive care; coordination of care; and facilitating access to specialty, emergency and chronic care.

Maintaining a relationship with a primary care provider is especially important for people living with HIV/AIDS. The HIV Clinical Guidelines Program of the AIDS Institute's Office of the Medical Director has established comprehensive clinical guidelines for primary care of people living with HIV. Being familiar with these clinical guidelines will enable support services providers to educate their clients about HIV primary care and play a key role in promoting positive health outcomes for their clients.

Key Point:

Support services providers who are aware of HIV primary care guidelines can actively educate their clients about HIV primary care and help empower them to access the full range of services available to maximize their health. Support services providers should work with the client and the entire care team to:

1. help the client advocate for his/her health care needs and preferences;
2. address any barriers to the client's participation in primary care;
3. encourage the client to see the primary care provider at least four times per year;
4. educate clients about appropriate use of primary, emergency and long term care;
5. help clients understand and complete all needed laboratory work;
6. assess and address a variety of psycho-social issues including housing, employment and entitlements essential for promoting wellness;
7. assess and address mental health and substance use issues;
8. refer and educate clients about available prevention and health promotion services;
9. promote communication, coordination of care and case conferencing as needed.

The complete guidelines titled "Primary Care Approach to the HIV-Infected Patient", including references, can be found at: <http://hivguidelines.org/>

* The *Improving Health Outcomes Series* is designed to give support services providers important information about HIV clinical care guidelines. The clinical guidelines highlighted in this series were developed by the HIV Clinical Guidelines Program of the Office of the Medical Director, AIDS Institute. This series describes the role that support services providers can play in supporting the efforts of medical providers. Please note that these roles will vary based on a support service provider's specific job responsibilities, training and work setting.

MEDICAL APPOINTMENTS FOR PEOPLE WITH HIV

Primary Care Visits

An important question facing every person living with HIV is, “Should I see a general primary care provider or a specialist in treating HIV?” Both HIV specialists and primary care providers should be capable of taking care of people with HIV at all stages of the disease. However, general primary care providers should consult with an HIV specialist when beginning or changing an HIV+ patient’s treatment regimen.¹ A provider is considered an HIV specialist when he/she has attended a certain number of continuing education programs and has experience treating a certain minimum number of patients with HIV per year.

Recommendation # 1: The entire care team should work with the patient to keep on-file a current, signed copy of the “HIPAA Compliant Authorization for Release of Medical Information and Confidential HIV Related Information”. This promotes communication and coordination between support providers and primary care providers.

Recommendation # 2: Support services providers should play a critical role in initiating primary care for people living with HIV by:

- Explaining the elements of primary care and referring clients to reputable primary care providers; and
- Taking steps to prepare the clinical provider to address language barriers, such as the need for a translator or sign language interpreter.

Recommendation # 3: Support services providers should educate their HIV+ clients about primary care and encourage active participation in HIV primary care as follows:

- All patients who are clinically stable should see their primary care provider at least once every four months;
- Additional visits may be needed as follows:
 - At the beginning of care;
 - When the person is having a specific health problem; and/or
 - When starting or changing anti-retroviral treatment.
- If the patient’s primary care provider is not an HIV specialist, the provider should consult with an HIV specialist when beginning or changing treatment.

Individuals living with HIV may need to access emergency care, specialty care, chronic care services, home health care services and other more intensive health care services. When the support services provider is kept abreast of the client’s clinical status, he/she is best able to work with the primary care provider and the client to identify the appropriate level of care for the patient. Routine case conferencing between medical and support services providers is critical to promoting effective coordination of care.

Recommendation # 4: Support services providers should reinforce that the primary care provider is the patient’s primary point of contact with the health care system. Based on recommendations from the primary care provider, the support services provider should help the patient access additional health services as needed.

The Comprehensive Physical Exam

Primary care includes the provider performing an annual comprehensive physical exam for patients living with HIV. The elements of this exam should include:

Element	Explanation
Vital signs, examining the patient's general appearance and asking about symptoms	Checking vital signs, appearance and symptoms is critical to monitoring the patient's health status, disease progression and effectiveness of treatment. Heart rate, blood pressure, weight and general appearance should be examined annually and during every visit. The provider should also ask about any specific symptoms.
Pain assessment	HIV+ patients are at increased risk for certain painful conditions. Addressing pain is important to the patient's general sense of well-being. Treatment of pain can be complicated if the patient has a history of substance use. However, patients should not be denied treatment for pain because of history of substance use.
Eye exam	Patients who report visual disturbances or who have a CD4 count below 50 should be referred to an ophthalmologist initially and every 6 months.
Oral exam	Providers should examine the patient's lips, mouth, gums, teeth, tongue and throat and refer for annual dental exam if the patient does not already have regular dental care.
Skin exam	Close examination of the patient's skin may offer the first sign of progression of HIV disease, other related conditions or toxicity from treatment.
Lymph node exam	Swollen lymph nodes are common among people living with HIV and should be monitored regularly.
Chest exam	The chest exam includes listening to the patient's heart and lungs for any abnormalities.
Abdominal exam	The abdominal exam allows the provider to detect enlargement of the organs, sensitivity in the areas of the abdomen or increased fat that may develop as a treatment side effect
Genital and rectal exam	Since patients may be reluctant to report symptoms of sexually transmitted diseases, the provider should examine the patient for ulcerative lesions and should examine the anal region. All HIV+ women should have a pelvic exam by their primary care provider or gynecologist at least annually.
Neurological exam	The neurological exam allows the provider to detect any changes in nerve functioning, body strength and mobility and changes in the patient's thinking processes

Recommendation # 5: Support services providers who are familiar with what is included in the comprehensive exam can help clients to:

- Be prepared for the exam;
- Identify strategies for answering any client questions about the exam; and
- Take advantage of the opportunity to report any new symptoms or changes.

LABORATORY ASSESSMENTS

Laboratory assessments and diagnostic screenings are an important part of primary care. In order for primary care providers to effectively manage a patient, he/she must have access to a variety of laboratory test results.

Assessment	Diagnostic Screen	Frequency
Immune system	CD4 lymphocyte count and percent	Initial and at least every 4 months
Viral load	Quantitative HIV RNA testing	Initial and at least every 4 months
Drug resistance	Resistance testing (genotype and phenotype)	Initial, at start of treatment and if treatment fails
Blood	Complete blood count	Initial and at least every 4 months
Kidney and urinary tract	Urinalysis Serum creatinine, BUN, total protein, and albumin	Initial and at least annually Initial and at least every 4 months
Metabolism	Fasting blood sugar Fasting lipid profile, including cholesterol	<u>Patients receiving HAART:</u> Before starting HAART, 3-6 months after starting and annually thereafter <u>Patients not receiving HAART:</u> Initial and annual
Liver	Screening for Hepatitis A, B and C Serum liver enzymes	Initial Initial and at least every 4 months for patients receiving HAART
STIs	Syphilis (all patients) Gonorrhea and Chlamydia (women)	Initial and on-going if at risk
Additional Tests	Amylase and lipase testing; Varicella antibody screening for adults with no history of chicken pox.	Initial

Recommendation # 6: Support services providers who are aware of the routine laboratory screening and assessments that are included in primary care should:

- Routinely check-in with clients about the status of lab work and encourage them to talk with their provider if lab work has not been ordered or completed;
- Help the client understand and complete all ordered lab work; and
- Help the client overcome any barriers to completing the lab work.

OPPORTUNISTIC INFECTIONS, IMMUNIZATIONS AND HEALTH MAINTENANCE

People living with HIV whose immune systems are significantly weakened are susceptible to opportunistic infections. Especially early in the epidemic, opportunistic infections were a common cause of death among people with HIV/AIDS. Laboratory assessment of the person's CD4 count will help providers identify patients who have a

weakened immune system. In addition, primary care providers perform a number of screenings for opportunistic infections including:

- Tuberculosis - performed initially and at least annually
- Cervical Pap test - for women: initial, 6 months and at least annually, if results are normal
- Anal Pap test - performed initially and annually for MSM, women with a history of cervical cancer and persons with a history of anogenital warts
- Toxoplasmosis - initial

Primary care guidelines recommend starting preventive treatment for several opportunistic infections when CD4 counts go below a certain level as follows:

- Pneumocystis jirovecii pneumonia (PCP) - initiated if CD4 <200 or 14%
- Toxoplasma encephalitis (TE) - initiated if CD4 <100 and patient has + screening
- Mycobacterium avium complex (MAC) - initiated if CD4 <50 and when needed

In some cases, if the person's immune system improves through anti-retroviral treatment, the preventive treatment for opportunistic infections may be stopped.

Immunization

Immunizations against infectious diseases are an extremely important component of care for people living with HIV. Concerns about vaccination for people with HIV include the potential danger from live vaccines and the ability of the patient's immune system to respond effectively to the vaccine. Clinical guidelines advise primary care providers to administer vaccines against the following illnesses: Tetanus, Diphtheria and Pertussis; Measles Mumps and Rubella (MMR); Influenza (not FluMist); Hepatitis A and B (in certain cases); Varicella; and, Human Papillomavirus (for women). Immunization schedules are modified for pregnant women and people with very low CD4 counts.

Age-Appropriate Health Maintenance

As people with HIV age, they should receive the same health maintenance screenings as others. Primary care providers instruct patients to perform breast and testicular exam and refer patients for colorectal cancer screening and other cancer screenings.

Recommendation # 7: Support services providers should actively encourage clients living with HIV to discuss screening and prevention of opportunistic and other infections with their primary care provider and take advantage of recommended immunizations.

MENTAL HEALTH, SUBSTANCE USE AND HEALTH PROMOTION

Primary care providers and support services providers have many important opportunities to work together to address the mental health, substance use, prevention and health promotion needs of people living with HIV. Primary care guidelines direct clinical providers to address these issues with their patients and patients often greatly value talking with their health provider about these issues. Primary care providers often have limited time with patients and need on-going assistance from support services providers to ensure that these issues are properly addressed and that the patient has access to needed mental health, substance use, prevention and health promotion services. Below is a list of assessments to be performed by the primary care provider including the elements to be addressed and the frequency of the assessment.

Psychosocial Assessment and Support Services

Elements: Housing status; employment status; educational level; presence of family / social support system; living will; health care proxy; permanency planning for children
Frequency: Initial and repeated annually

Mental Health Assessment and Services

Elements: Depression; anxiety; post traumatic stress disorder; suicidal ideation; sleep and appetite problems; psychiatric history, including psychotropic medication
Frequency: Initial and repeated annually

Substance Use Assessment and Services

Elements: Use of alcohol and other substances; possible effect of substance use on patient's health; referral for treatment; harm reduction options; options for obtaining new needles and syringes
Frequency: Initial and ongoing as needed

Partner Notification and Safer Sex

Elements: Importance of disclosure to partners; options for partner notification; counsel that HIV transmission can occur during unprotected sex even if patient has undetectable viral load; safer sex options; condom use; avoiding use of non-oxynol 9
Frequency: Initial and routine, on-going basis

Tobacco Use Assessment and Services

Elements: Smoking status; the importance of stopping smoking; offer referral to smoking cessation program
Frequency: Initial and offered throughout care if needed

Reproductive Health

Elements: Discuss family planning options; prevention of mother to child transmission of HIV; clinical guidelines for pregnant women living with HIV
Frequency: Initial, as needed

Domestic Violence

Elements: All male and female patients should be asked about current or previous domestic violence; emphasize confidentiality; explain exceptions to confidentiality such as the provider's responsibility to report child abuse
Frequency: Initial and repeated annually

Diet and Exercise

Elements: Importance of a healthy diet and regular exercise; diet and exercise and its impact on risk for diabetes, high blood pressure, lipid abnormalities; role of diet in managing medication side effects
Frequency: Initial and ongoing as needed

Recommendation # 8: Support services providers should work in collaboration with the primary care provider to assess, provide referrals and monitor client progress with regards to their mental health, substance use, prevention and health promotion needs. When the appropriate HIV-specific release of information is signed and in effect, this can be accomplished through case conferencing, sharing records and providing regular updates on client progress.

¹ Note: Additional specific clinical guidelines on Antiretroviral Therapy provide guidance on medications, initiating, monitoring and changing treatment regimens. For more details, visit www.hivguidelines.org