HIV Infected Women: Psychological Issues

Chapter 9:

Psychosocial Issues, Mental Health, and Substance Abuse

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Chapter 9: Psychosocial Issues, Mental Health, and Substance Abuse

Chapter 9 at a Glance

Psychosocial Issues, Mental Health, and Substance Abuse

Although healthcare providers for women living with HIV focus primarily on the physical manifestations of the condition, understanding the psychosocial, cultural, mental health, and substance abuse issues faced by HIV infected women is important to optimizing care. By developing a comprehensive treatment plan for the HIV infected woman that includes emotional support and treatment for coexisting psychosocial and mental health conditions, the care provider can help the woman to feel that the entirety of her experience is being addressed. This chapter reviews the principal psychosocial, cultural, mental health, and substance abuse issues relevant to women with HIV infection and makes recommendations for provider response, evaluation, and management.

Major Psychosocial and Cultural Issues Faced by Women with HIV Infection

A woman with HIV infection potentially faces many psychosocial issues that can significantly affect her ability to access or accept care. For many women, HIV infection is just one additional challenge in a life filled with poverty, abuse, substance use, and other hardships, and it may not even be perceived as the biggest problem.

Gender inequality: Gender inequality contributes to the spread of HIV infection (Table 9-1) and magnifies many of the problems women experience after becoming infected. Compared with men, women often have both less control over their sexuality and less power in many other spheres of their lives.

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Table 9-1

Gender Norms that Contribute to the Spread of HIV Infection

Men
- Gender norms related to masculinity can encourage men to have more sexual partners and older men to have sexual relations with much younger women
- Homophobia stigmatizes men who have sex with men, making them more likely to keep such activity covert and to have a female partner as a cover

Women
- Women and girls often have less information about HIV and fewer resources to take preventive measures
- Because of economic dependency and unequal power relations, women are often unable to negotiate safer sex practices
- Women may be subjected to forced sex, which can cause tears and lacerations in the vaginal mucosa and anal lining, thereby increasing the risk of HIV transmission
- Women who fear interpersonal violence may be less likely to disclose their HIV serostatus

Sources: Adapted from *Gender Issues—HIV & AIDS*. United Nations Development Fund for Women; *Gender, Women, and Health: Gender Inequalities and HIV*. World Health Organization (WHO). 2012

Race/ethnicity: In the United States, women living with HIV are disproportionately African-American or Hispanic. Many of these women have experienced stigma related to their race, ethnicity, or country of origin, and HIV may be particularly stigmatizing within their own communities. Language and cultural beliefs about health may act as barriers to care, and there may be lack of awareness and health literacy definicts, as well as other myriad social and structural barriers. Recent studies also highlight sometimes disparate treatment by health care providers. Healthcare providers must offer respect, awareness, and acceptance of cultural differences and proactively address these health disparities. They should develop a basic knowledge of a patient's culture, such as the involvement of family members in decision making (important in many Hispanic cultures), the use of alternative therapies or traditional healers (common in some African cultures), and rituals relating to birth and death. Language differences should be addressed with appropriately trained medical interpreters; in general, family members should not be asked to interpret.

Economic problems: HIV infected women are more likely than HIV infected men to be poor, unemployed, and uninsured or under-insured (*Clin Inf Dis* 2007;45:S255); women may be less likely to be able to keep their healthcare appointments because of a lack of transportation and may be unable to afford their medications. Poverty may lead some women to exchange sex for money, food, or other material support, placing them at increased risk for acquiring HIV. Poverty may also lead women to stay in abusive relationships.

Childbearing and childcare: The woman with HIV infection often has children, one or more of whom may also be HIV infected. She may be stigmatized if she becomes pregnant or expresses the desire to have children. Caring for her children will generally take precedence over caring for herself and lack of childcare may be a further barrier to accessing care.

Other caretaking: The woman with HIV is often a caretaker for other family members, who may include her husband or partner, aging parents, and/or grandchildren. Attending to these responsibilities may take priority over meeting her own needs and may result in the woman neglecting her own care.

Cultural issues and societal perceptions/pressures: Perceptions and expectations of women, including HIV infected women, vary in different cultures and societies. These expectations commonly center on childbearing, sexuality, and submission to men. Women are often expected to be virgins when they marry, to have several children after marriage, and to submit to sex or violence within relationships without complaint or choice. When women do not meet the expectations placed on them, they may feel guilt and shame and may pay a heavy price in terms of stigma or even safety.

Stigma/disclosure: Stigma has profoundly adverse effects on the prevention and treatment of HIV in women. For example, disclosure of one's HIV status can help with medication adherence, relationship authenticity, and prevention of transmission (*J Nurs Scholarsh* 2004;36(2):122); however, because of stigma, women who are infected may not disclose their status to a partner, family, or friends for fear of rejection, abandonment, or violence. The HIV infected woman may not feel comfortable insisting that her partner use a condom, fearing that the request may arouse suspicion about her serostatus. She may

be at increased risk for nonadherence because she does not want to take her antiretroviral medications in front of others, fearing that people may ask questions about the pills and her reasons for taking them. Table 9-2 presents issues women may need to consider prior to disclosing their HIV serostatus.

Table 9-2	
Decisions and Considerations Regarding Disclosure of HIV Status	
Decisions	**Considerations**
Who will make the disclosure?	Will the patient disclose for herself or designate someone else to do so on her behalf?
Who will be told?	Partners? Children? Family? Friends? Employer? Coworkers? Health care providers?
When will disclosure take place?	Immediately after diagnosis or after a period of adjustment? Before disclosure is made by someone else? Any time that feels right?
Under what circumstances will disclosure be made?	What are the necessary conditions for disclosure to occur?
How much information will be shared?	Will the patient tell all the details of her diagnosis?
What are the reasons for disclosure?	Is disclosure necessary to obtain needed services? To have the support of friends and family? To prevent transmission of infection? To prevent someone else from telling?
Are there any reasons not to disclose HIV status?	What are the times and circumstances when it may be best not to disclose (e.g., is there a possibility of harm?)?

Source: *Qual Health Res* 2006;16(10):1350

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Interpersonal violence: More than four million women a year in the United States are harmed by their husbands, boyfriends, or other intimate partners (*JAMA* 2010;304:596). Although no statistics are available on the number of HIV infected women who are victims of interpersonal violence (IPV), Gielen et al. (*Trauma Violence Abuse* 2007;8:178) found in a review of studies on IPV and HIV that HIV infected women appear to experience IPV at the same rates as uninfected women. Rates of adult lifetime physical or sexual IPV were roughly equivalent across studies and between HIV infected and uninfected women; more than 60% of women, regardless of HIV status, reported experiencing IPV. Abuse was both more frequent and more severe among HIV infected women, however, than among HIV uninfected women.

IPV is more complex for HIV infected than uninfected women. Those who are in abusive relationships are at risk for potential re-infection with HIV and for infection with other STDs because men who are violent are more likely to engage in risky sexual practices (*Sex Health* 2010;7:25). Abusive male partners are more likely than other men to be HIV infected; therefore, women who experience IPV have a higher incidence and prevalence of HIV (*Science*

2010;329:145). Women learn the futility of resisting their partners' attempts to control the timing and circumstances of sex because of their experiences of male dominance in sexual relationships. Women who are depressed, abusing substances, or dissociating from post-traumatic stress disorder (PTSD) are more likely to be at risk of IPV (*Science* 2010;329:145).

Because IPV is so common in many women's lives and because there is help available for women who are being abused, care providers should ask every patient about domestic violence, with such questions as the following: (ACOG Committee Opinion No. 518; *Obstet Gynecol* 2012;119:412)

- Within the past year, have you been hit, slapped, kicked, or otherwise physically hurt by someone?
- Are you in a relationship with a person who threatens or physically hurts you?
- Has anyone forced you to have sexual activities that made you feel uncomfortable?
- Have you ever been the perpetrator of violence?

If the woman is newly diagnosed, the clinician should ask about concerns she may have if/when her partner learns of her HIV serostatus.

Special Considerations

Homelessness: Structural and societal factors contribute to the increased numbers of homeless women, particularly since the economic recession of 2008 (*Curr HIV/AIDS Rep* 2007;4:181). The deinstitutionalization of mental health services, low wages, limited employment opportunities for women with few job skills, and difficulties receiving and maintaining government entitlements all contribute to homelessness among women.

Women are particularly susceptible to less visible forms of homelessness, such as staying with friends or family, "couch surfing," or exchanging sex for shelter. Transitions in and out of homelessness occur frequently for women in this vulnerable position. Riley et al. reported that female gender was one of the strongest predictors of poor health among homeless adults (*Curr HIV/AIDS Rep* 2007;4:181).

Women without stable housing are more likely to use illicit drugs, have multiple sex partners, and report poor physical and mental health compared with their sheltered counterparts. Exchanging sex for money, drugs, housing, food, and safety exposes women to violence and sexually transmitted infections, including potential infection or re-infection with HIV, yet women without stable housing may resort to this strategy for survival and may be unable to negotiate safer sexual practices. With competing needs for housing and food, and perhaps also for the care of children, appropriate health care may not be a priority for HIV infected women, especially if they are asymptomatic. Women who are homeless are more likely to use emergency health care services and to use health services in general inconsistently. They may feel that the stigma they already experience as a result of HIV infection is compounded by their marginal housing situation and may be less likely to search for assistance with either housing or health care (*Curr HIV/AIDS Rep* 2007;4:181). Care providers should be consistent in asking about their HIV infected patients' living situations,

whether or not they have enough food, and whether or not they have access to electricity and water, as these basic needs must be met before women can effectively manage their HIV infection.

Incarceration: The prevalence of HIV infection among incarcerated women is roughly double that among incarcerated men (*J Assoc Nurses AIDS Care* 2009;20:50). Life circumstances outside of prison tend to be very different for incarcerated women than for incarcerated men: women have higher levels of poverty, more exposure to violence and abuse, more substance abuse, and are more likely to face unstable living conditions. Incarcerated women also are more likely than incarcerated men to have used sex work to buy food and drugs; they are thus at greater risk than men for HIV infection.

Privacy is necessarily limited in prison, which may make inmates who are concerned about disclosure of their HIV status reluctant to access healthcare. Lack of medical privacy, or the lack of privacy when taking one's medications in prison, has been shown to be a barrier to adherence to antiretroviral therapy (ART) for the imprisoned (*J Assoc Nurses AIDS Care* 2009;20:50). By denying medical privacy to inmates, prisons inadvertently may be reducing ART adherence rates and increasing the risks of treatment failure and drug resistance, which could have public health consequences upon the release of inmates to the community. Positive interactions with prison healthcare providers, including time for private conversations about medications, can help HIV infected incarcerated women adhere to an ART regimen. Similarly, individualized decisions regarding the method of medication administration (e.g., keeping one's own medications, directly observed therapy) can also improve adherence. Education of prison staff, healthcare providers, and inmates can reduce the stigma associated with HIV infection, improve a woman's desire to protect her health, and increase adherence behaviors (*J Assoc Nurses AIDS Care* 2009;20:50).

Lesbian and transgender patients: Special issues, particularly relating to stigma and discrimination, face the HIV infected patient who is lesbian or transgendered. It is important that healthcare providers inquire about sexual practices in a nonjudgmental fashion (e.g., "Do you have sex with men, women, or both?") and also ask about specific practices in order to best advise about safe sex. Because many of these patients have had negative experiences with the healthcare system or with individual healthcare providers, it is critical to openly discuss concerns they may have related to care as a lesbian or transgendered person and to actively work to build trust and foster mutual respect.

Mental Health Issues

General Considerations

Mental health problems are common in the setting of HIV infection in women. Psychiatric illnesses often co-occur with HIV infection and have been linked with poor medication adherence and with the risk of suicide (*AIDS Care* 2009;21:1432). In one study of subjects with a dual diagnosis of HIV and

mental illness, HIV infected women were more likely than HIV infected men to have a serious mental illness, defined as a diagnosis of schizophrenia or major affective disorder, and at least one inpatient or two outpatient treatment contacts with healthcare providers related to these diagnoses (*Psychiatr Ser* 2009;60:974). The most common causes of psychiatric hospitalizations for HIV infected women include mood, anxiety, and psychotic disorders. Alcohol/substance abuse is significantly associated with mood, adjustment, anxiety, personality, and psychotic disorders. The most vulnerable women are those who are triply diagnosed (i.e., with HIV infection, a chronic mental illness, and a substance abuse disorder).

The cost of managing patients with multiple diagnoses is high. One study found that health care expenditures for triply diagnosed patients were nearly twice as high as those for people with HIV infection in general (*AIDS Care* 2009;21:1547). Inpatient care (36%), medications (33%), and outpatient services (31%) each accounted for roughly one-third of expenditures; costs were highest for patients on Medicare or Medicaid, not in stable residences, or with poor physical health or high viral loads (*AIDS Care* 2009;21:1547). Women were more likely than men to have poor access to care, defined as no outpatient medical visits, at least one emergency room visit without an associated hospitalization, and at least one hospitalization (*AIDS Care* 2009;21:1547).

Both men and women with HIV are more likely to experience a range of mental health issues, which most commonly include feelings of acute emotional distress, depression, anxiety, PTSD, and cognitive impairment (*Mental Health Screening: A Quick Reference Guide for HIV Primary Care Clinicians*. New York State Department of Health. 2012; http://www.hivguidelines.org/wp-content/uploads/mental-health-screening-06-21-2012.pdf. Accessed 7/18/2012).

Psychosis is more common among patients with HIV who abuse substances, particularly stimulants, than in the general population. With any change in mental status, a medical cause should be considered before determining that the cause is solely psychiatric.

Assessment

It is helpful to assess a patient's general psychosocial status by inquiring about the following:
- Who does the patient consider to be family?
- Does she have a social support system?
- Does she have a partner?
- What kind of work does she do? If unemployed, how does she spend her time?
- Does she have children? If yes, how many?

The care provider should also inquire about the patient's living situation, transportation needs, income adequacy, concerns for the future (including advance directives for healthcare planning), spiritual/religious support, and disclosure status.

It is important to obtain a detailed psychiatric history, including any prior use of psychotropic medications and any history of hospitalizations for mental health issues. Depression in particular can be a recurring problem and it will be helpful to know what medications or other treatments were effective for this disorder in the past. Complex psychiatric disorders require an interdisciplinary approach. Table 9-3 lists mental health disorders that should be assessed at baseline and at least annually in the HIV infected female patient.

Table 9-3	
Screening for Mental Health Disorders	
Condition	**Screening Considerations**
Alcohol and/or Substance Abuse	• The provider should inquire as to type, quantity, and frequency of alcohol and other substance use and whether the patient has experienced adverse consequences from this use • Addiction to alcohol and recreational drugs and the work required to obtain these substances can become the driving force in a patient's life, resulting in neglect of a woman's health and/or that of her children
Anxiety	• Anxiety is a common symptom in HIV infected patients; if it is severe or persistent, the patient may have an anxiety disorder. Other psychiatric disorders can also present with significant anxiety. • Anxiety can present with a wide range of physiological manifestations, including shortness of breath, chest pain, racing/pounding heart, dizziness, diaphoresis, numbness/tingling, nausea, or a sensation of choking. A medical etiology for such symptoms should first be ruled out. • Other possible presentations include fear, worry, insomnia or excessive sleeping, impaired concentration and memory, ruminations, compulsive rituals, and avoidant coping • Appetite may be affected; people may eat more or less than usual when depressed or anxious. A 24-hour diet recall or an inquiry about how a patient's clothes are fitting can help to assess changes in appetite.
Cognitive Impairment	• Because cognitive impairment may have an organic cause, current immune- system status and other symptoms should be considered • It is often helpful to ask significant others and/or family members if they have noted any change in the patient's cognitive status • The Mini Mental State Exam is a good, reliable tool for assessing cognitive impairment
Depression	• Depression is the most common mental health disorder in the HIV infected patient population, Depression may, however, be difficult to distinguish from symptoms such as fatigue. • People may eat or sleep more or less than usual when depressed • With depression it is common to wake earlier than usual and be unable to go back to sleep or to have repeated awakenings during the night • Asking two simple questions about mood and anhedonia ("Over the past 2 weeks, have you felt down, depressed, or hopeless?" and "Over the past 2 weeks, have you felt little interest or pleasure in doing things?") may be as effective as using more formal instruments to screen for depression (*Screening for Depression in Adults: Recommendation Statement.* U.S. Preventive Services Task Force. 2009; http://www.uspreventiveservicestaskforce.org/uspstf09/adultdepression/addeprrs.htm. Accessed 7/16/2012) • To obtain more information and track treatment efficacy, the Patient Health Questionnaire (see p. 350) may be helpful

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Table 9-3 *continued*

Screening for Mental Health Disorders

Condition	Screening Considerations
Post-Traumatic Stress Disorder	• Because many HIV infected women have experienced a great deal of childhood and/or adult trauma, it is important to determine if the patient has symptoms of PTSD. These symptoms can become overwhelming and can make it difficult for the woman to cope with daily living, including the self-care (e.g., taking regular medications, making medical-care visits) required for a chronic illness. • Management may require an interdisciplinary approach, including counseling to resolve the underlying cause(s) of PTSD symptoms • PTSD may produce a variety of physical symptoms (e.g., insomnia, fatigue, headaches, muscle/joint pain, gastrointestinal upset). If no physiological factors are found that account for these symptoms, the provider should consider that the cause may be PTSD.
Psychosis	• Physiologic cause(s) of symptoms must first be ruled out, particularly with an acute onset of symptoms that may include 　- Delusions, grandiosity, or false beliefs 　- Hallucinations, which are most commonly auditory but can affect any of the senses 　- Agitation 　- Suspiciousness, or being mistrusting and very guarded 　- Hostility, or acting in an abusive or uncooperative manner 　- Lack of drive or initiative 　- Social withdrawal 　- Emotional flatness or unresponsiveness 　- Lack of spontaneity 　- Concrete thought or difficulty in thinking abstractly 　- Paucity of speech 　- Poor communication skills 　- Stereotyped thought or inflexible thinking that may seem unreasonable 　- Physical symptoms that may involve poor grooming and hygiene
Suicidal and/or Violent Ideation	Determine at baseline and at periodic intervals if the patient either has a history of or is currently experiencing suicidal/violent ideation. This is particularly important in circumstances that may exacerbate a mental health disorder (see below). Suicidal and/or violent ideation may be recurring features of depression. If these features are present, emergency psychiatric care is needed.

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

Source: *HIV and Suicide: Risk Assessment & Intervention.* Mountain Plains AIDS Education and Training Center. 2007

Triggers that may exacerbate an existing mental health disorder among women with HIV include the following (*The Role of the Primary Care Practitioner in Assessing and Treating Mental Health in Persons With HIV.* © New York State Department of Health AIDS Institute, 2000-2012; http://www.hivguidelines. org/clinical-guidelines/hiv-and-mental-health/the-role-of-the-primary-care-practitioner-in-assessing-and-treating-mental-health-in-persons-with-hiv/. Accessed 8/1/2012):

- Learning of an HIV diagnosis
- Disclosing HIV status to others
- Beginning ART
- Physical illness, new symptoms, signs of disease progression, adverse changes in lab values
- Hospitalization
- Death of a significant other
- Lifestyle changes, e.g., loss of job, loss of income, end of relationship, relocation, birth of a child
- Making end-of-life and permanency planning decisions
- Any major problems with children, e.g., poor performance in school, acting out, illnesses

Specific Mental Health Conditions

Depression

Women with HIV infection have high rates of depression. In a longitudinal examination of data collected from the WIHS, which followed a representative sample (n=2,792) of HIV infected U.S. women for 10 years, 53% of the women were depressed at baseline and depressive symptoms were an independent predictor of mortality (*J Acquir Immune Defic Syndr* 2009;51:399). HIV infected people with depression are also less adherent to ARV regimens (*Psychiatr* Q 2009;80:131; *AIDS Patient Care STDS* 2008;22:313). It is therefore important to assess for depression at baseline and at least annually; in a woman with a history of depression, assessment should occur at each visit. A positive response to two questions ("During the past 2 weeks, have you experienced little interest or pleasure in doing things?" "Have you felt down, depressed, or hopeless?") should prompt a more thorough assessment.

Screening tools: Although many well-established depression screening tools are available, many of them include somatic items similar to HIV-related symptoms or to the side effects of some ARV medications. See Table 9-4 for the Patient Health Questionnaire (PHQ), a tool that is designed to approximate the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) criteria for depression but that is free of somatic items. Specifically designed for use in the primary care setting, the PHQ has been studied in 5,780 patients in primary care and medical specialty outpatient centers (*Cancer* 2011;117(1):218). A Spanish version has also been validated (*Textbook of Psychosomatic Medicine*. Arlington VA: American Psychiatric Publishing, Inc.; 2005).

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Table 9-4

Patient Health Questionnaire

Instructions: How often have you been bothered by each of the following symptoms during the past 2 weeks? For each symptom put an "X" in the box beneath the answer that best describes how you have been feeling.

Symptoms	Frequency in Past 2 Weeks			
	Not At All	Several Days	More than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things				
2. Feeling down, depressed, or hopeless				
3. Trouble falling or staying asleep, or sleeping too much				
4. Feeling tired or having little energy				
5. Poor appetite or overeating				
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down				
7. Trouble concentrating on things, such as reading the newspaper or watching television				
8. Moving or speaking so slowly that other people could have noticed—or the opposite: being so fidgety or restless that you have been moving around a lot more than usual				
9. Thoughts that you would be better off dead or of hurting yourself in some way*				

10. If you are experiencing any of the problems listed above, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?	☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult
11. If these problems have caused you difficulty, have they caused you difficulty for 2 years or more?	☐ Yes, I have had difficulty with these problems for 2 years or more. ☐ No, I have not had difficulty with these problems for 2 years or more.

* If you have had thoughts that you would be better off dead or of hurting yourself in some way, please discuss this with your health care provider, go to a hospital emergency room, or call 911.

Severity scores: For each reply, not at all = 0; several days = 1; more than half the days = 2; nearly every day = 3

Number of Symptoms: —————   **Severity Score:** —————

Source: *JAMA* 1999;282(18):1737

Scoring the PHQ: The PHQ can assist in diagnosing depression as well as in planning and monitoring depression treatment. The PHQ score has three components: 1) number of depressive symptoms; 2) severity score; and 3) functional assessment. The number of depressive symptoms is used to aid in making the diagnosis of depression. The severity score and functional assessment are measured at initial assessment and regularly after treatment begins to determine baseline depression severity and assess ongoing patient progress.

Diagnosis (number of depressive symptoms): For questions 1–8, count the number of symptoms for which the patient checks "More than half the days" or "Nearly every day." For question 9, count the question positive if the patient checks "Several days," "More than half the days, or "Nearly every day." Use the following interpretation to diagnose depression subtypes:

- 0–2 PHQ symptoms: not clinically depressed
- 3–4 PHQ symptoms: other depressive syndrome (items 1 and 2 must be among the symptoms checked)
- 5 or more PHQ symptoms: major depression (items 1 and 2 must be among the symptoms checked)

Severity score: Assign a score to each response using the following number values:

- Not at all = 0
- Several days = 1
- More than half the days = 2
- Nearly every day = 3

Total these values to obtain the severity score. Use the following interpretation to determine severity:

- 0–4: not clinically depressed
- 5–9: mild depression
- 10–14: moderate depression
- 15 or higher: severe depression

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Functional assessment: The final two questions on the PHQ ask the patient how emotional difficulties or problems affect work, home life, or relationships with other people, and if the difficulty has lasted for 2 years or more.

1. If the patient responds to question 10 with "Very difficult" or "Extremely difficult," then his/her functionality at work, at home, or in relationships with other people is significantly impaired.

2. If the patient has had difficulty with these problems for 2 years or more (question 11), then consider the diagnosis of dysthymia (chronic depression), which may require different management strategies from those used to treat acute depression.

Several general medical disorders may be considered in the differential diagnosis of major depressive disorder (Table 9-5).

Table 9-5

Differential Diagnosis of Major Depressive Disorder

Condition	How Differentiated from MDD
Adjustment disorder with depressed mood	Sadness is rarely as profound as with MDD; little anhedonia; no vegetative symptoms; identifiable precipitant; responsive to environmental change; suicidal ideation and intent may still occur; severe cases may respond to antidepressants
Bipolar disorder	Racing thoughts; increased energy; decreased need for sleep; irritability or angry outbursts; hypersexuality; symptoms may coexist with depressed mood in a mixed bipolar state
Delirium	Fluctuating mental status with altered level of consciousness; distractibility; inability to focus or sustain attention; dysarthric speech; agitation; medical etiology; onset usually acute
Dementia	Less concern with cognitive decline; more gradual changes; may respond with laughter; worse at night; specific neurological deficits; CT or MRI scan often abnormal
Grief	Onset associated with loss; able to respond to positive changes in the environment with enjoyment or less sadness; decreasing severity over time; preoccupation with deceased or loss; "psychotic" symptoms related to the deceased (i.e, seeing or being visited by the deceased); rare suicidal intent, although reunion fantasies may exist
Medication- or substance-induced mood disorders	Onset with use of steroids, anticholinergics, sedative-hypnotics, anticonvulsants, anti-Parkinsonian drugs, beta-blockers, anti-TB medications, sympathomimetics, AZT, d4T, and all illicit drugs (urine toxicology screen, medication history)
Organic mood disorder	Identifiable etiology linked by time; may be associated with cognitive deficits; test for specific medical conditions (e.g., TSH, B12, VDRL or RPR, CNS evaluation); no family history

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

Source: Adapted from *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;364.

Anxiety

Although depression is the most prevalent mental health problem experienced by HIV infected women, anxiety can be a problem as well. HIV infected women had significantly higher anxiety symptom scores than uninfected women (*Am J Psychiatry* 2002;159:789). Because anxiety and depression are considered by many to be two faces of a single disorder, clinicians should assess for both depression and anxiety if a woman exhibits symptoms of either disorder. Symptoms of anxiety can be very troubling for women and may require intervention. Women with HIV infection may become anxious thinking about the future, may feel uncertain about what will happen to them, and may shut down because they believe they cannot cope. Women with limited social support may be particularly susceptible to developing anxiety symptoms. Often the victims of neglectful or abusive parents themselves, many women with HIV have not been taught the coping skills that would help them successfully negotiate life's hurdles. When anxiety symptoms are severe or persistent, a

woman may have an anxiety disorder, which may manifest as generalized anxiety disorder, panic disorder, obsessive-compulsive disorder, or PTSD (*Anxiety Disorders*. National Institute of Mental Health. 2009; http://www.nimh.nih.gov/health/publications/anxiety-disorders/nimhanxiety.pdf. Accessed 7/17/2012).

Screening for anxiety: Questions to ask include the following (*DSM-IV-TR*; Arlington, VA: American Psychiatric Association; 2000):

- Do you often worry or feel nervous?
- Are you often fearful of interacting with other people?
- Do you ever feel jittery, short of breath, or like your heart is racing?
- Do you ever feel as if you might lose control or fear that you may be "losing it"?

Screening for PTSD: If there is reason to suspect PTSD, the following questions may be helpful in screening for that disorder (*DSM-IV-TR*; Arlington, VA: American Psychiatric Association; 2000):

- In your life, have you ever had any experience that was so upsetting, frightening, or horrible that you
  - Have nightmares about it or think about it when you do not want to?
  - Try hard not to think about it or go out of your way to avoid situations that remind you of it?
  - Are constantly on guard, watchful, or easily startled?
  - Feel numb or detached from others, activities, or your surroundings?

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Wide range of manifestations: Anxiety can present with a wide range of physiologic manifestations, as outlined in Table 9-3. Just as with depression, women with a history of anxiety are susceptible to symptom recurrence. An anxiety disorder occurs when symptoms interfere with a woman's daily function, interfere with personal relationships, or cause marked subjective distress. Anxiety-like symptoms may be caused by other mental health disorders, making it difficult, for example, to distinguish depression with agitation from an adjustment disorder with anxious mood. Adjustment reactions, however, usually follow a stressful event, which is rarely the case with clinical depression. Moreover, adjustment reactions are less likely to present with the vegetative symptom complex seen in depression, including insomnia, diminished appetite, loss of pleasure/interest, feelings of guilt, and fatigue (*The Role of the Primary Care Practitioner in Assessing and Treating Mental Health in Persons With HIV*. © New York State Department of Health AIDS Institute, 2000-2012. Accessed 8/1/2012).

Underlying medical conditions, such as CNS pathologies, systemic or metabolic illness, endocrine disorders, respiratory or cardiovascular conditions, or substance intoxication/withdrawal, can cause anxiety-like symptoms, as can

certain medications. Once these have been ruled out as the source of symptoms, the clinician should determine which anxiety disorder is causing the symptoms. Table 9-6 outlines how to distinguish among various anxiety disorders.

Table 9-6	
Distinguishing Among Anxiety Disorders	
Disorder	**Distinguishing Characteristics**
Adjustment disorder with anxious mood	History of stressful situations causing nervousness or upset
Generalized anxiety disorder	Worrying/ruminating about a variety of things for months
Obsessive-compulsive disorder	Intrusive, disturbing thoughts; compulsive rituals
Panic attacks/ panic disorder	Discrete episodes of intense anxiety/fear with chest pain, pounding heart, diaphoresis, shortness of breath
Phobia	Fear/avoidance of certain situations, places, or objects
PTSD	History of a traumatic event that continues to cause great distress, with symptoms lasting more than 1 mo (if the event occurred less than 1 mo ago, this is an acute stress disorder)

Source: *The Role of the Primary Care Practitioner in Assessing and Treating Mental Health in Persons With HIV*. © New York State Department of Health AIDS Institute, 2000-2012

For some patients, if symptoms are mild, basic supportive and behavioral interventions may be sufficient. A variety of strategies may be helpful, including the following:

- Express empathy
- Educate the patient about anxiety
- Reassure the patient that anxiety can be the cause of somatic symptoms
- Identify the psychological factors that contribute to anxiety
- Prepare the patient for stressful situations and assist in the development of positive coping mechanisms
- Teach her simple breathing exercises; slow, deep, focused breathing can be helpful

Psychopharmacology

General Guidelines

The following general principles should guide the prescription of psychotropic drugs to HIV infected women (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;365)

- **Start low, go slow:** Evidence indicates that, in general, women require lower doses of antipsychotic medications than men. Use slow upward titration as with geriatric patients (*Diabetes Care* 2004;27:596; *Am J Psychiatry* 2004;161:1324).

- **Expect the unexpected:** HIV infected patients often experience unusual side effects, common side effects at low doses, or complicated drug-drug interactions

- **Monitor dynamically:** Changes in weight or metabolism, changes in other medications, or episodes of medical illness require frequent updating and re-evaluation of dosing or choice of medications. This is particularly important with increased weight or abdominal girth, new onset of hyperlipidemia, or hyperglycemia.

- **Coordinate among disciplines:** Psychiatrists and primary health care providers should be in regular communication with each other about clinical updates, dosing changes, and major medical events

- **Suspect substances:** Depression may be complicated by alcohol use, anxiety by withdrawal syndromes, and mania by psychostimulant use. Patients often forget that when their substance consumption has decreased, their CNS sensitivity to the effects of these substances increases over time.

- **Address medication adherence:** Use medication boxes, simple regimens, written instructions, coordination with antiretroviral therapies, and patient education. Nonadherence or discontinuation may diminish the overall treatment effect if adherence is not specifically targeted (*J Clin Psychiatry* 1999;60:741).

- **Attend to potential drug-drug interactions:** Drug-drug interactions are a concern when coprescribing psychotropic and antiretroviral (ARV) medications. The primary cytochrome P450 systems at issue with psychiatric medications are CyP2D6 and CyP3A4 (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;365). Most studies that have examined the concurrent use of antiretroviral (ARV) drugs and psychotropic medications have included few women. For drug interactions between psychotropic medications and ARVs, see Table 13-8, p. 500.

SSRIs: Selective serotonin reuptake inhibitors (SSRIs), the drugs most commonly used to treat depression, are also effective against a variety of anxiety disorders (*Depress Anxiety* 2007;24:185). The SSRIs have a range of effects, from activating or stimulating to sedating.

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Bupropion: Bupropion is often used for smoking cessation; it has no known drug-drug interactions and no sexual side effects. It may be helpful to decrease craving in patients with a history of substance abuse.

Antipsychotics: Second-generation antipsychotic agents (e.g., aripiprazole) are routinely recommended over traditional antipsychotics (e.g., haloperidol), except for acute or short-term use, because of their potential to improve psychotic symptoms and the lower associated incidence, compared with traditional antipsychotic agents, of extrapyramidal side effects and long-term risk of dyskinesia.

Side effects: Common potential side effects of all antidepressant medications include agitation, irritability, sedation, sexual dysfunction, weight gain, headache, gastrointestinal distress, dry mouth, and activation of mania. Benzodiazepine use may be complicated by tolerance, dependence and withdrawal syndromes, including rebound anxiety, and patients should be warned about sedation, cognitive effects, and slowed reflexes when using these agents. Patients who experience severe or unusual side effects, have multiple diagnoses, require multiple medications, or are not responding to routine doses of initial medications should be referred for psychiatric consultation (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;366).

Common Psychiatric Medications

Table 9-7 lists common psychiatric medications (in alphabetical order within drug classes; order does not indicate priority for use).

Table 9-7

Common Psychiatric Medications

Disorder	Medications and Common Dosing Ranges*
Alcohol Dependence Initiate only after alcohol withdrawal for maintenance of abstinence	• Acamprosate (Campral): 333 mg tid; continue even if relapse • Disulfiram (Antabuse): up to 500 mg qd x 1–2 wk; maximum 500 mg qd • Naltrexone (Revia): 50 mg qd; must also be opioid-free x 7–10 d
Alcohol Withdrawal Doses needed may be higher with significant tolerance or combined alcohol and benzodiazepine/ barbiturate dependence Observe carefully and stop treatment if signs of respiratory depression or if patient is difficult to arouse	• Alprazolam (Xanax): 0.5–1 mg bid x 7–10 d • Chlordiazepoxide (Librium): 50–100 mg initially, to be followed by repeated doses as needed until agitation is controlled; dosage then may be reduced to maintenance levels; maximum dose 300 mg qd. In acute setting, initial doses may be given IM or IV. • Clorazepate dipotassium (Tranxene): Maximum 90 mg qd; divide doses bid-tid: - Day 1: initial, 30 mg; then 30–60 mg - Day 2: 45–90 mg qd - Day 3: 22.5–45 mg qd - Day 4: 15–30 mg qd - Day 5 and after: 7.5–15 mg qd until patient's condition is stable • Avoid excessive reductions on successive days • Lorezapam (Ativan): 2 mg q 6h for 4 doses, then 1 mg q 6h for 8 doses
Anxiety Disorders, Panic Attacks, PTSD Unless otherwise noted, increase dose gradually to lowest effective dose	• Citalopram† (Celexa): For panic disorder, 20–30 mg qd; maximum dose 60 mg qd • Escitalopram† (Lexapro): For generalized anxiety disorder, 10–20 mg qd • Fluoxetine† (Prozac): For panic disorder, 10–60 mg qd • Paroxetine† (Paxil): - Generalized anxiety disorder: 20–60 mg qd - Panic disorder: 10–60 mg qd (immediate release); 12.5– 75 mg qd (controlled release) - PTSD: usual effective dose is 20 mg qd • Sertraline† (Zoloft): For panic disorder and/or PTSD, 25–200 mg qd A.M. • Venlafaxine† (Effexor): For generalized anxiety and/or panic disorder, 37.5–225 mg qd in single dose (extended release) • Alprazolam† (Xanax): - Anxiety: 0.25–0.5 mg tid to maximum 4 mg qd in divided doses (immediate release or orally disintegrating tablet) - Panic disorder: 0.5 mg tid (immediate-release or orally disintegrating tablet) to maximum 10 mg qd in divided doses; 0.5–1 mg qd (extended release); usual dosing range 3–6 mg qd • Clonazepam† (Klonopin): For panic disorder, 0.25 mg bid up to maximum 4 mg qd in 2–3 divided doses • Lorazepam† (Ativan): For anxiety, 2–10 mg qd divided bid-tid • Buspirone (Buspar): For anxiety, 5 mg bid-tid or 7.5 mg bid–60 mg qd in 2–3 divided doses • Duloxetine† (Cymbalta): For generalized anxiety disorder, 30–120 mg qd; delayed-release capsules should be swallowed whole—do not cut, crush, chew, or sprinkle

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Table 9-7	continued

Common Psychiatric Medications

Disorder	Medications and Common Dosing Ranges*

Bipolar Mood Disorder
 	
Unless otherwise noted, increase dose gradually to lowest effective dose
	• Aripiprazole (Abilify): For mania or mixed episodes, 15–30 mg qd
	• Carbamazepine (Tegretol): 800–1600 mg in divided doses; may increase in increments of 200 mg qd, titrated slowly by blood levels (4–12 mcg/ml)
	• Lamotrigine (Lamictal): 25–200 mg qd
	• Lithium carbonate: ***Use requires ability to obtain lithium levels, as toxicity can occur at doses close to therapeutic levels***
	  - Acute mania: 600 mg tid (immediate-release tablet and capsule); 1800 mg qd (extended-release tablet) in 2–3 divided doses; desired serum level 1–1.5 mEq/L
	  - Maintenance therapy: 300 mg 3–4 x qd (immediate-release tablet and capsule); 900–1200 mg qd (extended-release tablet) in 2–3 divided doses; desired serum level 0.6–1.2 mEq/L
	• Olanzapine (Zyprexa): 10–15 mg qd; increase in 5 mg increments at intervals not less than 24 h; maximum dose 20 mg qd
	• Quetiapine (Seroquel):
	  - Depression phase: 50 mg qd (regular release and extended release), with rapid scale-up in initiation phase; usual maintenance dosage range is 400–800 mg qd, given in divided doses bid
	  - Manic phase: 50 mg bid (regular release); increase over 4–6 d, usual dosage range 400–800 mg qd, given in divided doses bid; 300 mg qd (extended release); increase over 3 d; usual dosage range 400–800 mg qd
	• Risperidone (Risperdal): 2–3 mg qd; may increase in increments of 1 mg qd to maximum 6 mg qd
	  - Valproate/valproic acid (Depakote): For acute mania, 250 mg tid (delayed release); increase rapidly to lowest effective dose; maximum 60 mg/kg/d; usual trough plasma level 50–125 mcg/mL; 25 mg/kg/d qd (extended release); increase rapidly to lowest effective dose; maximum dose 60 mg/kg/d; usual trough plasma level 85–125 mcg/mL
	• Ziprasidone (Geodon): For acute mania or mixed episodes, 40 mg bid with food; titrate rapidly to lowest effective dose; maximum dose 80 mg bid

Insomnia	• Diphenhydramine: 25–100 mg q hs • Eszopiclone (Lunesta): 2–3 mg q hs • Lorazepam (Ativan): 2–4 mg q hs • Temazepam (Restoril): 7.5–30 mg q hs • Trazodone (Desyrel, Oleptro): 25–50 mg q hs • Zolpidem (Ambien): 5–10 mg q hs (immediate release); 6.25–12.5 mg q hs (extended release); also available as oral spray and sublingual tablet with maximum 10 mg q hs

| Table 9-7 | *continued* |

Common Psychiatric Medications

Disorder	Medications and Common Dosing Ranges*
Major Depressive Disorder (with or without anxiety) Unless otherwise noted, increase dose gradually to lowest effective dose	• SSRIs: - Citalopram† (Celexa): 20–40 mg qd - Escitalopram† (Lexapro): 10–20 mg qd - Fluoxetine† (Prozac): 20–80 mg qd in A.M. or 90 mg q wk - Paroxetine† (Paxil): 20–50 mg qd (immediate release); 25–62.5 mg qd in A.M. (controlled release) - Sertraline† (Zoloft): 50–200 mg qd • Bupropion† (Wellbutrin): - 100 mg bid (immediate release); increase slowly to maximum 450 mg qd in 3–4 divided doses - 150 mg once qd (sustained release); increase slowly to maximum 200 mg bid - 150 mg qd (extended release); increase slowly to maximum 450 mg qd, given as single dose • Duloxetine† (Cymbalta): Start with 20 mg bid; maintenance dose 60 mg qd; maximum dose 120 mg qd • Mirtazapine† (Remeron): 15–45 mg q hs • Venlafaxine† (Effexor): - 75–225 mg qd (immediate release) in 2–3 divided doses - 37.5–225 mg qd (extended release) in single dose

Opiate Dependence	• Buprenorphine: **Prescribing of buprenorphine for this indication is limited to qualifying physicians who have notified HHS of their intent**
	 - Induction: 12–16 mg/d SL; adjust dose in 2–4 mg increments to level that suppresses opioid withdrawal effects (typical range 4–24 mg qd)
	 - Rapid detoxification (with naltrexone and clonidine): 3 mg/d SL for 3 d
	 - Methadone maintenance therapy:
	  ° Start 15–30 mg x 1, then 5–10 mg prn q 2–4 h prn; maximum 40 mg on day 1
	  ° Adjust dose to prevent withdrawal symptoms x 24 h, block euphoric opioid effects
	  ° Stabilize dose x 10–14 d, then decrease dose by up to 10% q 10–14 d
	  ° Doses >100 mg/d require documentation; maintenance therapy permitted only in FDA-approved program
	
	• Naltrexone:
	 - Do not attempt treatment unless patient has remained opioid-free for at least 7–10 d. Verify self-reporting of abstinence from opioids in opioid addicts by analysis of urine for absence of opioids.
	 - Patient should not be manifesting withdrawal signs or reporting withdrawal symptoms. If there is any question of occult opioid dependence, perform naloxone challenge test. If signs of opioid withdrawal are still observed following naloxone challenge, do not attempt treatment with naltrexone. Naloxone challenge can be repeated in 24 h.
	 - Initiate treatment carefully, with an initial dose of 25 mg qd. If no withdrawal signs occur, patient may be started on 50 mg qd thereafter
	 - Extended-release naltrexone also available

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Table 9-7	*continued*

Common Psychiatric Medications

Disorder	Medications and Common Dosing Ranges*
Opiate Withdrawal	• Clonidine: 0.3–0.6 mg in 3 divided doses • Methadone: - Short-term detoxification: ° 15–30 mg as initial dose, then 5–10 mg q 2–4 h prn; maximum 40 mg on day 1; adjust dose to suppress withdrawal symptoms ° Stabilize dose x 2–3 days, then decrease dose by up to 20% q 24–48 h ° Doses >40 mg/d require documentation - Drug detoxification: ° Opioid abuse: Initial dose 15–30 mg orally; additional 5–10 mg can be given 2–4 h later if needed ° Adjust dose cautiously over first week based upon control of withdrawal 2–4 h post dose ° Usual total daily dose 40 mg qd; keep on stable dose for 2–3 d, then decrease in 1–2-d intervals according to response ° Detoxification treatment usually occurs over 21 d - Opioid abuse, maintenance therapy: ° Individualize maintenance doses ° Titrate to a dose that prevents symptoms for 24 h ° Usual maintenance doses range from 80–20 mg qd
Psychotic Symptoms and/or Schizophrenia Unless otherwise noted, increase dose gradually to lowest effective dose Periodically reassess need for treatment; d/c if ANC <1000; consider d/c if unexplained decrease in WBC	• Aripiprazole (Abilify): 10–15 mg qd; maximum 30 mg qd • Olanzapine (Zyprexa): 5–10 mg qd; maximum 20 mg qd • Paliperidone (Invega): 6 mg qd A.M. (extended release); maximum 12 mg qd; do not cut, crush, or chew • Quetiapine (Seroquel): - Start at 25 mg bid (regular release); usual effective range is 150–750 mg qd, in divided doses; maximum 800 mg qd - With extended-release formulation, start at 300 mg qd; target dose range 400–800 mg/d; maximum 800 mg/d • Risperidone (Risperdal): Start at 1 mg qd or bid; maximal effect usually seen with 4–8 mg qd; do not cut or chew orally disintegrating tablet • Ziprasidone (Geodon): Start at 20 mg bid with food; maximum 80 mg bid

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

*All doses are for oral administration, unless otherwise noted. Many psychiatric medications are now available in extended-release, rapidly dissolving, liquid, and parenteral forms.

†Taper dose gradually to discontinue

Source: Adapted from *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;367. Dosing recommendations from Epocrates® Online

Substance Abuse

Substance *abuse* is differentiated from substance *dependence*; in the latter the impairment is more pervasive and includes physical dependence and withdrawal symptoms.

Substance Use and Addictive Disorders: DSM-V-TR Criteria
(*DSM-V-TR*; Arlington, VA: American Psychiatric Association; 2013)

The old categories of substance abuse and dependence have been replaced with the new "substance use and addictive disorders" classification. The term "dependence" was felt to be misleading, often applied to tolerance and withdrawal, which are normal responses to prescribed medications that affect the central nervous system. The new category for addictive diseases includes a variety of "substance-use disorders" broken down by drug type.

Substance use disorder:

A. A maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by two or more of the following, occurring within a 12-month period:

1. Recurrent substance use resulting in a failure to fulfill major role obligations at work, school, or home (e.g., repeated absences or poor work performance related to substance use; substance-related absences, suspensions, or expulsions from school; neglect of children or household)

2. Recurrent substance use in situations in which it is physically hazardous (e.g., driving an automobile or operating a machine when impaired by substance use)

3. Continued substance use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the substance (e.g., arguments with spouse about consequences of intoxication, physical fights)

Tolerance, as defined by either of the following:

- Need for markedly increased amounts of the substance to achieve intoxication or desired effect
- Markedly diminished effect with continued use of the same amount of the substance

Withdrawal, as manifested by either of the following:

- Characteristic withdrawal syndrome for the substance

- Same or a closely related substance is taken to relieve or avoid withdrawal symptoms

- Substance is often taken in larger amounts or over a longer period than was intended

- Persistent desire or unsuccessful efforts to cut down or control substance use

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- A great deal of time is spent on activities necessary to obtain the substance (e.g., visiting multiple doctors or driving long distances), use the substance (e.g., chain smoking), or recover from its effects

- Important social, occupational, or recreational activities are given up or reduced because of substance use

- Substance use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance (e.g., current cocaine use despite recognition of cocaine-induced depression, continued drinking despite recognition that an ulcer was made worse by alcohol consumption)

- Craving or strong desire or urge to use a specific substance

Women who have a substance use disorder expend an extraordinary amount of time and energy in pursuit of their drug of choice at the expense of their own health and the health and well-being of their children.

Scope of the problem: An estimated one in five new HIV diagnoses in women is related to injection drug use (*HIV/AIDS among Women*. U.S. Centers for Disease Control and Prevention [CDC] HIV/AIDS Fact Sheet. 2008; http://www.cdc.gov/hiv/topics/women/pdf/women.pdf. Accessed 7/26/2012) and 60% of new AIDS cases in women represent sexually acquired HIV from drug-using partners (*Medical Care of HIV-Infected Substance-Using Women.* © New York State Department of Health AIDS Institute, 2000-2012; http://www.hivguidelines.org/clinical-guidelines/womens-health/medical-care-of-hiv-infected-substance-using-women/. Accessed 7/26/2012). Few specific data exist on substance abuse disorders in HIV infected women. The WIHS found that 27% of HIV infected women reported crack, cocaine, or injection drug use (*AIDS* 1999;13:591). Crack cocaine in particular has disproportionately affected African-American women. Women who smoke crack are more likely than other women to sell sex or have an STD; women who smoke crack also have more sexual partners (*Health and Human Rights* 1998;2(4):42).

Methamphetamine (i.e., meth, speed, ice, crystal, crank) abuse is a significant problem in the United States, though it has been decreasing in recent years; in some parts of the country, methamphetamine is the third most common drug of abuse after alcohol and marijuana. Although limited data are available on methamphetamine use by HIV infected women, this drug is known to increase risky sexual behavior and has been associated with an increased proportion of drug-treatment admissions in pregnancy. (*Methamphetamine Use and Risk for HIV/AIDS*. CDC. 2007; http://www.cdc.gov/hiv/resources/factsheets/meth.htm. Accessed 8/1/2012).

Greater vulnerability: At a more complex level, the intersection of HIV infection, poverty, and race/ethnicity in HIV infected women places them on the outer fringes of society and increases their vulnerability to substance use/abuse. Substance abuse in women may begin because of childhood trauma, in an attempt to numb the pain and shame felt as a result of sexual abuse. If a woman left home in her teens because of abuse, she may resort to survival sex, and substance use may continue in order to counteract despair and shame. Women who are injection drug users (IDUs) are more likely than male

IDUs to adopt the drug-use patterns of and share needles with their partners. Although women often start using drugs and alcohol at older ages than men, some studies suggest that women become addicted more quickly, with a more "telescoped" course from use to abuse. Although the incidence of alcohol abuse or dependence is greater among men than women, women with alcohol abuse or dependence are more likely to seek medical help but less likely to be identified by their healthcare providers (*J Gen Intern Med* 2002;17:387). Drug-involved women often rely on their partners to procure the drugs they share and because women are often injected by their partners, they are "second on the needle," which increases their risk for infection with HIV. For women who have a substance abuse problem, refusing to share needles and syringes can also increase the risk of physical and sexual violence, further potentiating risks for HIV infection and re-infection (*Lancet* 2010;376:312).

Whether HIV is acquired sexually or through IDU, ample evidence exists that substance abuse plays a significant role in the lives of women who abuse drugs or alcohol (*J Assoc Nurses AIDS Care* 2004;15(5):48). Sharing injection equipment, exchange of sex for drugs, and the likelihood of risky sexual behaviors (e.g., unprotected sex, multiple sexual partners), particularly when under the influence of drugs or alcohol, are all increased in the setting of substance abuse and all increase risk for HIV (*HIV/AIDS among Women*. CDC HIV/AIDS Fact Sheet). Although reports of substance abuse in HIV infected women often focus only on IDU, noninjection drugs also play a critical role in HIV transmission due to impaired decision making and disinhibition that leads to high-risk behaviors.

Substance abuse following HIV diagnosis: Women may exhibit three patterns of substance abuse upon learning of their HIV infection. Many accelerate their use/abuse out of despair and uncertainty and/or a belief that death is imminent (*J Assoc Nurses AIDS Care* 2004;15(5):48). Some decrease their use or stop altogether, realizing that they must be able to participate in a plan of medical care if they are to survive and understanding that continued use of drugs/alcohol would likely preclude optimal care. A few nonusers initiate use of drugs/alcohol, for many of the same reasons given by those who accelerate use (*J Assoc Nurses AIDS Care* 2004;15(5):48). Continued or accelerated substance use in the context of an HIV diagnosis also adds to the stigmatization women feel, particularly those who are mothers.

Substance Abuse Comorbidities

HIV infected women who abuse drugs and/or alcohol are at risk of developing other medical conditions (Table 9-8). These comorbidities can be difficult to treat with coexistent HIV infection and signs and symptoms of the various conditions may be difficult to distinguish. Comorbidities may also accelerate HIV progression and/or complicate HIV management (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005). Several factors, including lower body weight, lower total body water, and lower levels of alcohol dehydrogenase, may contribute to greater sensitivity to alcohol's long-term effects among women compared with men.

Table 9-8

Medical Conditions and Sequelae Associated with Drug and Alcohol Abuse

- Bacteremia
- Cancer
- Cellulitis
- Cirrhosis
- Cognitive dysfunction
- Cutaneous abscesses
- Endocarditis
- Hepatitis (A, B, C, D and GB virus C)
- HIV
- Pneumonia
- Poor nutrition
- Septic emboli
- Sexually transmitted infections
- Thrombophlebitis
- Trauma
- Tuberculosis

Source: *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;380

The conditions listed in Table 9-8 represent only a few of the many disease states that are either directly associated with or exacerbated by substance abuse. Excessive alcohol use also places women at risk for epilepsy, psychiatric disorders, cardiomyopathy, peptic ulcer disease, pancreatitis, and malignancies. Smoking tobacco is the most common cause of lung cancer and airway diseases and has been implicated in other malignancies such as cervical carcinoma (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;380; *Gynecol Oncol* 1994;55(1):91). Methamphetamine use has been associated with neurologic deficits, severe dental problems, arrhythmias, hypertension, seizures, depression, suicidal ideation, and psychosis (*Addiction* 2010;105:991).

Liver disease: Both HIV and alcohol abuse appear to accelerate viral hepatitis–induced liver damage and are major risk factors for progression of liver disease and death from liver disease (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;380); *AIDS Res Hum Retroviruses* 2002;18:757). End-stage liver disease has become the leading cause of death in specific patient populations with HIV infection.

Antiretroviral therapy: Treatment with ART is associated with improved outcomes in HIV infected patients with substance abuse and comorbidities such as hepatitis (*Hepatology* 2001;34:283). This underscores the importance of the timely identification and treatment of substance abuse and its sequelae as well as HIV. In both substance abuse treatment programs and primary care clinics, strategies are needed to identify and manage HIV and recognize comorbid conditions associated with HIV and/or substance abuse or have established linkages into appropriate care (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;381)

Identification of Substance Abuse

Problems with substance and/or alcohol abuse can be identified in several ways. Table 9-9 provides clues that may be picked up when a woman's clinical history is taken.

Table 9-9

Clues to Drug and Alcohol Abuse

Medical History	Behavior	Social History
• HIV infection • Endocarditis • Hepatitis B or C infection • Septic emboli • Septic thrombophlebitis • Pancreatitis • Cirrhosis	• Agitation • Somnolence • Disorientation • Erratic behavior • "Doctor hopping" • Frequent unexplained accidents	• Inability to retain employment • Child custody loss • Seemingly unexplainable financial difficulties • Relationship distress

Source: *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;383

Specific questions such as the following can assess for drug use or abuse:

• Have you ever used any street drugs such as heroin, methamphetamine, ecstasy, cocaine, crack, or marijuana?

• When was the last time? How often do you use?

• Are you interested now in any substance use services or treatment?

There are also screening tools that are effective in identifying drug use, such as the ASSIST and the DAST.

If the patient has a history of substance abuse or is currently using, proceed with further evaluation and referral to a treatment program or mental health specialist. Intervention is indicated when there is evidence of adverse affects owing to substance abuse on the woman's physical and/or mental health, relationships, or job.

Assessing for alcohol abuse: Several tools are available to screen for alcohol abuse in women. One measure is the TWEAK questionnaire (*Alcohol Clin Exp Res* 1991;15(6):991):

• **T**olerance: How many drinks can you hold ("hold" version; ≥ 6 drinks indicates tolerance) or How many drinks does it take before you begin to feel the first effects of the alcohol? ("high" version; ≥ 3 indicates tolerance).

• **W**orried: Have close friends or relatives worried or complained about your drinking in the past year?

• **E**ye openers: Do you sometimes take a drink in the morning when you first get up?

• **A**mnesia: Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?

• **K**ut down: Do you sometimes feel the need to cut down on your drinking?

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Score 2 points each for a positive response to Tolerance or Worried; 1 point each for a positive response to Eye opener, Amnesia or Kut down; the range of summed points is 0 to 7. A score of 3–7 indicates that the patient has an alcohol problem.

Another measure is the T-ACE (*Am J Obstet Gynecol* 1989;160(4):863):
- How many drinks does it take for you to feel high? (**T**olerance)
- Have people **A**nnoyed you by criticizing your drinking?
- Have you ever felt you ought to **C**ut down on your drinking?
- Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover? (**E**ye opener)

Any woman who answers "more than two drinks" on the Tolerance question is scored 2 points. Each yes to the subsequent three questions scores 1 point. A score of 2 or more is considered a positive screen and the woman should be referred to a specialist for further assessment.

The care provider can also ask about quantity and frequency of alcohol use. For women, more than seven drinks per week or more than three drinks on any one occasion may put them at risk for developing alcohol dependence (Women and Alcohol. National Institute on Alcohol Abuse and Alcoholism [NIAAA]. 2011; http://pubs.niaaa.nih.gov/publications/womensfact/womensfact. htm. Accessed 8/1/2012). One standard drink is equivalent to 12 ounces (354.9 mL) of beer, 5 ounces (147.9 mL) of wine or 1.5 ounces (44.4 mL) of 80-proof spirits (*Women and Alcohol*. NIAAA. 2011).

Physical symptoms or signs of long-term alcohol abuse include the following (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005):
- Loss of appetite, eating poorly, weight loss
- Spider angiomas on the skin
- Swelling or redness of the palms of the hands
- Redness on the face, especially the nose and cheeks
- Repeated skin sores or abscesses
- Numbness or tingling in feet and hands (this symptom could also indicate peripheral neuropathy related to HIV or ART)
- Unsteady gait
- Abnormal liver function tests, other liver problems such as cirrhosis

The physical signs of other substance abuse depend on which drug(s) are being abused. Physical examination findings are limited but may include injection marks, nasal lesions or recurrent epistaxis, poor dentition, or poor nutritional status. Signs or symptoms of intoxication or withdrawal are highly suggestive of substance use disorder. A toxicology screen or blood alcohol level may also be of use (*Ferri's Clinical Advisor*. Philadelphia, PA: Elsevier; 2011). Cocaine snorting can be suspected by observation of damaged nasal mucosa; hypodermic marks or "tracks" suggest IDU, although the absence of visible marks does not rule this out. The single most useful examination is of the eyes: nystagmus is often seen in abusers of sedatives/hypnotics or cannabis; dilated pupils are often seen in people under the influence of stimulants or hallucinogens or in withdrawal from opiates; pupillary constriction is a classic

hallmark of opioid effect. Evidence of multiple minor (or past major) injuries can also be a clue to possible substance abuse (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;385).

Drug Testing

Drug testing for substances of abuse may be performed for clinical indications (e.g., need to exclude drugs as cause of acute change in mental status or behavior) or when required for legal indications. Drugs may be detected in almost any fluid or tissue in the body (false-positive screens for marijuana and the benzodiazepines have occurred in patients taking EFV). The most common samples used for drug tests are urine, blood, saliva, hair, sweat, and breath (*Addiction* 1999;94:1279).

Urine tests: Urine testing is the most available, useful, and reliable testing format for clinicians to use. Test kits are available for use in offices and at home that require the simple collection of a urine sample. Urine testing, however, has numerous limitations, including the ability to detect only recent drug or alcohol use. Adulterated urine samples and changes in urine acidity may prevent the quantification of illegal drugs in urine.

Other tests: Blood testing is available to many caregivers and is more accurate for the quantitative detection of drugs in the user; however, it is more expensive and more cumbersome than urine analysis. Saliva may be useful and correlates well with drug levels in the blood. Hair analysis has the advantage of detecting drug use over a 1- to 3-month period, depending on a person's hair growth rate (*Anal Bioanal Chem* 2010;397(7):2987; *J Forensic Leg Med* 2010;17:254; *Ther Drug Monit* 2010;32:318). Sweat testing is another noninvasive test that is useful for monitoring drug relapse during drug treatment. It is designed to continuously monitor a person's drug use over a period of time through a special absorbant pad placed on the skin. The pad collects microscopic amounts of sweat produced over time and is analyzed later for the presence of drugs. Breath testing is a reliable tool for measuring blood alcohol levels.

Interpretation: Drug test results may be difficult for the inexperienced care provider to interpret because they may be confounded by secondary drug exposures, chemical characteristics of the drugs to be detected, drug-level variations in different body tissues and fluids, and test-method variations. Drug testing properly used is a useful adjunct to clinical and behavioral drug-use assessment and is a useful but limited drug-use screening tool. Drug testing may also be helpful during substance abuse therapy and follow-up (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;385).

Pregnancy: Drug screening in pregnancy should be performed only with consent; the pregnant woman must be informed of the potential ramifications of a positive test result, including any mandatory reporting requirements. Providers should be aware of laws and regulations in their jurisdictions regarding the reporting of maternal toxicology testing (ACOG Committee Opinion No. 473; *Obstet Gynecol* 2011;117:200).

Treatment Readiness and Harm Reduction

Unmet treatment need: Combined data from the Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Surveys on Drug Use and Health conducted from 2004 to 2006 indicate that, on average, 6.3 million women annually (9.4% of women aged 18–49) needed treatment for a substance use (illicit drugs or alcohol) problem (*The NSDUH Report: Substance Use Treatment among Women of Childrearing Age*. SAMHSA. 2007; http://www.samhsa.gov/data/2k7/womenTX/womenTX.htm. Accessed 7/17/2012). Of the women aged 18–49 who met the criteria for needing substance use treatment in the previous year, 84.2% neither received it nor perceived the need for it; 5.5% did not receive treatment even though they thought they needed it. The reasons for not receiving substance use treatment among women with an unmet treatment need were as follows: 36.1% were not ready to stop using alcohol or illicit drugs, 34.4% could not cover their treatment costs because of lack of or inadequate health insurance coverage, and 28.9% did not seek substance use treatment because of social stigma.

Treatment: For women who want treatment for substance abuse, drug/alcohol use treatment programs should be provided through community resources, along with education programs, social and work skills-building programs, health care, and programs to prevent sexually transmitted infections (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;388). Table 9-10 describes the components of drug and alcohol treatment.

Table 9-10

Components of Drug and Alcohol Abuse Treatment

Personal Needs	Treatment Needs
• Family services	• Behavioral therapy
• Housing and transport	• Clinical and case management
• Financial services	• Intake and processing
• Legal services	• Treatment plans
• HIV/AIDS services	• Pharmacotherapy
• Educational services	• Continuity of care
• Medical services	• Substance use monitoring
• Vocational services	• Self-help/peer support groups
• Child care services	• Substance education
• Mental health services	
• Family planning services	

Source: *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;388

The number of substance-abuse treatment programs is inadequate, especially for women with few or no resources and/or no insurance. Even when treatment is available, the patient may not be ready to go into treatment. Concern for children leads many women to seek treatment for substance abuse problems; however, many treatment programs do not accept women who are pregnant. Women with young children may have ongoing difficulty accessing outpatient day treatment and residential programs because of inadequate childcare

resources. Fear of the removal of children from the home by the welfare system and lack of emotional support from substance-abusing partners are other obstacles that may deter women from seeking substance abuse treatment.

Most patients do not seek treatment until symptoms and associated consequences are severe. Compared with men, women's drug-use problems tend to occur at an older age and to develop more rapidly. Additionally, women often learn of their HIV infection and other comorbid conditions later than men. The late diagnosis of drug use and other conditions may result in shorter survival. The confluence of factors that complicate health care for female substance abusers underscores the importance of the early engagement and retention of women in care (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;388).

Harm reduction: Although barriers exist, harm reduction remains critical. Harm reduction refers to measures aimed at reducing the harm caused by substance abuse; these measures may be a first step in moving toward abstention. Harm-reduction techniques for women who are IDUs include the following: (*Cleaning Works*. 2012; http://www.thewellproject.org/en_US/Living_Well/Health/Cleaning_Works.jsp; Accessed 7/17/2012)

- Use clean sterile needles and syringes every time injection drugs are used.
- Do not share needles, syringes, cotton, or cookers with others when injecting.
- Participate in a needle exchange program if available and legal (these usually have other health promoting services [e.g., HIV/hepatitis screening, referral for treatment of substance abuse]).
- Purchase sterile equipment without a prescription from a pharmacy, if available.
- If these safer options are not adopted and needles and syringes are shared, reduce the risk of infection by always cleaning them in bleach and water immediately after use and just before reuse. Although not risk free, bleach cleaning is an important risk-reduction tool. (Hydrogen peroxide or rubbing alcohol may be substituted if bleach is not available; hard alcohol, not beer or wine, should be used if there are no other cleaning solutions available.)
- For greater cleaning effectiveness, take the set apart, remove the plunger from the barrel and soak both in bleach for at least 30 seconds.
- If the cooker (spoon) must be reused, soak it in bleach for at least 30 seconds and then rinse it with clean water.
- Because bleach loses its effectiveness with exposure to light, store all bleach for cleaning needles and works in a container that blocks light from passing through it.

Pharmacologic Interventions for Addiction

Managing withdrawal symptoms: Today even the most severe physical withdrawal symptoms can be managed with appropriate pharmacologic treatments that control or prevent serious medical consequences of drug or alcohol withdrawal. Medications like methadone can help to stabilize an opiate-dependent patient and facilitate a return to productive functioning. Other important pharmacologic interventions include the treatment of

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comorbid conditions common in drug- and alcohol-abusing populations, such as the treatment of depression. The use of antidepreirected at the effects of drugs of abuse. Pharmacologic treatments for drug use are well known but not well understood by many healthcare providers. Several classes of medications may be used to treat, modulate, or prevent ongoing drug use (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005; *Basic Principles for Treatment and Psychosocial Support of Drug Dependent People Living with HIV/AIDS*. WHO. 2006; http://www.who.int/substance_abuse/publications/basic_principles_drug_hiv.pdf. Accessed 7/17/2012).

Opiate addiction: Opioid agonists such as methadone and buprenorphine are used to treat opiate-dependent persons. When used to treat addiction, these drugs block the ability of the illicit drugs to attach to opiate receptors, therefore thereby decreasing drug craving without causing euphoria.

The use of opioid agonists is the most misunderstood medical approach to addiction treatment. Although methadone and buprenorphine are addictive, they are successful in helping addicts stop the negative and harmful behaviors associated with drug use and begin to concentrate on developing the skills to discontinue drug use entirely. It is drug craving that is associated with drug-use relapse and criminal behavior and it is the prevention of drug craving that makes substitution medications work successfully as part of a drug treatment program (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;389; *Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence*. WHO. 2009; http://www.who.int/substance_abuse/publications/Opioid_dependence_guidelines.pdf. Accessed 7/17/2012).

- **Methadone:** Methadone suppresses withdrawal for 24 hours (four to six times the duration of the effects of heroin) and decreases or eliminates drug craving; it is not sedating, can be dosed once per day, and can be administered orally. Furthermore, it is medically safe even when used continuously for 10 years or more.

- **Buprenorphine:** Buprenorphine is a partial opioid agonist for office-based and program-based treatment of opioid addiction. Some of the advantages of using buprenorphine are milder withdrawal symptoms, a lower risk of overdose, and availability to patients in the offices of physicians trained and certified in the medication's use. If used at the proper dosage, buprenorphine is as effective as methadone (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;389). Recent reports show that buprenorphine/naloxone treatment can be successfully integrated into HIV clinical care in a variety of practice settings (*J Acquir Defic Syndr* 2011;56 (suppl 1):S68).

These medications are not a cure for drug dependence but are important adjuncts to care. It has been shown that while an opiate user is taking methadone, she is much less likely to commit a crime and is more likely to succeed in completing a drug treatment program. When combined with behavioral therapies or counseling and other supportive services, these pharmacologic approaches are highly effective for treating heroin addiction, particularly in those with long-term dependence and repeated prior treatment failures (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005; *Guidelines for the Psychosocially Assisted Pharmacological Treatment of Opioid Dependence*. WHO. 2009).

Opioid antagonist medications such as naloxone and naltrexone block the effects of morphine, heroin, and other opiates. As antagonists, they are especially useful as antidotes. Naltrexone, which has a duration of action ranging from 1 to 3 days depending on the dose, blocks the pleasurable effects of heroin and is useful in treating some highly motivated individuals, such as professionals who do not want to lose their jobs. It is also successful in preventing relapse by former opiate dependent individuals released from prison on probation (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005). Naltrexone is now available as an extended-release formulation, given by IM injection once every 4 weeks.

Alcohol addiction: Disulfiram (Antabuse) is used in the context of alcohol abuse treatment to cause negative effects when the patient consumes alcohol. The drug interferes with alcohol metabolism, causing the production of acetaldehyde, a noxious chemical that causes severe flushing, nausea, and vomiting. The effectiveness of therapy depends on the patient's adherence to a daily medication dose. Acamprosate is a newer drug currently used in Europe that increases alcohol abstinence and decreases craving by affecting g-aminobutyric acid and glutamate brain receptors. Naltrexone also has been found to decrease alcohol craving and relapse; it was approved by the U.S. Food and Drug Administration in 1994 for the treatment of alcohol dependence (*Am J Psychiatry* 1999;156:1758; *Arch Gen Psych* 1992;49:876; *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;390). Naltrexone is now available as an extended-release formulation, given by IM injection once every 4 weeks.

Cocaine addiction: Although no effective medications are available to treat cocaine addiction, the treatment of comorbid mental health problems may improve the likelihood that a patient will stop using cocaine or crack. Pharmacologic therapies have been specifically targeted at decreasing the dysphoric effects of cocaine withdrawal. Unfortunately, studies examining multiple generations of antidepressant medications such as fluoxetine, sertraline, maprotilene, phenelzine, trazodone, and lithium have not demonstrated the success of those drugs in assisting with the permanent cessation of cocaine or crack use (*NIDA Res Monogr* 1997;175:36). Dopaminergic agents such as bromocriptine, amantadine, haloperidol, bupropion, and others have also not been proven to be effective. In studies using desipramine, carbamazine, and bupropion, however, the mental-health effect of these drugs was clinically helpful for a patient's successful drug cessation in drug treatment programs (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;390); *Psychiatr Clin North Am* 1999;22:401).

Methamphetamine addiction: Evidence is limited on pharmacologic treatments for methamphetamine abuse; however, three double-blinded placebo-controlled trials using modafinil, bupropion and naltrexone have shown positive results in reducing amphetamine or methamphetamine use. The agonist replacement medications d-amphetamine and methylphenidate have shown promise in two studies (*Br J Clin Pharmacol* 2010;69(6):578).

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Nonpharmacologic Approaches

Behavioral and cognitive interventions: Behavioral and cognitive interventions are a vital part of drug and alcohol addiction treatment and prevention. Cognitive-behavioral therapies are based on the assumption that learning processes play an important role in the development of drug use and dependence and are therefore important to efforts to reduce use and dependence. Behavioral methods are employed to identify high-risk relapse situations, extinguish triggers to drug use, develop self-monitoring of use behavior, and establish competing coping responses. By learning to recognize situations conducive to substance use, patients can develop individual coping strategies to avoid circumstances that place them at risk for relapse. Perhaps the single most important factor for short- and long-term relapse prevention is the learning and application of individual coping skills. Avoidance of other drug users and drug-use environments are key tools for maintaining abstinence (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005).

At least 11 research-validated therapies use a variety of behavioral, social, and incentive-based systems to treat drug use. The objectives of these programs include

- removing patients from stressful environments to get care (short-term and long-term residential homes),
- providing alternatives to pharmacologic treatment (outpatient drug-free programs), and
- providing community-specific interventions (community-based programs for drug users and recently released criminals).

Several effective psychotherapy programs are based on a patient's willingness to recognize drug use as a problem and to stay off drugs, with or without incentives (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;392).

Twelve-step programs: Twelve-step self-help groups and meetings are important nonmedical, behavioral drug-use intervention and prevention activities used by millions of people. These meetings emphasize fellowship and provide support for maintaining abstinence from alcohol, other drugs, or addictive behaviors like overeating. These programs are not intended to replace medical and behavioral drug-use treatments but are meant to add to their effectiveness. The largest 12-step groups are Alcoholics Anonymous (AA); Narcotics Anonymous (for all drug users, including alcoholics); Al-Anon, to support family members and friends of alcoholics and drug users; and Overeaters Anonymous (*Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;392). Other self-help resources include Rational Recovery, which does not have the religious overtones of AA, and Moderation Management.

Pregnancy and Substance Abuse

Alcohol: Data from SAMHSA's National Surveys on Drug Use and Health, conducted in 2002 through 2007, were used to compare alcohol-drinking rates, frequency, and quantity among women aged 15–44. Those surveyed were divided into three groups: 1) pregnant women; 2) recent mothers (i.e.,

had a child within the previous 12 months); and 3) all other women in this age group. Pregnant women (11.6%) were significantly less likely to have used alcohol in the past month than recent mothers (42.1%) or all other women (54.0%). Among current alcohol drinkers, pregnant women drank alcohol on fewer days than other women. Pregnant women also had fewer drinks on their drinking days (*The NSDUH Report: Substance Use Treatment among Women of Childrearing Age.* SAMHSA, 2007; http://www.samhsa.gov/data/2k7/womenTX/womenTX.htm; Accessed 7/17/2012).

Alcohol use in pregnancy is associated with the risk of fetal alcohol syndrome, a congenital syndrome characterized by growth retardation, facial abnormalities, and CNS dysfunction. Skeletal abnormalities and structural cardiac defects are also seen in the fetal alcohol syndrome, but it is the performance deficits that are most obvious. Decreased IQ, fine-motor dysfunction, and hyperactivity are all common findings (ACOG Technical Bulletin No. 195; *Int J Gynaecol Obstet* 1994;47(1):73; *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;395).

Illicit drugs: Combined 2004 and 2005 data showed that among pregnant women aged 15–44 years, 3.9% reported using illicit drugs in the previous month. This rate was significantly lower than that among women aged 15–44 who were not pregnant (9.9 %) (*The NSDUH Report: Substance Use Treatment among Women of Childrearing Age.* SAMHSA. 2007).

Tobacco: Tobacco smoking during pregnancy is associated with increased perinatal mortality, bleeding complications in pregnancy, low-birth-weight infants and preterm delivery, and a possible increase in behavioral and learning problems among school-aged children whose mothers smoked during pregnancy (ACOG Committee Opinion #471; *Obstet Gynecol* 2010;166:1241; *Am J Psychiatry* 1996;153(9):1138). It is estimated that there could be as much as a 10% reduction in fetal and infant deaths if all pregnant women stopped smoking (*Am J Epidemiol* 1988;127(2):274).

Opiates: Opiate dependence in pregnancy is associated with a sixfold increase in maternal obstetric complications, including low birth weight, preeclampsia, 3rd-trimester bleeding, malpresentation, fetal distress, and meconium aspiration. Neonatal complications include narcotic withdrawal, which occurs in most newborns, poor postnatal growth, microcephaly, neurobehavioral problems, and increased neonatal mortality. A systematic review found a 74-fold increase in sudden infant death syndrome among children born to women who used opiates during pregnancy (*Cochrane Database Syst Rev* 2008;(2):CD006318).

Methamphetamine: Methamphetamine use in pregnancy is associated with low birth weight, small-for-gestational-age babies, and neurodevelopmental abnormalities both in neonates and in childhood (ACOG Committee Opinion No. 479; *Obstet Gynecol* 2011;117(3):751).

Cocaine: Cocaine use in pregnancy poses both maternal and fetal hazards, some of which stem from the intense vasoconstriction associated with cocaine (malignant hypertension, cardiac arrhythmias, and cerebral infarction). Cocaine has been associated with premature rupture of membranes, preterm labor

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and delivery, growth retardation, delays in cognitive development, and placental abruption. Cases of in utero fetal cerebral infarction have also been documented (*Am J Obstet Gynecol* 1987;157:686; *Guide to the Clinical Care of Women with HIV*, 5th ed. 2005;395).

HIV infection, substance use, and pregnancy: No data are available on rates of alcohol and/or substance abuse among HIV infected pregnant women. However, any substance abuse during pregnancy is of concern, especially in the setting of HIV. Substance use has been associated with an increased risk for perinatal HIV transmission (*Adv Exp Med Biol* 1993;335:211; *N Engl J Med* 1996;334:1617); although rates of perinatal transmission have decreased dramatically in developed countries, this problem has not been completely eradicated. Some residual transmission may be related to substance use among pregnant women. Exposure to drugs of abuse during pregnancy may increase mother-to-child transmission of HIV through a variety of mechanisms (*J Neuroimmune Pharmacol* 2010;5:507). A study of HIV infected mothers who were actively abusing substances found that most received inadequate or no prenatal care and that denial and substance use were the primary intrinsic barriers to disclosure and care. Substance-abusing pregnant women with HIV also may be less adherent to ART regimens during pregnancy. Attention to potent social and institutional barriers that impair the ability of the most marginalized women to disclose their HIV status and accept care is essential to maximizing the prevention of perinatal transmission (*Soc Sci Med* 2006;62(1):59). All pregnant women with a substance abuse problem should be offered treatment during pregnancy in consultation with maternal-fetal medicine and substance-abuse experts.

Treatment Retention and Relapse

Among clients discharged from substance-abuse outpatient care settings, treatment completion is highest among those who reported primary alcohol abuse and lowest among those who reported primary opiate or cocaine abuse. Both male gender and increased educational level were associated with a greater likelihood of completing outpatient treatment. Furthermore, patients who were referred to treatment by an employer, an employee assistance program, or the criminal justice system were more likely to complete outpatient treatment than patients referred by other sources (*Treatment Outcomes among Clients Discharged from Outpatient Substance Abuse Treatment*. SAMHSA. 2009; http://oas.samhsa.gov/2k9/outptTX/outptTX.pdf. Accessed 7/18/2012). Relapse is common and to be expected, and does not indicate failure or hopelessness. Indeed, women may make many attempts to stop substance abuse before succeeding; the clinician can play a major role in this journey by accepting the woman at whatever point she is in a recovery trajectory.

Antiretroviral Therapy and Substance Abuse

HIV infected women who are active substance abusers are less likely to be able to adhere to their ARV regimens than are women who are not abusing substances (*AIDS Care* 2009;21:168). A past or current history of substance

abuse, however, should not lead to automatic denial of ART; patient readiness should be assessed on an individual basis. Women previously treated for drug dependence may be more adherent that the general population or other groups. A strong patient-provider relationship, including trust and engagement with the provider, has been associated with improved ARV adherence (*AIDS Patient Care STDS* 2000;14:189).

Several ARV agents decrease methadone levels. When these agents are co-administered, the patient should be monitored for opiate withdrawal symptoms and the methadone dose increased if needed. Of note, when methadone is administered to a patient taking ZDV, the ZDV concentration is increased by >40%; the patient should be monitored for a potential increase in ZDV-related adverse effects. With newer ARV agents and dosing schedules that allow for once-daily ART regimens, directly observed therapy (DOT) in the setting of a methadone clinic may be an option for adherence support in some patients.

Tobacco

Most people with HIV infection also smoke cigarettes and are thus at high risk for tobacco-related disease and death (*AIDS Educ Prev* 2009;21(3 suppl):14; *Smoking Cessation in HIV Infected Patients*. © New York State Department of Health AIDS Institute, 2000-2012; http://www.hivguidelines. org/clinical-guidelines/adults/smoking-cessation-in-hiv-infected-patients/. Accessed 8/1/2012). Information about the tailoring of smoking-cessation interventions to HIV infected people, and specifically to HIV infected women, is sparse. The U.S. Public Health Service guidelines recommend brief, individual smoking-cessation counseling sessions in which the following five components (the "5 As") are addressed at each clinical encounter (*AIDS Educ Prev* 2009;21(3 suppl):14):

1. Ask about tobacco use at every encounter

2. Advise smokers to quit

3. Assess willingness to quit

4. Assist with quitting

5. Arrange follow-up

Smokers' telephone quit lines, which offer free counseling and smoking cessation materials, are a cost-effective intervention with demonstrated efficacy. Other group and individual counseling interventions are available, with motivational interviewing and cognitive-behavioral interventions in particular being effective (*AIDS Educ Prev* 2009;21(3 suppl):14; *Smoking Cessation in HIV Infected Patients*. © New York State Department of Health AIDS Institute).

Pharmacological interventions, which include nicotine replacement therapy (gum, patches, lozenges, inhalers, and nasal spray), bupropion, and varenicline, have increased quit rates. Consideration of patient preferences, cost of the intervention, prior quit attempts, patient characteristics, and comorbidities

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should help to determine the best intervention. A combination of nicotine replacement therapies usually works better than a single agent. Initial dosing depends on the number of cigarettes smoked per day; dosing should be tapered over the course of treatment. The usual course of treatment is 10–12 weeks. Sustained-release bupropion, alone or in combination with nicotine replacement therapy, is effective. Varenicline, which relieves withdrawal symptoms and reduces the rewarding aspects of nicotine use, has been shown to be more efficacious than bupropion; however, adverse neuropsychiatric events have been reported with varenicline and the patient should be closely monitored (*AIDS Educ Prev* 2009;21(3 suppl):14; *Smoking Cessation in HIV Infected Patients*. © New York State Department of Health AIDS Institute).

Conclusion

HIV infection in women must be considered in the context of baseline psychosocial and cultural issues, as well as potential mental health and substance abuse conditions. The willingness and ability to address these concerns compassionately, directly and effectively will play a crucial role in the effective care and treatment of the medical manifestations of HIV and in the quality of life of the HIV infected woman.

Chapter 10:

Adolescents

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Chapter 10: Adolescents

Chapter 10 at a Glance

HIV in Adolescents

The HIV epidemic continues to evolve among adolescents, defined as youth aged 13–24 years. The prevalence of disease has been influenced by improved survival of perinatally infected youth after the introduction of effective antiretroviral therapy (ART) as well as changes in incidence rates. As youth explore intimacy and sexuality and develop autonomy, adolescence becomes a time of heightened vulnerability, including risk for HIV infection. This chapter focuses on young women as it reviews the epidemiology of HIV/AIDS in adolescents and provides guidelines for HIV counseling and testing, medical and psychosocial care, and strategies for linking HIV infected and at-risk youth to care.

Epidemiology

Global Summary

Adolescents are at high risk for HIV. In 2009, 33.3 million people worldwide were living with HIV, of whom 2.6 million were newly infected. More than 40% of those new infections occurred in youths aged 15–24 years. A decline in HIV incidence among adolescents over the past decade has been attributed to improved knowledge of transmission and changes in risk behavior, including improved condom use, reduction in multiple partnerships, and delayed sexual debut (*UNAIDS Global Report 2010*, www.unaids. org/globalreport/Global_report.htm). Despite these positive trends, the prevalence in young women continues to outpace prevalence in men; rates are almost 3 times higher among young women in Sub-Saharan Africa than among men (*UNAIDS Global Report 2010*).

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U.S. Summary

In 2009, approximately 8,400 adolescents (1,670 women and 6,722 men) were newly diagnosed with HIV infection in 40 States and five U.S. dependent areas. These numbers are based on confidential name-based HIV infection reporting since at least January 2006, and they bring the cumulative total of HIV cases in this age group to 29,746 Significant racial and ethnic disparities exist: The majority of new infections occur among black/African-American and Latina youth. Most new infections in women (about 90%) occur through heterosexual contact, and 10% result from injection drug use (IDU). Of the 10,206 young women living with HIV at the end of 2008, 59% were exposed through heterosexual contact; 7%, through IDU; and the remainder, predominantly through perinatal transmission. The increase in heterosexual transmission in women has contributed to a decrease in the male-to-female ratio of AIDS cases. At the onset of the HIV/AIDS epidemic in the United States, diagnoses of AIDS were rare among adolescent women; however, in 2009 approximately one-quarter of AIDS diagnoses for this age group

occurred in women (CDC, *HIV Surveillance in Adolescents and Young Adults, July 2011.* www.cdc.gov/hiv/topics/surveillance/resources/slides/adolescents/index.htm)

Risk Factors

Adolescents are at increased risk for HIV and sexually transmitted infections (STIs) because of the interplay among behavioral, biological, and socioeconomic factors (Institute of Medicine 2011. *The Science of Adolescent Risk-Taking: Workshop Report*).

Sexual Behaviors

During adolescence, sexual activity is often initiated; risk-taking and experimentation are normative; and many sexually active adolescents fail to take appropriate prevention precautions, despite basic knowledge of HIV transmission and prevention. A majority of adolescent females with HIV are infected through heterosexual intercourse. This situation is consistent with widespread lack of awareness of the potential risk for HIV infection among sexually active adolescent and adult women. For example, among adolescents known to be HIV infected, 75% of young women are unable to identify their partners' risk factors (*Pediatrics* 1993;91:730). Moreover, for many adolescents "having sex" means heterosexual vaginal intercourse, but some adolescent females may engage in receptive anal intercourse in the belief that doing so preserves their virginity and is safer (*J Nurs Scholarsh* 2003;35:231).

High risk for STIs: Youth and inexperience are no protection against STIs. Adolescents are at high risk for STIs and account for half of all new infections diagnosed in the United States. In 2006, 1 million youth and young adults aged 10–24 were diagnosed with chlamydia, gonorrhea, or syphilis. Evidence of HPV is detected in 25% of women aged 15–19 and in 45% of women aged 20–24. In 2006, 750,000 young women under age 20 became pregnant (Guttmacher Institute. U.S. Teenage Pregnancies, Births and Abortions: National and State Trends and Trends by Race and Ethnicity January 2010 http://www.guttmacher.org/pubs/USTPtrends.pdf). The data on STIs and pregnancy are markers for unsafe sexual activity. In addition, ulcerative and inflammatory STIs increase susceptibility for HIV infection.

Youth risk behavior: According to the 2009 Youth Risk Behavior Survey (*MMWR* 2010;59 SS5:1), nearly half (46%) of all female high school students in the United States are sexually active, including 62.3% of 12th graders. African-American high school students were more likely to be sexually active than their Caucasian and Hispanic counterparts (58.3% vs. 44.7% and 45.4%, respectively). During their most recent sexual encounter, only 54% of female high school students reported using a condom. Many teens follow a pattern of sexual serial monogamy and may not consider themselves as having multiple partners. Of high school students surveyed, 11% of all females and 18% of African-American females reported four or more lifetime sexual partners.

Younger teens, particularly females, are least likely to be considered at risk or to be screened for STIs, particularly if they are asymptomatic—and the majority of STIs in females are asymptomatic. For example, chlamydia is asymptomatic in 75% of infected women, and approximately 50% of women with gonorrhea infections have no symptoms. This pattern is especially concerning because adolescent females have the highest age-specific incidence rates for both gonorrhea and chlamydia. The REACH cohort of high-risk adolescents confirmed these findings (*J Adolesc Health* 2001;29 suppl 3:49).

Young women with HIV infection (either perinatally or behaviorally acquired) are also engaging in high-risk behaviors. A study of 166 HIV infected adolescents, ages 13-21, (53% female) found that 105 were sexually experienced and that 44% reported having unprotected sex. Eighty percent of the adolescents had not informed their partners of their HIV status, and 19 females became pregnant (*J Acquir Immune Defic Syndr* 2010;55:380). These data stress the need for ongoing discussions about sexual risk behaviors.

Substance Use

More than 1 in 5 female high school students (20% to 24%) report episodic heavy drinking or current marijuana use; 12% report using inhalants, and 2% have injected illegal drugs (*MMWR* 2010;59 SS5:1). Substance use can impair judgment and increase potential for high-risk behaviors.

Biological Risk

Several biological factors also contribute to heightened risk in adolescent females. During puberty, as the cervix matures and the single-layer columnar epithelium of the cervix is replaced with thicker, multilayered squamous cells, the cellular lining becomes less susceptible to infection. Until this occurs, the cervix is much more vulnerable to STIs, particularly chlamydia and gonorrhea, which have an affinity for columnar cells and have been shown to facilitate other STI transmission. The same cervical anatomy is responsible for the increased risk of HPV infection in adolescent women. Moreover, HIV appears to increase the risk of progression of HPV disease. High-risk HPV DNA has been found in cervical samples of up to 77% of HIV infected adolescents; 70% of the adolescent women with high-risk HPV DNA had cytologic abnormality and 21% had high-grade dysplasia within 3 years of follow-up (*Arch Peds Adolesc Med* 2000;154:127). Moreover, male-to-female transmission of STIs is much more efficient than female-to-male transmission, given the larger surface area of the lower female genital tract and mechanics of sexual intercourse, which can result in mucosal trauma to women. In addition, STIs, which facilitate HIV transmission, are more likely to remain asymptomatic in women and, thus, unrecognized and untreated for a longer period.

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Socioeconomic Risk and Access to Care

Poverty, poor access to care, and lack of education and prevention skills further increase vulnerability to HIV. Additional barriers include mistrust of the healthcare system, fear of inappropriate disclosure, and providers' lack of expertise in providing care for adolescents. In addition, adolescents are the most underinsured group in the United States and are the least likely to receive office-based medical care or to use primary care services (*Bull NY Acad Med* 1993;70:219). With less access to either employer-provided insurance benefits or public insurance options, 30% of youth aged 18–24 have no health insurance (U.S. Census Bureau 2009, www.census.gov/prod/2009pubs/p60-236.pdf). Even when they have insurance coverage through their parents, adolescents may be reluctant to use it out of fear of disclosure of sensitive medical issues. Moreover, many adolescents use emergency and walk-in facilities for acute care needs. As a result, they lack a primary care provider (or medical home) that can ensure ongoing care and address prevention and health promotion needs. Because adolescence is a time when help-seeking behaviors and attitudes about health and self-care are formed, the experiences adolescents have with healthcare providers are especially important. They form the basis for future provider–client interaction, communication patterns, and relationships.

Special Populations

Specific populations of teens, including those who are lesbian, bisexual, or transgender; homeless or runaway; injection drug users; or mentally ill, are at especially high risk of HIV exposure. Also at higher risk are youth who have been sexually or physically abused, incarcerated, or placed in foster care. These youth experience increased vulnerability and multiple health and social problems because of abuse and neglect and lack of services and care. Lesbian and bisexual females may view themselves at lower risk, but those who are sexually active with gay male peers are at risk for infection because of higher HIV prevalence among gay males (*Lesbian and Gay Youth: Care and Counseling*, Columbia University Press; 1998).

Issues in HIV Care for Adolescents

Cornerstones of adolescent care include consent policies, confidentiality, accessibility, outreach, testing, and linkage to care and prevention. Even though youth prefer healthcare settings that are geared to their needs, most teens will not receive care in adolescent programs. Although most facilities are unable to offer the ideal one-stop shopping for teens, quality care can be provided by identifying a staff member and/or provider team that wants to work with adolescents and by adapting adult and family programs to meet the needs of adolescents. For example, programs can accommodate walk-ins, because youth do not often plan ahead; address payment barriers; and provide

flexible appointments that will not conflict with school or work. In 2007, the Health Resources and Services Administration (HRSA) created a comprehensive website on HIV care for youth (www.hivcareforyouth.org).

Confidentiality and Legal Issues

All States have laws that allow minors to consent to treatment without parental consent for specific health services, including emergency care, treatment for STIs, reproductive healthcare, and substance abuse treatment services. In many States, the law includes the right to consent for HIV counseling and testing. However, not all providers are aware of these rights or understand their significance for adolescents, and rights vary by State and the medical service provided. The *Compendium of State HIV Testing Laws* is available at nccc.ucsf. org and hivlawandpolicy.org. Providers should know that lack of confidentiality may cause adolescents to avoid or delay needed care. Even though parental consent may not be needed to provide an HIV test or HIV-related care, providers should carefully assess an adolescent's cognitive capacity to understand the implications of having HIV disease and should encourage the involvement of a supportive adult in the adolescent's care.

Counseling and Testing

Routine testing recommended: Since 2006, the CDC has recommended that medical providers routinely offer HIV testing to all patients aged 13–64. This recommendation is based on several factors, including the considerable number of HIV infected people who are unaware of their infection or not linked to care, advances in medical treatment that make early diagnosis and treatment life saving, and the prevention benefits of widespread knowledge of serostatus. Most youth and, often, their providers think they are not at risk of HIV infection (*J School Nurs* 2001;17:198). Most youth also prefer to have healthcare providers initiate discussions about HIV testing, prevention, and risk assessment (*Pediatrics* 2006;117:e468). All adolescents should receive HIV prevention education and should routinely be offered HIV testing. This process enables providers to identify HIV infected youth, provide ongoing medical care and support services, relieve their patients' anxiety, and reinforce preventive behaviors for youth who are not HIV infected. For adolescents who are not sexually active, counseling provides an opportunity to talk about sexual readiness, delaying intercourse, and low-risk ways to explore intimacy. Routine testing also serves to identify the few perinatally infected adolescents who have not previously been tested, often because they were asymptomatic slow progressors (*HIV Med* 2009;10:253). Teens of HIV infected parents or whose parents died of unknown causes should certainly be tested, even if they are not sexually active.

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The ACTS Program

The Adolescent AIDS Program at Montefiore Medical Center, New York, has developed a streamlined approach that enables providers to routinely incorporate HIV screening into their clinical encounters with adolescents (and clients of any age). The program, called Advise–Consent–Test–Support (ACTS), teaches healthcare providers to do the following:

- **A**dvise patients to get an HIV test, and ask if patients are ready to be tested today; if they are not, answer the patients' concerns and then encourage testing.

- **C**onsent patients according to applicable State law. As of 2011, an increasing number of States are moving away from requirements for specific written consent to an opt-out approach, in which HIV testing is included under general consent for care, as encouraged by the CDC.

- **T**est with rapid or conventional HIV test.

- **S**upport patients after testing.

For patients who are not infected, support consists of providing test results and informing patients about ways to take an active role in avoiding HIV infection. A care provider may help patients choose a prevention plan (e.g., abstinence; reduced number of partners; condom use for oral, vaginal, and anal sex). Patients should also be encouraged to get retested annually and advised about when more frequent testing is appropriate (i.e., following unprotected sex, sex with new partners, infection with an STI, or pregnancy or if there are any signs of acute HIV infection).

For HIV infected patients, support should focus on informing patients of test results, addressing immediate and short-term coping abilities, and providing links to appropriate medical care. Patients should be counseled about transmission prevention, which may entail informing sex partners personally or eliciting the help of the local health department to inform partners. Finally, patients should be encouraged to engage in safe sex.

The ACTS program is designed to facilitate practice change within the healthcare system through a four-step process:

- Obtain buy-in from clinic and administrative leadership.

- Implement planning, which includes identifying the role of all staff and process flow.

- Train care providers in the use of the ACTS approach.

- Utilize routine monitoring and evaluation to assess implementation efficacy.

ACTS has successfully increased routine counseling and testing in community health centers, school-based clinics, hospitals, cities throughout the United States, and in other countries in citywide and provincial scale-ups (see www. adolescentaids.org).

Overcoming barriers: Testing options such as rapid testing for antibodies in oral fluids are helpful with youth who are afraid of needles. Those options also allow providers to offer testing in a variety of settings, including mobile vans, school-based clinics, and drug treatment programs. Meeting adolescents' needs for flexibility, accessibility, and low- or no-fee HIV testing is important in overcoming primary barriers to accessing care and can serve as an entry point to care. Ensuring access to HIV counseling and testing is essential to enabling adolescents to receive ongoing treatment and care.

Risk assessment and counseling: HIV screening and testing can be streamlined and incorporated into the clinical visit, but prevention counseling and risk assessment takes more time. Because adolescents may have misconceptions about aspects of HIV transmission and prevention, providers should assess a youth's baseline understanding and capacity to understand basic concepts of HIV disease and viral transmission. Effective HIV counseling for adolescents should be culturally sensitive and tailored to adolescents' developmental needs, i.e. information provided at a level of comprehension consistent with the age of the client. In addition, providers should take special precautions to ensure confidentiality in institutional settings such as foster care, residential treatment, or detention centers. Elements of a youth-friendly risk assessment are summarized in Figure 10-1.

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Figure 10-1
HIV Risk Assessment for Adolescents

1. Engage and Assess

- Create a confidential atmosphere
  - Assure youth that visit is confidential and explain ability to consent for testing per local laws.
  - Assure youth that getting tested is his or her choice.
  - Acknowledge that it can be embarrassing to discuss sexual behaviors.
  - Help youth identify a supportive adult who is aware that he or she is being tested.

- Assess HIV/AIDS knowledge
  - Allow youth to verbalize his or her understanding of HIV; clarify misconceptions, then fill gaps in knowledge.
  - Assess youth's feelings about testing and previous HIV testing experiences.
  - Ask if youth knows anyone with HIV/AIDS (eg., sexual partner, family member).

- Assess sexual risk
  - Assess sexual behaviors without making assumptions about sexual orientation: Not all youth are heterosexual, and not all youth who have engaged in same-sex behavior self-identify as lesbian or gay.
  - Assess number of youth's partners, age differential, and partners' known risks.
  - Assess frequency of substance use in the context of sexual behavior.
  - Assess consistency of condom use and obstacles to use such as lack of assertiveness, desire to become pregnant, fear of violence, and religiosity.
  - Assess for history of sexual abuse or rape (coerced sex).
  - Assess for history of sex work and transactional sex.

- Assess substance use and other risks
  - Assess level of drug and alcohol use, context in which use occurs, and reasons for use.
  - Review risk of impaired judgment that may lead to unsafe sex.
  - Assess potential need for drug treatment.
  - Assess violence and substance use in home and community.

2. Reduce Risk

- Discuss abstinence.
- Discuss sexual activities that don't involve exchange of body fluids (e.g., outercourse or frottage).
- Demonstrate proper use of male condom, female condom, and dental dam on anatomical model and provide opportunity for practice.
- Rehearse (role play) effective ways to communicate risk reduction with sexual partner(s).
- Discuss harm-reduction strategies, if youth is using drugs.
- Develop a personalized risk-reduction plan.
- Discuss postponing sex, if youth is not sexually active.
- Determine referral needs (e.g., medical, psychosocial, school/vocational, substance abuse, reproductive health, legal, housing, psychiatric).

Condom use: Several intrinsic and extrinsic factors, outlined in Figure 10-2, affect condom use among adolescents. Knowledge of appropriate condom use and widespread availability of condoms are especially important in promoting risk-reduction behaviors among youth. All facilities that provide

healthcare for adolescents should make condoms available, and providers should demonstrate condom use with anatomical models. Gender and power imbalances in relationships make condom use especially difficult for adolescent women, who may have older partners and who are just beginning to develop communication and negotiation skills. Helping youth identify their personal values may increase self-esteem and help them resist pressures to engage in sexual risk behaviors.

Figure 10-2
Factors That Encourage and Discourage Condom Use

Encourage Use
- Knowledge about condoms
- Belief in effectiveness
- Discussion with healthcare provider
- Self-esteem and self-efficacy
- Communication and negotiation skills
- Availability and accessibility

Discourage Use
- Drug and alcohol use
- Relationship power imbalances
- Peer pressure
- Lack of effective sex education
- Lack of media and cultural support

Prevention

Promoting abstinence and risk reduction among adolescents is especially challenging because developmental characteristics encourage concrete, short-term thinking and experimentation and increased reliance on peers. Thus, successful primary and secondary prevention programs for adolescents are those that provide interventions to increase self-esteem and self-efficacy, build social skills, and provide basic information geared to the adolescent's developmental level, using a peer-support model (*Psychosom Med* 2008;70:598). For high-risk youth, the AIDS Risk Reduction Model (*Health Educ Q* 1990;17:53) has been widely used to foster primary and secondary prevention. The model is based on three stages of behavior change: (1) acknowledging that a behavior is risky (behavior labeling), (2) committing to change, and (3) taking action to reduce high-risk activity.

School-based programs: School-based programs that provide comprehensive health education in conjunction with school health clinics offer optimal opportunities to reinforce positive health behaviors and ensure routine screening for a range of health and mental health concerns. They are especially important to efforts to reduce risk and identify sexually active youth who are at risk for STIs and pregnancy. A comprehensive review of school-based programs designed to reduce risky behavior in teens found that adolescents who received AIDS education were less likely to engage in sexual activity and more likely to practice safer sex than peers who lacked AIDS education in school (*Public Health Rep* 1994;109:339). In particular, successful prevention programs focus on building skills, reinforcing age- and experience-based values and norms that help prevent unprotected sex, and discussing social influence and pressure. School clinics also offer an important venue for access to condoms and appropriate instruction on condom use. Although not widely available, school clinics provide an important site for HIV counseling

and testing for in-school youth, given new rapid testing options. Ultimately, successful prevention must also involve society and the media—until youth see abstinence, condom use, and safer sex discussions incorporated into sex scenes in music videos and movies, they will not believe that these practices are the social norm.

Adolescents who are HIV infected are also in need of risk-reduction counseling to prevent transmission of HIV to uninfected sexual partners and to prevent acquisition of other STIs or reinfection with other HIV strains. Previous data show high prevalence of risky sexual behaviors and the attendant high risk of STIs among youth. (*Perspect Sex Reprod Health* 2004;36(1):6-10; *MMWR* 2010;59 SS5:1). Multiple studies of HIV infected youth reveal a significant unplanned pregnancy rate, which is further evidence of high-risk behaviors (*HIV Med* 2011;12:118).

Linking Youth to Care

Barriers to care: Linking HIV infected youth to care is essential in meeting their needs for risk-reduction education and appropriate ongoing HIV medical and psychosocial care. Barriers to care include stigma associated with HIV, lack of independent transportation, dependence on parents for health insurance or other financing for care, and feelings of vulnerability. Many HIV infected youth do not know they are infected, and many providers are not aware of available community service agencies that can address adolescents' multiple mental health and social service needs. Community outreach is a primary component in ensuring access to care for youth with HIV disease. Programs often use peer-based outreach, because adolescents are more likely to listen to their peers.

Outreach: Unlike adult women, who have more opportunities to obtain HIV testing and to access care related to their reproductive health needs, adolescents who are not pregnant require proactive outreach efforts to promote HIV testing and engage them in care. These efforts include citywide campaigns to encourage testing and to make it more widely available with direct linkages to adolescent healthcare facilities. Another crucial element is social marketing, using the media (radio, TV, Internet, and mobile phones) that youth prefer for their communication and entertainment. To effectively reach adolescents, it is crucial that social marketing be continually updated and use the words and formats preferred by youth. Every 5 years brings a new generation, and marketing and outreach must be continually updated to reach these new generations.

Linkage to care is a crucial step in ensuring that newly identified HIV infected youth can access life-saving care. Knowing where youth are identified can also help guide expanded testing and collaboration programs. A survey conducted among 12 sites in the National Institutes of Health (NIH)-funded Adolescent Trials Network assessed the referral sources for 400 HIV infected youth who were identified and linked to care in 2009 (Futterman, unpublished data). Medical sites were the referral source for almost half the patients (48%); public health departments accounted for 21% of referrals; community-based

organizations, 16%; self, friend, or family, 10%; and other, 8%. This survey highlighted the importance of medical providers as referral agents as well as the full spectrum of sites involved in youth testing.

HIV Clinical and Psychosocial Care

Although the natural history of HIV infection in adolescence is still being defined, the course of disease among youth who acquire HIV sexually appears to follow that of adults. Descriptive studies of HIV infected adolescents in care consistently show that most youth enter care with significant immune dysfunction and that clinical status varies markedly by transmission category. Most HIV infected youth acquire their infection sexually and enter care while asymptomatic but with enough immune dysfunction to qualify for initiation of ART. In the NIH- and HRSA-funded REACH cohort (a national prospective study with sites in 13 cities to identify the course of disease in adolescents), 49% of HIV infected females and 66% of HIV infected males had CD4+ cell counts below 500/mm^3 at study entry. Although a similar percentage of females and males had AIDS at study entry (16% of females and 18% of males), viral loads were higher in the males: 9% of females but 23% of males had viral load above 50,000 copies/mL (*J Adolesc Health* 2001;29 suppl 3:8). The higher CD4+ cell count values and lower viral loads, yet similar percentage of AIDS among adolescents, provide a different perspective for the debate about whether females progress to AIDS at lower viral load and higher CD4+ cell counts.

In contrast, youth who are perinatally infected often have a much more serious course during adolescence, reflecting the effects of long-term infection. In many cases, the course of illness in adolescence also reflects the often complex patterns of resistance that result from treatment with serial mono or dual therapy that was based on earlier standards of care and medication availability. Of note, one study that predated the era of highly active antiretroviral therapy showed that among perinatally infected children, one-fifth remained asymptomatic with CD4+ cell counts > 500/mm^3. With the introduction of HAART, the subpopulation of perinatally infected youth will continue to grow as more survive and age into adolescence. Dramatic declines in mortality associated with HAART were demonstrated in the PACTG-219 study (*J Acquir Immune Defic Syndr* 2010;53:86), but those gains are tempered by the fact that mortality rates still remain 30 times greater than in uninfected matched cohorts.

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Perinatally infected youth are often confronted with their own physical disabilities, which may include multiorgan system disease, delayed puberty, body dysmorphisms, and developmental delay. Their difficulties may be compounded by isolation, stigma and, often, the death or illness of one or more parents. At the same time, HIV infected youth are challenged by the tasks of adolescence, including the emerging sense of self and the need for independence. Some youth are first told of their infection during adolescence

even after having taken medications for years. Clinicians also need to be aware that some slow-progressing perinatally infected youth might not even be diagnosed until adolescence.

Physical Exam, Laboratory Tests, and Immunizations

Privacy is an important consideration in the adolescent physical exam, because most adolescents have a high level of modesty that is often compounded by anxiety about physical changes and a lack of understanding about their anatomy. Physical examinations for adolescents should follow guidelines used for adults; however, when prescribing medications, providers should use the Tanner staging of puberty, presented in Table 10-1, which characterizes development of breasts, genitalia, and pubic hair (*Comprehensive Adolescent Health Care*, 2nd ed. St. Louis: Mosby; 1998).

Table 10-1

Classification of Sex Maturity Stages (Tanner Scale)

Stage	Pubic Hair	Breast	Penis	Testes
I	Preadolescent	Preadolescent	Preadolescent	Preadolescent
II	Scanty, long, slightly pigmented, downy	Breast bud stage; elevated breast and papilla; increased areolar diameter	Slight enlargement	Enlarged scrotum and testes; pink; changed skin, texture
III	Darker, coarser, curlier	Enlarged breast and areola with no contour separation	Increased length	Increased size
IV	Adult type, but less; no spread to medial surface thighs	Areola and papilla form secondary mound	Glans enlarged; increased breadth	Enlarged, skin darker in color
V	Adult distribution with spread to medial thighs	Mature stage; projection of nipple	Adult size	Adult size

Adapted from *Growth at Adolescence*, 2nd ed. Oxford, England: Blackwell Scientific Publications; 1962.

Routine screening: Because sexually active adolescents are at very high risk for STIs, providers should routinely screen with cervical cytology and for chlamydia, gonorrhea, syphilis, and hepatitis B and C; they also should follow TB screening guidelines for adults with HIV infection. Pregnancy testing should be performed when indicated by history or exam findings, and it should always be considered with missed menses, abnormal bleeding, or development of pelvic pain.

Immunizations: Adolescents require more immunizations than adults; immunizations are listed in Figure 10-3. HIV infected adolescents can safely receive most childhood vaccines, although efficacy may vary. Those with severe immunosuppression (CD4+ cell count <200/mm^3; CD% <15%) should not receive MMR or varicella vaccine. Oral polio and intranasal influenza vaccine are contraindicated in HIV infected patients. The CDC provides vaccination guidelines, including catch-up schedules, for patients older than 18 years of age (www.cdc.gov/mmwr/preview/mmwrhtml/mm5901a5.htm) and younger than 18 years of age (www.cdc.gov/vaccines/recs /schedules/default.htm).

Because immunizations may briefly boost viral load, they should be scheduled on the same day as or after viral load measurements. At present, CD4+ cell counts and viral load measurements are interpreted as for adults and used to guide treatment.

Figure 10-3
Immunizations for Adolescents

- Measles, mumps, and rubella (MMR) booster if CD4+ cell count is stable >200/mm^3
- Diphtheria-tetanus toxoid (TdaP) booster
- Hepatitis B vaccine (3 in series)
- Hepatitis A vaccine (2 in series; not routine for females, but recommended for males who have sex with males)
- Influenza (yearly)
- Pneumococcal vaccine (PPSV-23) >age 2 years and booster 5 years after
- HPV (3 in series) age 9–26
- Varicella zoster vaccine for contacts (not currently approved for HIV infected people; can consider for those with CD4+ cell count >200/mm^3)
- Meningococcal conjugate vaccine (MCV4; 2 in series) age 11–12, booster at age 16–18

Source: *AIDS Clin Care* 1999;11:17. Reprinted with permission.

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HIV Treatment

Medication dosing: Adolescents have not been studied extensively in the clinical trial system; thus, few direct data about dosing regimens are available. The U.S. Department of Health and Human Services (HHS) has included the treatment recommendations (based on expert opinion) for postpubertal adolescents with adult treatment guidelines. Because pubertal changes may affect pharmacokinetics, dosage is based on Tanner staging rather than on age. For example, pediatric dosing should be used for adolescents who have entered or are in early puberty (Tanner stage I/II), whereas dosing for adolescents in midpuberty (Tanner III/IV) should be based on whether they have completed the growth spurt. Adolescents who have completed puberty (Tanner V) should receive adult dosages (www.aidsinfo.nih.gov). Factors that should be considered in choosing the initial treatment regimen for adolescents include results of viral resistance testing (genotype or phenotype), pill burden, potential side effects, and likelihood of adherence.

ART and contraception: Note that several key medications commonly prescribed to adolescents have significant interactions with antiretroviral medications, including combined estrogen/progestin contraceptives, which may be less effective and/or cause more side effects when taken with antiretrovirals. Clinicians may consider switching to progestin-only methods, such as depot medroxyprogesterone acetate or the etonogestrel implant, both of which provide very effective and longer term contraception without the need to take daily pills. Concomitant use of a barrier method of contraception should be stressed. Efavirenz has been associated with risk of birth defects; since pregnancy is often unplanned in youth, this medication should generally be avoided in young women, unless other effective and well-tolerated options are not available. Currently, clinicians are advised to avoid tenofovir until patients reach Tanner IV/V. (For more information on drug–drug interactions, see the U.S. Public Health Service adult and adolescent guidelines at www.aidsinfo.nih.gov).

Adherence: Treatment adherence, which is challenging for adults, can be especially challenging for adolescents, who struggle with a range of developmental tasks that require them to balance dependence with increasing autonomy. As with any successful work with adolescents, the first step in promoting adherence is to establish a solid therapeutic alliance. Providers must develop a systematic approach that facilitates adherence by addressing four areas of interaction: (1) building trust, (2) assessing and facilitating readiness, (3) helping teens initiate and practice a new treatment regimen, and (4) providing ongoing support for adherence. This approach is outlined in Figure 10-4, which describes the EARS approach: Engage, Assess, Ready, Support. This approach addresses barriers to maintaining a complex medication schedule for adolescents, such as lack of privacy in school, home, or residential settings; the need to develop a reminder system; and the incongruity of having a serious illness while exhibiting few visible indicators of disease. In a Los Angeles adolescent HIV/AIDS program, the most common reasons for missing medication reported by youth include forgetfulness, side effects, the inconvenience of having to take so many pills, and the fact that taking the medication is a continual reminder of being HIV infected (*J Adolesc Health* 1998;22:160). Patients should be screened for depression, a known cause of nonadherence (*Arch Pediatr Adolesc Med* 2005;159:764).

Figure 10-4
Adherence: Use Your EARS

Engage
- Establish therapeutic alliance and build trust—the goal is to have youth participate actively in all aspects of treatment.
- Address immediate needs: health, housing, insurance, family, and partners.
- Educate about HIV infection—transmission, disease course, and benefits of medications.

Assess
- Stage of HIV infection
- Mental and cognitive abilities
- Physical ability to take medicines
- Support systems and disclosure issues (family and friends)
- Readiness to begin medications

Ready
- Decide with adolescent on a regimen that integrates clinical needs with lifestyle—show different pills and combinations.
- Solidify support systems: family, treatment buddy, or both.
- Practice chosen regimen with surrogate vitamins; distribute medications into a weekly medication planner and program 1-day pill timer with the adolescent.
- Address adherence barriers discovered in the practice run.

Support
- Provide ongoing support with frequent clinic visits and phone contact.
- Acknowledge and address side effects.
- Develop strategies to ensure tolerability and regularity.
- Facilitate interactions with other youth who are taking medications.

Source: *AIDS Clin Care* 1999;11:17. Reprinted with permission.

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Psychosocial Issues

An understanding of adolescent development is crucial to working effectively with adolescents as partners in their healthcare. In addition to the physical changes of puberty, adolescence consists of a series of cognitive and psychosocial phases that are key to successful maturation yet are greatly confounded in the setting of HIV infection. The Adolescent AIDS Program has identified five key issues that adolescents with HIV/AIDS must address in coping with their changing health status: (1) receiving an HIV diagnosis; (2) disclosing HIV status to parents, partners, and others; (3) coping with HIV disease; (4) becoming symptomatic; and (5) preparing for death (*J Adolesc Health* 1993;14 supp:S1). Family members can play a key role in the care of the HIV-infected adolescent if they are engaged and supportive.

Receiving an HIV diagnosis: Providers should instill a sense of hope and encouragement when giving adolescents an HIV diagnosis. Asymptomatic youth must learn to balance healthy denial and preoccupation with HIV infection. Concrete thinking makes it difficult for some youth to integrate the concept of disease latency and asymptomatic infection. Support is essential in helping youth integrate this life-changing information. Individual and peer-group interventions with psychologists and social workers can help

facilitate adjustment. Psychotropic medication may be needed to manage preexisting psychiatric problems or anxiety and depression that may accompany the diagnosis.

Disclosure of HIV status: After learning of an HIV diagnosis, adolescents face the hurdle of deciding whom to inform and when to disclose their HIV status. Although the involvement of a supportive adult is ideal, telling parents is difficult for many adolescents, who fear losing their parents' love and support or worry about hurting them. The need to rely on adults because of illness sharply contrasts to the developmental need to establish independence and identify with one's peer group. For gay or substance-using youth, disclosure to one's parents may be especially threatening because they may have to reveal their HIV status, sexuality, and drug use all at once, which could lead to rejection, harassment, or violence. Disclosure becomes a particularly salient issue with advancing disease or initiation of ART because it is difficult to conceal medications from the people with whom one lives. Adolescence is one of the most observed times of life—young people often do not have space to call their own, and privacy is especially compromised for youth living in crowded homes or residential programs. In school, institutional bathrooms provide no seclusion for taking medications.

Disclosure to sexual partners is both ethically compelling and complicated. Of course, HIV infected adolescents should inform their sexual partners and engage in safer sex, but youth face several unique challenges in disclosing their HIV status. The adolescent social/sexual world is smaller, more intense, and often shorter lived than that of adults, so confidentiality is more easily compromised. Providers should be aware that adolescents in earlier stages of sexual development might have fewer partners, which could make an anonymous disclosure easier to figure out. If one person knows, then everyone in an adolescent's group might easily find out. Fear of rejection and loss of confidentiality are thus major concerns in disclosing to sexual partners. Providers should offer to help with disclosure and offer guidance in determining when it is safe and appropriate for a youth to disclose her HIV status. Role-playing and working through scenarios ahead of time can help an adolescent manage potential fears and concerns. Collaboration with the local public health department can also facilitate partner notification and identification of sexual networks.

Coping with HIV disease: Given the prognostic significance of viral load and CD4+ cell count, adolescents need to understand how these markers relate to the course of their HIV disease. However, these concepts are often difficult to understand for youth, who may be concrete thinkers. Adolescents also need guidance in learning how to interpret changes, because fluctuation in results may cause some youth to panic. Providers can help by explaining that variation is common and that fluctuations in values will not prevent adolescents from leading satisfying and productive lives.

Becoming symptomatic: The appearance of HIV-related symptoms can be especially disturbing for adolescents, who may have only superficially acknowledged their HIV status. The onset of HIV symptoms may pierce their denial. For some youth, becoming symptomatic may encourage them to fight HIV and may enhance treatment adherence and self-care. Others, however,

may feel overwhelmed and lose their motivation to care for themselves. When symptoms occur, providers should explain their significance, correct misconceptions, and ensure that adequate services and support are available.

Preparing for death: Many adolescents have limited experience with death and have naïve perceptions about what to expect. Introducing the topic by talking about living wills and healthcare proxies before HIV becomes too advanced is a practical way to help youth begin to deal with issues related to death. When clinically appropriate, providers can help adolescents explore their feelings about dying by discussing options for dying in the hospital or at home, talking about funeral or memorial services, and exploring child custody or permanency planning with adolescent parents.

Mental Illness and Substance Use

Mental illness and substance abuse are significant comorbidities for HIV infected adolescents. Accurate screening, diagnosis, and treatment are essential to helping adolescents cope with their HIV disease and successfully maintain their ART regimen. Case studies of adolescents and young adults with HIV indicate a high prevalence of depression, bipolar disorder, and anxiety; these mental health issues often predate an HIV diagnosis (*Arch Pediatr Adolesc Med* 2000;154:240). Similarly, many HIV infected adolescents report alcohol and drug abuse. Of adolescents in the REACH study, 14% percent of females and more than 25% of males reported weekly use of alcohol in the prior 3 months. During the same period, 7% of females and 20% of males reported using hard drugs (*J Adolesc Health* 1998;22:300; *J Adolesc Health* 2001;29 suppl 3:57). In addition, a high proportion of HIV infected youth report childhood sexual abuse, which has many psychological and behavioral sequelae, including depression, posttraumatic stress disorder, substance abuse, suicidality, and HIV risk behaviors.

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Age Transitions

As medical care continues to improve, a considerable number of HIV infected adolescents will be healthy enough to graduate from pediatric to adolescent to adult programs. Emerging adults require programs and providers that can address their developmental needs. They face the concurrent challenges of healthcare maintenance, medication adherence, and chronic illness within the context of maturing sexuality and establishing an independent life. The issues of transition to adult care have been addressed in the literature for other chronic illnesses, but HIV infection has some unique features. Young people can be quite reluctant to leave their established and trusted providers and care teams. In response, many adolescent HIV programs have increased their upper age limit from 21 to 24 years. However, there comes a time when transfer to adult care is appropriate. Most successful programs begin the transition process months before it occurs. Patients and staff work together to develop skills such as dealing with the medical system (making and keeping appointments),

maintaining entitlements (health insurance and housing), learning to give a medical history and track symptoms, learning to take and be responsible for medications, and learning when to report emerging symptoms. Patients must also learn self-management skills, including setting and achieving life goals such as education and employment or careers.

Summary

The high risk of HIV in adolescent females underscores the need to develop realistic prevention programs that build prevention skills. It also highlights the need for routine HIV counseling and testing for all sexually active teens in all programs that provide care for adolescents. Youth at high risk for HIV should be identified and engaged in primary care as soon as possible. Outreach is an important component of programs that seek to link HIV infected youth to care. Although most HIV infected youth will not receive services in adolescent programs, services can be readily adapted to provide a youth-centered approach by making such basic accommodations as flexible hours, low or no payment for services and care, and engaging providers who are knowledgeable about adolescents. Information on relevant clinical trials should be made available to adolescents as well. Wide dissemination of information to healthcare providers about providing adolescent-related HIV care should take place, such as use of Tanner staging for determining appropriate medication dosages.

Adolescents with HIV need intensive individual and group support to maintain their health and reduce transmission to others. Healthcare providers in all settings that serve adolescents need to assist in making services visible, flexible, affordable, confidential, culturally appropriate, and available for all adolescents.

Chapter 11:

Palliative and Supportive Care

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Chapter 11: Palliative and Supportive Care

Chapter 11 at a Glance
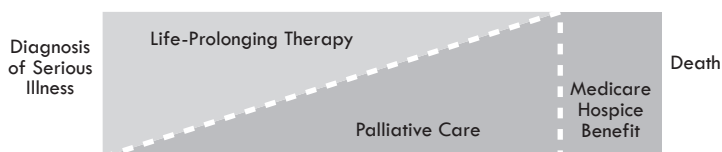
Therapy to Improve Quality of Life

Address Four Domains of Suffering

Palliative care is defined as therapy intended to improve quality of life, irrespective of quantity (*NEJM* 2004;30:2582). The term *palliative* is derived from the Latin *pallium* (cloak) and means to protect (or "cloak") from illness and suffering. Palliative care seeks to address the four domains of suffering—physical, psychological, social, and spiritual. Ideally, it involves an interdisciplinary team approach for pain and symptom management as well as for nonphysical needs that may arise during the course of illness. Those needs may be met with psychosocial support for marginalized patients, identification of substance abuse and mental health issues and provision of appropriate services, and advance care planning. When appropriate, care may also include facilitating transitions to end-of-life care, including hospice. High-quality palliative care begins at disease diagnosis and is delivered simultaneously with life-prolonging therapy throughout the course of illness (Figure 11-1). As a patient's illness progresses, palliative care takes on an increasingly important role.

Palliative care encompasses end-of-life care, including hospice. In the United States, patients on Medicare may choose to disenroll from Medicare and enroll in the Medicare hospice benefit, which requires a physician to certify that the patient is in the last 6 months of his or her life. This separation between palliative care in general and hospice is artificial and applies only in the United States. In other countries, the terms palliative care and *hospice* are often used synonymously (*Cancer J* 2010;16:423).

Supportive care is used in the literature and in practice to delineate a similar model of care. Supportive care is designed to support a patient and his or her family and caregivers during an illness that is not imminently terminal but is curable or has a good chance of recovery or survival. Supportive care describes many ambulatory programs, particularly in the areas of oncology and cardiac disease. Supportive care settings also include a focus on the four domains of suffering and an interdisciplinary model of care.

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Figure 11-1
Palliative Care's Place in the Course of Illness

Diagnosis of Serious Illness

Life-Prolonging Therapy

Palliative Care

Medicare Hospice Benefit

Death

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Rapid Expansion in the United States

The number of hospital-based palliative care programs increased from 658 in 2000 to more than 1151 in 2005 (*J Palliat Med* 2008;11:1094); in 2009, 41.6%% of all deaths in the United States took place under the care of a hospice program (http://www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf). A recent high-profile study showed that an early outpatient palliative care intervention improved quality of life and extended survival as much as cisplatin-based chemotherapy for patients with metastatic non-small-cell lung cancer. Although this result is not necessarily generalizable to other patient populations, it is encouraging (*NEJM* 2010;363:733). Additionally, palliative care is an increasingly accepted part of care not only for patients with cancer but also for those with other chronic diseases, such as congestive heart failure (CHF), chronic lung disease, and HIV.

Interdisciplinary Approach

As noted above, the delivery of comprehensive palliative care should involve an interdisciplinary team consisting of physicians, nurses, social workers, pastoral care representatives, and mental health care providers. High-functioning teams also successfully incorporate midlevel care providers, such as nurse practitioners, physician assistants, pharmacists, pain management specialists, and integrative therapists (massage, music, and art) as well as volunteers. The National Quality Forum has produced a document of preferred practices that delineate the parameters or measures of quality for palliative care programs; it should be referenced when initiating or enhancing delivery of palliative and supportive care (National Quality Forum 2006. *A national framework and Preferred practices for Palliative and Hospice Care Quality: A Consensus Report 2006*).

HIV as a Chronic Disease

Alleviate Suffering of Chronic Disease

Before the introduction of effective ART in the mid-1990s, the trajectory of HIV/AIDS was a downward spiral, and all care was palliative. HAART transformed HIV from a disease with a uniformly poor prognosis into a chronic disease with a slowly progressive course and occasional exacerbations, much like chronic obstructive pulmonary disease (COPD), CHF, and chronic malignancies. Patients began to have the potential for normal or nearly normal life spans. In the post-HAART era, the focus understandably shifted toward optimal use of life-prolonging medications. Palliative care for HIV was seen as mostly of historical significance, appropriate only for patients facing imminent death from AIDS (*JAMA* 2003;290:806, *Annals Int Med* 1998;129:899). However, symptom burden remains high despite ART (*Int J STD AIDS*

2006;17:400). Therefore, in the current treatment era, palliative care should be applied throughout the disease continuum to alleviate suffering associated with living for many years with a chronic disease.

HIV Disease Burden and the Role of Palliative Care

Today, HIV palliative care focuses on quality of life, maximized functional status, and treatment of complicated comorbidities (Figure 11-2). Unfortunately, the burden of HIV disease in the current treatment era remains high for several reasons.

Prevalence: Even though the number of new HIV diagnoses among US women has declined slightly from 2008–2011, HIV prevalence continues to increase as more infected individuals are living longer because of ART (http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm).

Pain and symptom burden: Patients living with HIV disease have significant pain and physical and psychological symptoms. Most studies of pain and symptoms in HIV come from the early treatment era, but emerging evidence indicates that pain and symptom burden remains high despite advances in therapy (*J Pain Symptom Manage* 2009;38:882).

Aging patients: As a result of effective ART, the population of patients with HIV is aging. In addition, a number of patients with HIV experience premature aging and are at increased risk for cardiovascular disease, metabolic complications, neurologic sequelae, frailty, osteoporosis, and malignancies, among other age-associated conditions (*AIDS Patient Care STDS* 2006;20:782, *J Acquir Immune Defic Syndr* 2008;49:S77, *J Acquir Immune Defic Syndr* 2009; 50:299, *Top HIV Med* 2010; 18:45, *J Acquir Immune Defic Syndr* 2003;33:281, *J Acquir Immune Defic Syndr* 2009; 52:203). Aging and comorbidities likely add to pain and symptom burden.

Death: People still die of HIV in the United States; 2010 data from the U.S. Centers for Disease Control and Prevention indicate that the death rate in women with HIV disease has leveled off at 4–5 deaths per 100,000 since 1998. Increasingly, death is occurring among non-Hispanic blacks, residents of the South, and people aged 45 years and older (http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm). Death from HIV has shifted "from fate to tragedy" (*Ann Intern Med* 1998;129:899) and is often due to nonadherence to medical care and ART, psychiatric and substance abuse comorbidities, and marginalization from the medical system.

Non-AIDS–related death: HIV patients die more often of non-AIDS–related causes, such as cardiovascular, hepatic, and pulmonary disease; non-AIDS malignancies; and substance abuse. They are at greater risk for those diseases than is the general population (*Ann Int Med* 2006;145:397, *J Acquir Immune Defic Syndr* 2006;43:27, *J Acquir Immune Defic Syndr* 2009;52:203).

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Thus, the role of HIV care providers is to alleviate suffering while treating the primary disease. If for no other reason, HIV providers today must learn and use the principles of palliative care to address the burden of HIV as a chronic disease. Additionally, evidence increasingly shows that management of symptoms in patients with HIV improves quality of life (*AIDS Behav* 2004;8:151, *CID* 2008;46:941), adherence (*J Acquir Immune Defic Syndr* 2002;31:211, *AIDS Beh* 2003;7:109, *Ann Behav Med* 2007;34:46, *AIDS Care* 2009;21:244), and virologic outcomes (*J Acquir Immune Defic Synd* 2010; 54:500). Palliative care for patients with HIV can be delivered by HIV primary care providers in addition to palliative care specialists when necessary.

Figure 11-2
Key Facts About Palliative Care in HIV

- Palliative care does not equate to end-of-life care and is not the same thing as hospice.
- Symptom burden in HIV patients, even in the current treatment era, remains high.
- Incorporating principles of palliative care, including pain and symptom management, early in the disease course can alleviate suffering and may improve quality of life, adherence, and virologic outcomes.
- Palliative care for patients with HIV can be delivered by HIV primary care providers in addition to palliative care specialists when necessary.

Pain and Nonpain Symptoms

This section focuses on pain and nonpain symptoms in ambulatory patients with HIV. As with other serious conditions prevalent in patients with HIV, such as syphilis and hyperlipidemia, pain must be assessed and treated, if present, in every patient.

Pain and other symptoms in patients with HIV are generally thought to result from several factors:

- Disease-related factors may include the acute effects and long-term sequelae of opportunistic infections (e.g., headache in cryptococcal meningitis, contractures resulting from a distant history of PML), AIDS-defining and non-AIDS-defining malignancies, and the effects of HIV itself or the body's immune response to it (e.g., peripheral neuropathy).

- Treatment-related factors may include the medications used to treat HIV disease (e.g., dideoxynucleoside-related peripheral neuropathy and protease inhibitor–related gastrointestinal distress)

- Other factors may include the nonspecific effects of a chronic illness and other causes of pain and symptoms unrelated to HIV (e.g., shortness of breath in COPD or edema in CHF)
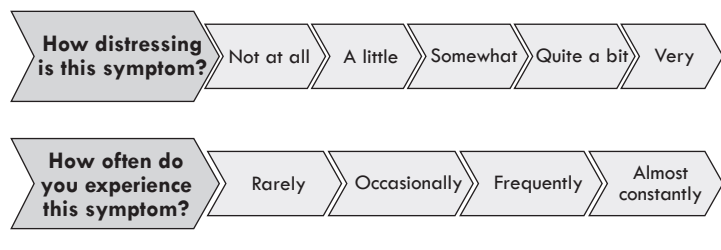
Prevalence of Nonpain Symptoms

In the current treatment era, symptoms remain prevalent, and it is essential to pursue the cause of the symptom by searching for treatable underlying etiologies. Simultaneously, an effort should be made to relieve the symptoms. This approach does not detract in any way from the evaluation; in fact, attention to symptom management may increase the likelihood of the patient returning for regular followup and enhance overall quality of life.

Most data on nonpain symptoms in patients with HIV comes from the early treatment era. In 1996, a study of 434 ambulatory patients with HIV found an average of 17 symptoms on the Memorial Symptom Assessment Scale (MSAS), a 32-symptom instrument (*Pain* 1996;68:315). The most prevalent physical symptoms other than pain were lack of energy, difficulty sleeping, and dry mouth (86%, 74%, and 69% respectively). A recent study of 350 ambulatory HIV patients in the current treatment era found a median of 9 symptoms (*J Pain Symptom Manage* 2009;38:882). The most common symptoms were lack of energy (65%), drowsiness (57%), and difficulty sleeping (56%). Numbness and tingling (44%) were also common, as were psychiatric symptoms, such as feeling irritable (50%), worrying (48%), and feeling sad (45%).

Assessment of Nonpain Symptoms

As part of an overall systems review, it is important to ask patients specifically about the types of symptoms mentioned above—namely, lack of energy, difficulty sleeping, psychological problems, and neuropathic pain. A systematic approach to assessment is more important than the specific instrument used. The MSAS is often used for research, but it may be too cumbersome for routine use in the clinical setting. If that is the case, then a standard symptom assessment tool that meets the needs of an individual clinical practice setting is recommended. When assessing physical symptoms, a patient should be asked about the degree to which a symptom causes bother or distress—i.e., not at all, a little bit, somewhat, quite a bit, or very much, as illustrated in Figure 11-3. For psychological symptoms, a patient should be asked about the frequency with which a symptom occurs—i.e., rarely, occasionally, frequently, or almost constantly. If a patient reports a symptom that is particularly distressing, then the response to these questions may be followed over time.

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Figure 11-3
Key Questions in Assessing Nonpain Symptoms

How distressing is this symptom?	Not at all	A little	Somewhat	Quite a bit	Very

How often do you experience this symptom?	Rarely	Occasionally	Frequently	Almost constantly

Management of Selected Symptoms

Clinicians should always investigate the cause of symptoms, particularly for potentially curable etiologies. While investigating a symptom, it is also important to begin to manage the symptom.

In a patient with HIV infection, multiple factors should be taken into consideration, including the stage of illness, current ART and other medications, and total symptom burden. As noted above, patients may have multiple simultaneous symptoms that require a comprehensive, patient-centered approach that focuses on the effect on quality of life of each symptom. Symptom clustering also should be considered (e.g., inadequately treated pain that leads to depression, sleep disturbance, shortness of breath, anxiety, poor appetite, and fatigue), so as not to overlook appropriate medications that may successfully treat multiple symptoms simultaneously. Discontinuation of nonessential medications that may cause a disturbing symptom should be explored as well.

Table 11-1 lists common nonpain symptoms with appropriate medication classes. A comprehensive listing of all symptoms and medications with dosages is beyond the scope of this chapter. Treatment of psychiatric and psychological symptoms is addressed in Chapter 9. It is also important to keep in mind that symptoms certainly will change and evolve as a patient's disease progresses. Therefore, use of medications may change over time as well.

Table 11-1

Common Nonpain Symptoms in HIV Patients

Symptom	Common Medications/ Classes Used in Treatment	Important Points/Notes
Fatigue	• Psychostimulants (dextroamphetamine, methylphenidate) • Steroids (dexamethasone, prednisone) • Other agents, depending on comorbidities (testosterone, opioids, sleep agents)	• Determine whether etiology is reversible. • Energy conservation counseling and/or an appropriate graduated exercise regimen may be helpful.
Weight loss/ anorexia	• Steroids (dexamethasone, prednisone) • Megestrol • Mirtazapine • Dronabinol	• Evaluate for inadequately treated comorbidities • Consider dietary or nutrition consultation. • Likely not reversible near end of life.
Insomnia	• Benzodiazepines (lorazepam, temazepam) • Antidepressants (trazodone, mirtazapine) • Chloral hydrate • GABA receptor nonbenzodiazepines (zolpidem, zaleplon) • Melatonin receptor agonist (ramelteon)	• Emphasize nonpharmacologic sleep hygiene. • Avoid chronic long-term use of meds.
Nausea/ vomiting	• Dopamine agonists (haloperidol) • Dopamine antagonists (prochlorperazine, chlorpromazine, promethazine) • Gastric motility agents (meclizine, hydroxyzine) • Antihistamines (meclizine, hydroxyzine) • Anticholinergics (scopolamine, glycopyrrolate) • Anxiolytics (lorazepam) • Steroids (dexamethasone) • 5-HT3 antagonists (ondansetron, granisetron)	• Thoroughly evaluate for mechanism and/or etiology. • Remember bowel history and avoid constipation. • Combinations of agents may be helpful. • 5-HT3 antagonists may have limited utility near end of life. • Sedation is a common limiting side effect.
Dysphagia/ odynophagia	• Antifungals (fluconazole, nystatin) • H2 antagonists (famotidine, ranitidine) • Proton pump inhibitors (omeprazole) • Steroids (dexamethasone) • Anticholinergics (hyoscyamine, glycopyrrolate) • Oral solutions (viscous lidocaine)	• Treatment of oropharyngeal comorbidities is crucial. • Complicates many other symptoms. • Very common near end of life. • Combinations of agents in oral solution may be helpful.

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Table 11-1	*continued*

Common Nonpain Symptoms in HIV Patients

Symptom	Common Medications/ Classes Used in Treatment	Important Points/Notes
Cough	• Guaifenesin (immediate or sustained release) • Nebulized saline • Guaifenesin with dextromethorphan • Guaifenesin with codeine or other opioid • Benzonatate	• Difficult to treat in many instances. • Treat underlying comorbidities when possible. • Provide smoking cessation counseling when appropriate. • May be productive or nonproductive.
Hiccups	• Chlorpromazine • Baclofen • Simethicone • Haloperidol • Anticonvulsants (gabapentin, valproic acid, carbamazepine)	• Search for reversible causes; usually self-limiting. • Relation to meals is important. • Nonpharmacologic measures may be beneficial. • Holding breath, gastric distention, vagal maneuvers may be helpful.
Pruritus	• Topical preparations (camphor–menthol lotion • Lidocaine ointment, hydrocortisone • Antihistamines (diphenhydramine, hydroxyzine) • Steroids (dexamethasone, prednisone) • Antidepressants (doxepin, mirtazapine, paroxetine)	• May have multiple etiologies. • Soaps, detergents, and fabrics are common offenders. • Cool environment is usually better than warm.
Dyspnea/ shortness of breath	• Immediate-release opioids (morphine, oxycodone, hydromorphone) • Benzodiazepines (lorazepam, alprazolam) • Nebulized medications (furosemide, fentanyl)	• Troublesome, common symptom near end of life. • Nonpharmacologic treatment (fan, relaxation, etc.) may be most helpful. • Opioids are a mainstay near end of life. • Nebulized meds are somewhat controversial.
Xerostomia	• Saliva substitutes • Chemical stimulants • Muscarinic agents (pilocarpine, cevimeline)	• Encourage ice, frozen fruits, etc. • Sour candies may increase saliva production. • Use humidified oxygen when appropriate. • Use muscarinic agents only with caution.

Prevalence of Pain

Most studies of pain in patients with HIV were conducted in the early treatment era. The largest study surveyed 274 patients, 62.6% of whom reported frequent or persistent pain during the 2 weeks prior to the survey. The mean rating of pain intensity was 5.4 on a scale of 1 to 10, and the mean rating for interference with general activity was 5.7 on a scale of 1 to 10. Pain prevalence in women was similar to that in men, but women reported significantly higher pain intensity. Pain was associated with the presence of AIDS-defining conditions (*Pain* 1996;68:315). In a study of symptoms in HIV patients in the current treatment era, 55% had pain, 60% of whom reported the symptom frequently. Pain was associated with female gender, advanced disease, and absence of antiretroviral (ARV) medications (*J Pain Symptom Manage* 2009;38:882). In a recent study, muscle aches and joint paints were one of the two symptoms most associated with the physical component of health-related quality of life in patients with HIV (*AIDS Behav* 2011; 15:853). Another recent study found that up to 15% of HIV Outpatient Study patients used prolonged analgesic therapy each year; variables associated with the initiation of prolonged analgesia included both HIV and non-HIV related factors. (*Clin J Pain* 2011;27:699).

Although more research is needed to understand HIV patients' pain in the current treatment era, the available data suggest that pain is widely prevalent in this population. Studies from the early treatment era suggest that pain is underrecognized and undertreated (*BMJ* 1997;314:23, *J Pain Symptom Manage* 1999;18:263, *Pain* 1996;65:243) and has a negative effect on quality of life (*AIDS Behav* 2004;8:151, *CID* 2008;46:941). Multisite pain syndromes are common as well–patients have musculoskeletal, neuropathic, and visceral pain syndromes simultaneously. Multisite syndromes may have distinct etiologies and require specific evaluations and treatments that can further complicate care plans, medical regimens, and patients' emotional response to their illness. Although referral to a pain specialist may be useful for patients with a history of previous substance abuse, it behooves the primary care provider to attempt to clarify the types of pain present to ensure adequate follow-up.

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Assessment of Pain

Brief Pain Inventory (BPI; *Ann Acad Med Singapore* 1994; 23 (2): 129): Many approaches to the assessment of pain in patients with chronic illness are available. Because no tool has been validated specifically in patients with HIV, having a systematic approach to assessing pain is more important than using a specific tool. A standard approach that is consistent with the intent of the BPI is generally recommended (*Ann Acad Med Singapore* 2004;23:129).The BPI has been validated in patients with chronic nonmalignant pain (*J Pain* 2004; 5:133) and has been used in studies of patients with HIV (*Pain* 1996; 68: 315). In its entirety, the BPI may be too long for many clinical settings, but when appropriate, it should be incorporated into a patient's ongoing pain assessment and treatment plan.

Pain evaluations should begin by simply asking whether the patient has had pain that affects quality of life during the past week. If the patient answers yes, in addition to usual questions about pain (e.g., location, quality, exacerbating and alleviating factors, duration), a few brief follow-up questions, illustrated in Figure 11-4, may be asked:

- **Severity:** How severe is your pain right now on a scale of 0 to 10, where 0 is *no pain* and 10 is *pain as bad as you can imagine?* On average? At its worst? At its least? (A pain scale, shown in Figure 11-5, may be used to help patients answer this question.)

- **Relief:** What current medications or therapies do you use to help alleviate your pain? How much relief do you get from these therapies, on a scale of 0% (*no relief*) to 100% (*complete relief*)? It is important to ask and document all medications or therapies that have been successful in the past; also emphasize reports of allergies or sensitivities to particular opioids or other pain medications.

- Interference: How much does the pain interfere with your general activity on a scale of 0 to 10, where 0 is *no interference* and 10 is *complete interference*? How does much does it interfere with your mood? Walking ability? Normal work? Relations with other people? Sleep? Enjoyment of life?

The answers to these questions can be followed over time.

Figure 11-4
Key Questions in Assessing Pain

On a scale of 0 to 10 — **How severe is your pain?** — On a scale of 0% to 100% — **How much relief do you have with your current therapy?** — On a scale of 0 to 10 — **How much does pain interfere with your life?**
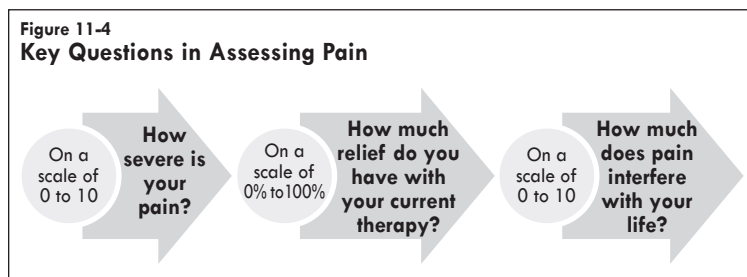
Several additional questions, noted below, may be especially helpful if patients have longstanding or multisite symptomatology. Discussing the questions below can build a therapeutic relationship that helps patients become more active in their care plan.

- Which of your pain locations is the worst today?
- When was the last time you remember being pain free?
- What are your goals, or what would be an acceptable pain score for you?
- If we meet these goals, what kinds of things would you like to do that you are not currently doing?
- What would be your time frame for acceptable pain relief?
- How do your emotions or stress affect your pain?

Figure 11-5
Pain Scale

0	1	2	3	4	5	6	7	8	9	10

No
Pain

Mild
Pain

Moderate
Pain

Severe
Pain
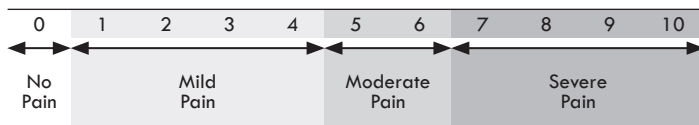
Approach to Pain Management

Initial medication selection: Although it has not been validated specifically in patients with HIV, the World Health Organization's (WHO's) pain ladder is a well-accepted approach to pain management (Figure 11-6).

Figure 11-6
WHO Pain Relief Ladder

Step 3: Severe Pain
Opioid (morphine, hydromorphone)
± Nonopioid analgesics
± Adjuvants

Step 2: Moderate Pain
Opioid (codeine, hydrocodone, oxycodone)
± Nonopioid analgesics
± Adjuvants

Step 1: Mild Pain
Nonopioid ± Adjuvants
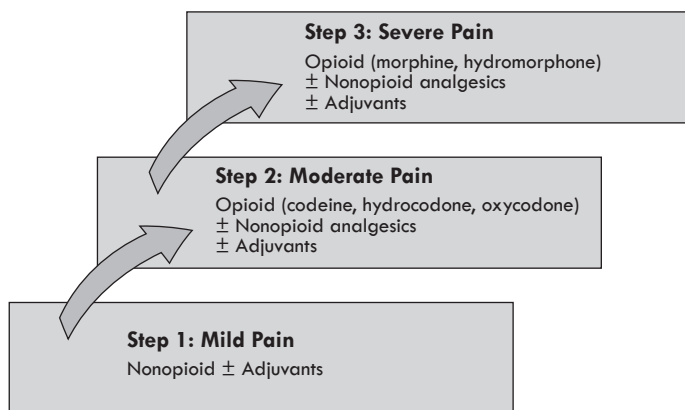
Source: World Health Organization. *WHO's Pain Relief Ladder*. Copyright © 2012. World Health Organization. Adapted with permission.

Principles for Use of WHO Pain Ladder

Initiation: Initiate pain medications according to the appropriate step on the WHO Pain Ladder. In the outpatient setting, this step may entail use of oral instead of intravenous medications, even for patients with moderate to severe pain. In the inpatient setting and in patients with severe pain, pain medications administered intravenously or subcutaneously may be needed for acute pain relief in opiate-naïve patients.

Starting doses for opioid-naïve patients with normal renal and hepatic function are listed in Table 11-2. The medication should be given every 4 hours around the clock, not on an as-needed basis. In addition to the around-the-clock doses, prescribe a breakthrough dose that is 10% of the total daily opioid dose, given every hour if the pain is not controlled.

Long-acting pain medication: Once pain is fairly well controlled, if it is expected to continue and not improve (e.g., pain related to a fracture that is healing), then it is appropriate to change to a long-acting pain medication for ease of administration.

- Calculate the dose of a long-acting medication by adding all doses taken in 24 hours (including breakthrough doses). Oral long-acting medications are usually given 2 or 3 times per day, so the total daily dosage must be divided by this number to get the amount of each dose.

- Fentanyl patches and methadone are preferred in patients with renal and hepatic failure (when using methadone, consult with a palliative care or pain specialist). Provide a breakthrough dose every 1 hour as needed; the breakthrough dose should be 10% of the total daily dosage.

- Adjust for incomplete cross-tolerance; see below.

Adjusting for incomplete cross-tolerance: When exposed to a new opioid, a patient will not have had the opportunity to become tolerant to that opioid's side effects. Therefore, as a rule of thumb, when converting between opioids or converting to long-acting medications, decrease the dosage by 25% to 50%. This adjustment is called "adjusting for incomplete cross-tolerance" to the new drug. Use an equianalgesic table, such as Table 11-2.

Fentanyl patches should never be used in opioid-naïve patients. To convert short-acting medications to fentanyl, see Table 11-3. To convert fentanyl back to short-acting medications, see Table 11-4. Note that liquid formulations, rectal suppositories, and sprinkles that can be mixed with food may be prescribed for patients who have with difficulty swallowing pills.

Most well-localized and acute pain can be controlled with the use of the pain ladder (*JAMA* 1995; 274:1870). Once a patient is on an appropriate dosage, side effects (except for slowed bowel motility) generally resolve within 7–10 days.

Table 11-2

Oral Opioid Dosing

Drug	Starting Doses for Naïve Patients	Equianalgesic Doses	Renal Impairment	Hepatic Impairment
Codeine	30-60 mg	200 mg	Avoid	Avoid
Oxycodone	5-10 mg	20 mg	Adjust dose and frequency	Adjust dose and frequency
Hydrocodone	2-4 mg	30 mg	Adjust dose and frequency	Adjust dose and frequency
Morphine (short-acting)	15-30 mg	30 mg	Avoid	Adjust dose and frequency; avoid in severe disease
Hydromorphone	2-4 mg	7.5 mg	Preferred, but decrease dose and frequency	Adjust dose and frequency

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Table 11-3			
Converting the Current Opioid to a Fentanyl Patch*			
Morphine, po mg/24 h	**Oxycodone, po mg/24 h**	**Hydromorphone, po mg/24 h**	**Replace with Fentanyl Patch at Following Dose (mcg/hr q 72 h)**
10–19	20–39	8–14	12
20–44	40–89	15–33	25
45–74	90–149	34–55	50
75–104	150–209	56–78	75
105–134	210–269	79–100	100
135–164	270–329	101–123	125
165–194	330–389	124–145	150
195–224	390–449	146–168	175
225–254	450–509	169–190	200
255–284	510–569	191–213	225
285–314	570–629	214–235	250
315–344	630–689	236–258	275
345–374	690–749	259–280	300
375–404	750–809	281–303	325
405–434	810–869	304–325	350
435–464	870–929	326–348	375
465–494	930–989	349–370	400

*PRN dosing for breakthrough pain: The breakthrough dose of oral morphine for a patient on a fentanyl patch is roughly 1/3 the fentanyl patch dose (e.g., if the patient is prescribed a fentanyl patch of 75 mcg/h q 72 h, the breakthrough dose is short-acting morphine 25 mg po q 1 h prn. If you want to use an opioid other than morphine, use the equianalgesic table to convert. As always, when starting a new opioid, adjust for incomplete cross-tolerance.

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Table 11-4

Converting a Fentanyl Patch to Another Opioid*

Fentanyl patch dose (mcg/hr q 72 h)	Replace With One of the Following Opioids (Total mg/24 h)**		
	Morphine po mg/24 h	Oxycodone po mg/24 h	Hydromorphone po mg/24 h
12	45	30	11
25	90	60	22
50	180	120	45
75	270	180	67
100	360	240	90

*PRN dosing for breakthrough pain: The breakthrough dose of oral morphine for a patient on a fentanyl patch is roughly 1/3 the fentanyl-patch dose (e.g., if the patient is prescribed a fentanyl patch of 75 mcg/h q 72 h, the breakthrough dose is short-acting morphine 25 mg po q 1 h prn. If prescribing an opioid other than morphine, use the equianalgesic table to convert. As always, when starting a new opioid, adjust for incomplete cross-tolerance.

**Divide recommended doses (mg/24 h) into 6 equal doses given q 4 h.

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Opioid Titration

For many patients, pain is not adequately relieved by the initial low-dose opioid. When that is the case, the care provider must titrate the patient's opioid dose to pain relief. Moderate pain requires titration every 24 hours, whereas severe pain may require more frequent titration. A patient may be instructed to alert the care provider if severe pain continues or if more than three to four doses of the breakthrough pain medication are taken, at which time the patient's total daily dosage may be increased by 25% to 50% for mild to moderate pain and by 50% to 100% for severe pain. Patient or caregiver diaries of breakthrough pain medication dosing are helpful in opioid titration. Patients undergoing titration should be seen frequently, as often as every week, and called as often as is necessary between appointments to ensure adequate pain relief.

Bowel Regimen

Constipation is expected with opioids and will not resolve without pharmacologic intervention. Unlike other side effects, tolerance does not develop over time with long-term opioid therapy. Therefore, all patients receiving opioids must also be started on a bowel regimen at the time of opioid initiation. A combination of a stool softener and a mild stimulating agent (such as docusate, 100 mg orally twice daily, and senna, 2 tablets daily) may be an effective initial regimen. If this regimen is ineffective, then the doses of these agents can be increased or an osmotic agent (such as lactulose, sorbitol, or polyethylene glycol) can be added. If those measures do not work, then

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a laxative suppository (e.g., Dulcolax) and enemas may be used. The newer agent methylnaltrexone can also be prescribed in severe refractory cases, but it is quite expensive, requires a subcutaneous injection, and can be used only once every 2 to 3 days.

Side Effects of Opioids

Table 11-5 outlines common side effects of opioids. Although respiratory depression is a much-feared side effect, it is unusual unless an opiate-naïve patient is given a large initial parenteral dose. Use of the Pain Ladder method and the starting doses described above is a safe approach. Patients should be counseled that side effects usually dissipate after a week of therapy.

Table 11-5

Common Side Effects of Opioid Analgesics

Constipation	Requires prescription of bowel regimen at the SAME TIME opioids are prescribed.
	Tolerance does NOT develop.
Drowsiness	Resolves after 24–36 h.
	Extended sleeping can be from exhaustion; may need psychostimulant, such as methylphenidate.
Nausea	Prescribe antiemetic with first opioid prescription.
	Resolves in several days; may need around-the-clock dosing initially.
Urinary retention	Uncommon side effect.
	Rotate opioids or adjuvants; may require catheter drainage of bladder.
Itching/ twitching	May indicate toxic levels due to impaired renal function.
	Lengthen interval; rotate opioids.

Nonopioid Analgesics

The most commonly used nonopioid analgesics are

- acetaminophen (starting dose 650–1000 mg orally every 6 hours, not to exceed 2-3 g/day in an adult with normal hepatic function or 2 g/day in patients with impaired hepatic function);

- ibuprofen (200-800 mg orally every 8 hours); and

- tramadol (50-100 mg orally every 4-6 hours, not to exceed 400 mg orally daily).

Prescribing opioids and nonopioids separately, as opposed to in combination pill form (e.g. oxycodone–acetaminophen) is better practice because it allows providers to titrate up opioids without exceeding the maximum dose of a nonopioid.

Adjuvants

Adjuvant medications are used to enhance the analgesic efficacy of opioids, to treat concurrent symptoms that exacerbate pain, and to provide independent analgesia. They may be used at all stages of the WHO Pain Ladder. Commonly used adjuvants include antidepressants, antipsychotics, anxiolytics, psychostimulants, anticonvulsants, and corticosteroids. Consider use of adjuvants for any patient with pain. In particular, it may be helpful to consider the mechanism of pain when selecting an adjuvant. For example, a patient with neuropathic pain may benefit from the anticonvulsant gabapentin, whereas a patient with colon cancer and liver metastases and right upper-quadrant pain may benefit from steroids for capsular pain. A complete discussion of initiation of adjuvant pain medications is beyond the scope of this chapter. However, care providers who are treating pain syndromes should be generally familiar with these medications and comfortable with the starting dosage while consulting with a pain management or palliative medicine specialist.

Adjuvants used in selected circumstances include:

- anticonvulsants (e.g., gabapentin, pregabalin, and carbamazepine) and GABA-receptor agonists (e.g., baclofen) for neuropathic pain;

- transdermal agents (e.g., the lidocaine patch) for postherpetic neuralgia and other localized pain syndromes;

- antidepressants, including tricyclic antidepressants (e.g., amitriptyline) and selective serotonin reuptake inhibitors (e.g., paroxetine, citalopram); and

- corticosteroids (e.g., dexamethasone) for pain due to increased intracranial pressure, pain due to bowel or bladder obstruction, bone pain, and spinal cord compression (Textbook of Palliative Medicine, 2006)

Adjuvant medications may be particularly helpful when patients have comorbid conditions such as depression, weight loss, or cachexia. Antidepressants may be beneficial for patients experiencing what has been described in the past as a "whole body" or more central-type chronic pain syndrome. As noted above, several adjuvant medications may be more helpful in patients who have a neuropathic component to their pain syndrome.

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Peripheral Neuropathy

Distal sensory polyneuropathy is the most common neurologic complication found in patients with HIV (*Neurol Clin* 2008;26:821). Prevalence estimates of clinically evident peripheral neuropathy in patients with well-controlled HIV in the current treatment era range from 13% to 49% (*Clin Infect Dis* 2005;40:148, *Arch Neurol* 2010;67:552, *Neurology* 2006;66:867).

Cause: Distal sensory polyneuropathy is thought to be caused by the direct effects of HIV on peripheral nerves. It is more common in patients with advanced disease and in those taking certain ARVs (i.e., DDI and d4T). It can occur at any CD4+ cell count. Risk factors include age greater than 40, CD4+ cell count nadir below 50/mm^3, diabetes, and use of DDI and d4T (*Clin Infect Dis* 2005;1:148, *Arch Neurol* 2010;67:552, *Clin Infect Dis* 2005;40:148, *Neurology* 2006;66:867).

Clinical presentation: Typical clinical presentation is numbness and tingling in the feet, which may progress up the legs and, less commonly, to the hands and arms in a stocking–glove distribution. The neuropathy is usually only sensory, but in rare cases it may have a motor component.

Diagnosis: Diagnosis is clinical. Workup should include tests to exclude other causes of peripheral sensory neuropathy (e.g., B12 level, diabetes screening, hepatitis C virus (HCV) testing, thyroid function tests, renal/hepatic function, serum and urine protein electrophoresis, syphilis screening, and careful review of the medication list for neurotoxic medications).

Recommended approach to treatment: Remove neurotoxic drugs, such as implicated ARVs and isoniazid, and treat coexisting conditions found on initial evaluation.

- **Antiepileptic drugs:** Initiate gabapentin 100 mg p.o. 3x/day with titration to a maximum dose of 3,600 mg daily (*J Neurol* 2004;251:1260) as tolerated.

- **Antidepressants:** Although studies in patients with HIV have not shown benefit over placebo (*Neurol* 1998;51:1682, *JAMA* 1998;280:1590), amitriptyline commonly continues to be used in this setting because of its efficacy in patients with diabetic neuropathy (*Neurol* 1987;37:589).

- **Topical agents:** Capsaicin has been shown to improve symptoms of peripheral neuropathy and may be used in combination with oral agents (*J Pain Symptom Manage* 2008;35:299, *Neurology* 2008;70:2305).

- **Opioids:** In recalcitrant cases, opioids may be added and have shown efficacy in many studies.

Patients With Substance Abuse Comorbidities

Managing pain in patients with a history of substance use is a particularly challenging problem that HIV care providers often face. Basic principles for pain management in substance users are outlined below. (Also see Chapter 9, *Psychosocial Issues, Mental Health, and Substance Abuse*.)

Approach to Pain Management in Substance Users With HIV Disease

- Substance users with HIV disease deserve pain control; we have an obligation to treat pain and suffering in all of our patients.

- Accept and respect the report of pain.

- Be careful about the label *substance abuse*; distinguish between tolerance, physical dependence, and *addiction* (psychological dependence or drug abuse) and *pseudoaddiction* (opioid-seeking behavior in a patient with undertreated pain).

- Not all substance users are the same; distinguish between active users, patients in methadone maintenance, and those in recovery.

- Individualize pain treatment.

- Utilize the principles of pain management outlined for all patients with HIV disease and pain (WHO Pain Ladder).

- Set clear goals and conditions for opioid therapy: Set limits, recognize drug abuse behaviors, make consequences clear, use written contracts, and establish a single prescriber.

- Use a multidimensional approach: pharmacologic and nonpharmacologic interventions, attention to psychosocial issues, team approach.

- Utilize pain diaries along with standard protocols for refills and periodic urine drug screens.

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Advanced Illness

Syndrome of Imminent Death

It is important to recognize when a patient is actively dying. Several features characterize the syndrome of imminent death. Early on, patients may be bedbound, have delirium, and have decreased oral intake. As they progress, they may become increasingly obtunded; develop noisy secretions (i.e., the *death rattle*); and eventually become comatose and febrile, with periods of irregular breathing interrupted by long pauses (*Syndrome of Imminent Death*, 2nd ed. Fast Facts and Concepts #3, July 2008; available at http://www.

eperc.mcw.edu/EPERC/FastFactsIndex/ff_003.htm. Accessed 9/15/2012). Figure 11-7 describes key physical and emotional aspects of care at the end of life. This guide is formatted for use as a pocket guide for care providers.

Figure 11-7
Pocket Guide to End-of-Life Care

Pocket Guide to End-of-Life (EOL) Care [side 1]

Comfort Measures at LIFE'S END

L Lips, mouth, and eyes moistened—use ice chips and artificial saliva and tears

I Incontinence of bowel and bladder expected—use catheter, bed pads

F Fevers expected—use around-the-clock antipyretics, oral or suppository

E Eliminate all but essential meds

S Symptom management—be aggressive

E Eating—less is expected; diet as desired

N Nursing call orders—revise

D Decubitus—skin care and/or turning every 2 hours

Pocket Guide to EOL Care [side 2]

Provide RPC (see below): Once the difficult decision to write a *Do Not Resuscitate (DNR)* order has been made, more remains to be done for a dying patient and the family. After writing a *DNR* order, remember to reverse your thinking and write an order to Provide *RPC*.

R = Reassurance: Continue to care for the patient and family. • Control symptoms that interfere with quality of life. • Find effective ways to cope with stress and to grieve. • Let patient and family concerns direct how and where care is provided.

P = Presence: Be there to talk with the patient and the family. • Visit regularly. • Sit down and hold a hand. • Listen respectfully.

C = Caring: Provide comfort measures. • Honor the individual. • Share touch and laughter.

Life Review: Facilitate life review, important conversations, and the exchange of important words: Thank you • I love you • Please forgive me • I forgive you • Goodbye

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Prognosis, Prognostication, and Hospice

The National Hospice and Palliative Care Organization has published guidelines hospice eligibility for patients with noncancer diagnoses, including HIV (*Hosp J* 1996;11(2):47). These widely used guidelines generally apply to patients who truly are at the end stage of their disease process and are no longer taking ART, although this is not always the case. The current guidelines were developed and published during a different era of HIV treatment, and they should be viewed as guidelines, not as absolute criteria. A brief summary and reference of hospice criteria for the diagnosis of advanced HIV is provided in Table 11-6.

Table 11-6

Guidelines for Determination of Hospice Eligibility

Patient meets the following criteria:

CD4+ cell count <25 cells/mm^3

or

persistent viral load >100,000 c/mL (2 or more assays at least 1 month apart)

and

Patient has at least one of the following conditions:

- CNS lymphoma
- Untreated or refractory wasting (loss of >33% lean body mass)
- *Mycobacterium avium* complex bacteremia, untreated, refractory, or treatment refused
- Progressive multifocal leukoencephalopathy
- Systemic lymphoma with advanced HIV and partial chemo response
- Refractory visceral Kaposi's sarcoma
- Renal failure in the absence of dialysis
- Cryptosporidium infection
- Refractory toxoplasmosis
- Palliative Performance Scale of <60% (*J Palliat Care* 1996;12(1):5; *J Pain Symp Manage* 1999;18(1):2)

Supporting documentation:

- Chronic persistent diarrhea >1 y
- Persistent serum albumin <2.5 g/dL
- Concomitant active substance abuse
- Age >50 y
- Absence of ART and prophylactic meds
- Advanced AIDS dementia complex
- Toxoplasmosis
- CHF, Stage IV
- Rapid decline or other comorbidities

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

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Prognostication: Prognostication in patients with HIV is increasingly complex. Patients may present after a long history of inability to adhere to therapy, perhaps as a result of substance abuse or psychiatric comorbidities, and with low CD4+ cell counts, high viral loads, and opportunistic infections. These patients often have dramatic responses to initiation of ART. They initially may appear hospice appropriate, but if started on ART, they may improve quickly. Sadly, some patients have sought treatment too late or have difficulty with medication adherence and continue to need hospice services. Others are appropriate for hospice services on the basis of comorbid conditions such as cirrhosis secondary to HCV or malignancy. These patients will have a disease course and life expectancy more consistent with the comorbid condition rather than their HIV disease, despite remaining on ART.

Goals of hospice: In the United States, hospice is an interdisciplinary program that delivers care for patients and families who have elected to live the final portion of their lives in nonhospital settings, such as home, skilled nursing facilities, or designated residential hospices. This choice allows patients to accomplish their personal goals and live life as fully as possible. In hospice, close attention is paid to management of pain and other symptoms and to relief of all suffering, whether physical, psychological, social, or spiritual. As noted earlier, criteria for hospice have been established, and all hospice admissions are certified by two physicians who verify that a patient's life expectancy is likely to be 6 months or less if his or her disease follows its expected course.

No penalty exists for estimating someone's life expectancy incorrectly. For instance, a patient with HIV infection who has a CD4+ cell count of $10/mm^3$ and recently received induction therapy with amphotericin for cryptococcal meningitis and is unable to adhere to ART would meet diagnostic criteria on the basis of her prognosis if her disease follows its expected course. If she outlives this estimate, the hospice medical director must determine whether the patient's prognosis is still 6 months or less if the disease follows its usual course. For as long as this is the case, the patient may remain in hospice. Therefore, it is reasonable to consider hospice referral for patients hospitalized for opportunistic infections who are not improving on appropriate therapy or who do not wish to continue receiving life-prolonging treatments.

Limitations of hospice: Hospices receive capitated payments from Medicare at a low daily rate. They must pay for all of a patient's care with that money; therefore, a hospice may have limited ability to provide expensive medications, whether or not those medications are considered palliative. These fiscal constraints limit the ability of many hospices to provide ART. The decision to provide expensive medications is made on a case-by-case basis. Medications that are relatively inexpensive and likely to prevent symptoms from occurring, such as maintenance fluconazole therapy, are more likely to be allowed.

It is possible that after receiving intensive symptom control and attention to social, spiritual, and psychological needs, a patient may decide to initiate ART. She may revoke the hospice benefit at any time and resume care under usual insurance coverage. The majority of hospice patients are those with end-stage malignancies. HIV was listed as a primary diagnosis for only 0.5% of all 2008 hospice admissions in the United States (http://www.nhpco.org/files/public/ Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf. Accessed December 28, 2011). The percentage of HIV-infected patients who die while enrolled in hospice is not known. Hospice care was the standard of care for many patients in the early HIV era. Now, it is just one aspect of what is available through palliative and supportive care referral and evaluation. Practitioners of palliative and supportive care may help patients and their families access hospice programs in their communities.

One common question is whether or when to discontinue ART for HIV-infected patients in hospice. ARV medications may cost thousands of dollars per month, and because hospice is paid at a relatively low capitated daily rate,

continuing those medications may be cost prohibitive to enrolling in hospice. Decisions about ART in such circumstances must be made on a case-by-case basis with careful consideration of the medications' added benefit, if any.

Advance Care Planning

HIV practitioners play a particularly important role in facilitating patient and family (or caregiver) dialogues regarding patient wishes and advance care planning. At various points during the course of a disease, opportunities exist for patients to define important aspects of their care. Those decisions should be revisited periodically, especially when circumstances change (e.g., new partner, change in clinical condition). Attention should be paid to cultural or spiritual beliefs that may affect end-of-life decisions.

Key Decisions in Advance Planning

- Surrogate decision makers: Laws regarding default surrogate decision makers vary by State. In general, it is usually preferable for a patient to choose and document a surrogate decision maker who can speak for the patient in the event that the patient lacks the capacity to make decisions.

- Preferences for artificial nutrition and hydration, resuscitation, and life support

- Custody or guardianship of children

- Preferred location of care at the end of life, if appropriate (e.g., home vs. hospital)

- Discontinuation of ART therapy

Ideally, the patient will discuss these issues with her treating provider, who should document the patient's preferences in an easily accessible place in the patient's medical record. It is also important that the patient discuss these issues with her surrogate, who may be in the difficult position of making decisions for the patient when the patient can no longer speak for herself.

Palliative medicine practitioners who are specifically trained to discuss these difficult and complex issues can help HIV providers have these important discussions. In addition, as a patient's illness advances and symptom burden increases, issues involving psychosocial conflict, spiritual distress, and cultural belief systems may become even more prominent and are amenable to palliative care attention.

The journey of many patients with HIV may be associated with loss of traditional family support systems. This loss can lead to complicated grief and caregiver burden, if not addressed. Once again, an interdisciplinary team facilitated by palliative and supportive care practitioners may be beneficial as a patient's clinical condition worsens. One additional advantage of hospice care in the terminal phases of HIV illness is that hospice is required to provide follow-up bereavement care for the primary caregivers for 1 year following the death of a patient enrolled in hospice.

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Grief and Bereavement

Grief is a normal reaction to a major loss. Its manifestations vary but may include physical, cognitive, behavioral, and emotional elements, such as a feeling of numbness, loss and longing, restlessness, frequent crying, difficulty sleeping, loss of appetite, and somatic complaints. The expected duration of grief is 1 to 2 years, after which most people return to their previous level of functioning. Risk factors for complicated grief—grief of longer duration or greater intensity than expected—include protracted illness; difficult terminal symptoms; death from a stigmatizing disease; death of a spouse, child, or other close relative; lack of social or financial support; and the bereaved person's own history of psychiatric or substance abuse (*Textbook of Palliative Medicine*, 2006). All of these factors are highly prevalent in patients with HIV. Many patients may also suffer from anticipatory grief as their condition worsens, and some have a variant of a grief response to loss at the time of their diagnosis (i.e., in sensing the loss of good health).

Physicians caring for patients with HIV need to be available to patients' family and friends during the bereavement process. Health care providers can use five principles of bereavement support to care for patients and families during this difficult time:

- View patient and family as one unit of care.
- Enable open discussion of illness and death-related concerns.
- Provide emotional support.
- Facilitate practical assistance.
- Respect cultural, ethnic, and religious practices.

Caring for the Caregiver

Caregiver burden is the "physical, emotional, and financial toll of being a caregiver" (*Gerontologist* 1986;26:253, *Am Fam Physician* 2000;62:2613). Caregiver burden has most often been studied in spouses of patients with dementia; results indicate high rates of depression, worsening physical health, and increased mortality (*Am Fam Physician* 2000;62:2613). People caring for patients with HIV may have HIV themselves; therefore, it is important to recognize a patient's caregiver(s) and assess for lack of social support and signs of caregiver burden, including stress, depression, and isolation (*Gerontologist* 1980;20;649).

Incorporating Principles of Palliative Care Into Everyday Practice

The HIV care provider's role is often that of a general internist for patients with HIV. To provide excellent primary care for this patient population, it is important to screen for common conditions. Providers routinely perform Pap smears; recommend mammography and colonoscopies; and screen for hyperlipidemia, syphilis, and many other conditions. Primary providers should also routinely screen for pain and symptoms, because these are just as common as other conditions, and are important to patients' quality of life.

Providers should screen patients for pain and symptoms at every visit. This task can be done quickly, as outlined earlier. Management of pain and other symptoms can be handled by the HIV care provider, and if necessary, patients may be referred to a palliative care or pain specialist. In caring for patients and their caregivers, the primary HIV care provider and interdisciplinary team can incorporate purposeful dialogue with patients regarding advance care planning and preferences if they experience disease progression.

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Chapter 12:

Occupational Exposure and Postexposure Management

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Chapter 12: Occupational Exposure and Postexposure Management

Chapter 12 at a Glance

HIV, HBV, and HCV Exposures Are Common

Exposures to HIV and hepatitis B and C (HBV and HCV) are common among healthcare workers, approximately 70% of whom are women (U.S. Bureau of Labor Statistics, 2007; Report 1002:30). Although universal precautions, safety devices, and other factors have reduced occupational exposures to bloodborne pathogens (BBPs), exposures continue to be a persistent problem in healthcare settings, and only a fraction of them are formally reported (National Institute for Occupational Safety and Health Pub. No. 2000-135). Safety measures, along with widely practiced HBV immunization and postexposure prophylaxis (PEP) for both HIV and HBV, have decreased the incidence of BBP transmission to healthcare workers over the past decade.

This chapter is designed to help the managing clinician decide whether PEP should be administered and to provide guidance for postexposure management.

Postexposure Management Should Not Be Delayed

Because HIV PEP efficacy depends on the timing of the first administered dose of antiretroviral (ARV) drugs, postexposure management is urgent and should not be delayed. The need for PEP is determined by assessing the risk and severity of the exposure and the source patient's risk for HIV or hepatitis infection. Although time to initiation is critical to PEP efficacy, it is equally important to determine when PEP is not warranted.

If Consultation Is Needed

PEPline: Consultation is available 24 hours per day from the National HIV/AIDS Clinicians' Consultations Center's Post-Exposure Prophylaxis Hotline (PEPline): 888-448-4911. PEPline provides expert guidance in managing healthcare worker exposures to HIV, HBV, and HCV. Callers receive immediate PEP recommendations.

Reporting

No nationwide central service exists for reporting healthcare worker exposures. All healthcare facilities must comply with Occupational Safety and Health Administration guidance in developing institutional policies for postexposure protocols, including institution-based reporting systems, systemwide prevention initiatives to minimize occurrence of work-related exposures, and incorporation of PEP into institutional occupational healthcare programs.

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Universal Precautions to Prevent Exposure

The phrase "universal precautions" is used to indicate that all patients should be considered potentially infectious and that safety measures should be applied universally, regardless of known risk factors, to prevent exposure to HIV, HBV, and other BBPs. Protective equipment and practices are used in the healthcare setting to protect healthcare workers and patients:

- **Gloves** are recommended for use in all procedures in which contact with infectious body fluid is likely (e.g., pelvic exam, phlebotomy, transfer of body fluid samples to a specimen cup).

- **Masks** are recommended for use when there is risk of blood or other infectious body fluid splash (e.g., during incision and drainage, insertion of chest tube, intubation, surgery).

- **Goggles or other eye protection** is recommended for use when there is risk of blood or other infectious body fluid splash.

- **Gowns** should be worn during surgery or with other procedures where there is significant risk of blood or other infectious body fluid splash or contamination of clothing.

- **Puncture-proof containers** should be available to dispose of used needles, scalpels, and other disposable sharp supplies. Needle and scalpel safety devices are also available in many higher resource settings.

- **Operating room and emergency department precautions:** Avoid direct hand-to-hand transfer of sharp instruments in the operating room and emergency department; instead, pass sharps from hand to pan or emesis basin to allow for greater control in handling.

The need for safety precautions should be made on the basis of the risk of the medical procedure being performed. Gloves and other precautions are not needed when contact with infectious body fluid is unlikely, as when shaking hands with a patient or performing a routine examination.

Exposure and Transmission

Transmission Risks

For BBP transmission to occur, an exposure must involve infectious body fluid from a source infected with a BBP, and it must involve a mechanism by which BBPs can be transmitted. If both factors are not present, then no risk of transmission exists and no further evaluation is required.

Figure 12-1
Body Fluids and BBP Transmission Risk

Body fluids that CAN transmit BBPs:

☑ Blood   ☑ Cerebrospinal fluid

☑ Semen   ☑ Pericardial fluid

☑ Vaginal fluids   ☑ Peritoneal fluid

☑ Amniotic fluid   ☑ Pleural fluid

☑ Breast milk   ☑ Synovial fluid

Body fluids that DO NOT transmit BBPs (unless visibly bloody):

☒ Saliva   ☒ Urine

☒ Vomitus   ☒ Feces

Decreasing transmission: If an exposure occurs despite universal precautions, several steps can be taken immediately to decrease transmission risk:

- **Mucous membrane exposure:** Rinse area thoroughly with water or saline.

- **Skin exposure:** Wash thoroughly with soap and water.

- **Needlestick:** Wash area thoroughly with soap and water. Do not squeeze or pinch, because doing so may increase blood flow to the area and hypothetically facilitate transmission.

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Risk and mechanism of exposure: Percutaneous exposures are of substantially higher risk for transmitting BBP than mucous membrane or cutaneous exposures. The risk associated with each mechanism of exposure is outlined in Table 12-1.

Table 12-1

Associated Risk When Exposure Source Patient Is HIV Infected

Route of Exposure	Risk of Exposure	Risk Determinants	Risk Qualifiers
Percutaneous*	~ 1/300 episodes	↑ Larger gauge hollow-bore needle ↓ Solid needle or instrument	• Risk of transmission from percutaneous exposures is increased with hollow-bore needles, visibly bloody devices, and deep injury. • Solid devices, such as lancets or suture needles, have rarely been involved in HIV transmission. • It is common for a discarded or found needle to cause percutaneous injury; however, in U.S. healthcare settings, found needles have been implicated in only 3 cases of transmission. Outside of the United States, no documented cases of transmission of HIV from a found needle have occurred.
Mucous† membrane	~1/1000 episodes	↑ Large volume ↓ Small volume	• Mucous membrane exposures usually involve infectious fluid contact with the eyes or mouth. The keratinized skin around the mouth that borders on mucous membrane is an effective protective barrier.
Cutaneous†	<1/1000 episodes	Compromised skin integrity	• Cutaneous exposures can transmit virus, but risk is present only when skin integrity is compromised (e.g., chapping, abrasion, open wound or burn, dermatitis). Prolonged contact with nonintact skin may increase risk of transmission. • Intact skin is an effective barrier that protects against transmission of BBPs.

Note: ↑ = increased risk; ↓ = decreased risk. Other abbreviations are defined in the list of Abbreviations and Acronyms, p. ix.

* A substantial proportion of percutaneous exposures occur in dental offices; however, no transmissions from patient to provider have been reported in the dental setting. The lack of transmission is likely a result of the nature of dental instruments, most of which are solid, and the use of very small-bore needles for anesthetic injection. It is also plausible that neutralizing antibodies present in saliva may decrease chances of virus transmission.

† Human bites expose both the biter (cutaneous exposure) and the bitten (mucous membrane exposure).

Source: *MMWR Recomm Rep* 2005;54(RR-9):1

Postexposure Assessment and Management

Baseline Laboratory Workup

If the exposure is considered one that may transmit BBP, then baseline testing for HIV, HBV, and HCV should be performed on the exposed healthcare worker and the source, when possible. Recommended tests are summarized in Table 12-2.

PEP efficacy depends upon timing of first dose: Do not wait for baseline test results to proceed with the decision to administer PEP, unless the results of the source patient's rapid HIV will be available within 1–2 hours. If the source patient's baseline rapid HIV Ab test is positive, then assume it represents a true positive result, and proceed with PEP while awaiting confirmatory Western blot results. If the confirmatory Western blot test is negative, then PEP can be stopped.

Table 12-2

Recommended Postexposure Baseline Laboratory Tests		
Baseline Tests	**Source Patient**	**Exposed Person**
HIV Ab or p24 antigen-HIV antibody (HIV Ag/Ab)	Yes	Yes
HIV Western blot or immunofluorescence antibody	Yes, if HIV rapid test positive	Yes, if HIV rapid test positive
HIV RNA PCR	Yes, if status is known to be positive, but recent viral load is not known	No
HCV Ab	Yes	Yes
HCV RNA PCR*	Yes	No
HBsAg	Yes	Yes, if immune status is unclear
HBsAb	No	Yes, if immune status is unclear

Note: Test abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

* With CD4+ cell count <200 cells/mm^3, a negative HCV Ab test may represent a false negative result, and HCV RNA can clarify HCV status of exposure source.

Source: *MMWR Recomm Rep* 2001;50(RR-11):1

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Window Period

The window period for HIV Ab seroconversion—after infection has occurred but before antibodies develop—can cause anxiety for both the patient and the provider around postexposure management. However, if the source patient's HIV test is negative at the time of the exposure, then PEP is not

recommended. Note that in the United States, no reports of HIV transmission to a healthcare worker from an exposure source who was in the window period have occurred (*MMWR* 2005;54(RR-9)).

Implications for postexposure management: The window period should be taken into consideration in postexposure management only when it is highly likely that a high-risk source patient is in a window period. This situation may occur when, in the 30 days prior to the exposure, the source patient shared needles with other drug users, was incarcerated, engaged in unprotected sex with multiple male partners (if male), could have been exposed through sex work (*MMWR* 2006;55:421), or had a potential exposure in a country with high HIV seroprevalence.

In assessing the likelihood of a source patient being in the window period, determine whether the patient has a history of recent illness consistent with possible acute HIV infection (see Chapter 4, *Primary Medical Care*). If acute HIV infection is suspected, then PEP should be started while confirmation of the source's HIV RNA level is pending. In acute infection, HIV RNA level is usually very high and risk of transmission is great.

U.S. Public Health Service Guidelines for PEP

Time is of the essence in initiating PEP: If PEP is indicated or is being considered, then time is of the essence for efficacy: The optimal time to start PEP is within hours of exposure, not days. The first dose should be given as soon as possible. Seventy-two hours post-exposure is considered as the outer limit of opportunity to initiate PEP; however, a delay of that scale is believed to compromise PEP efficacy. The 72-hour outside limit recommendation is based on animal studies; no human data are available. Initiating PEP after a longer interval (e.g., 1 week) might still be considered for exposures that represent a very high risk of transmission. PEP should be administered for 4 weeks.

Regimen: The USPHS no longer recommends that the severity of exposure be used to determine the number of drugs to be offered in a PEP regimen. A regimen containing 3 (or more) ARV drugs is now recommended routinely for all occupational exposures to HIV. These include newer ARV drugs that are better tolerated and have better toxicity profiles than agents previously recommended for PEP. Medications included in a PEP regimen should be selected to minimize side effects and toxicity, and optimize convenience in terms of dosing schedules to enhance likelihood of completion. Exposure to a source patient with an undetectable serum viral load does not eliminate the possibility of HIV transmission, and PEP should still be offered. Because of concerns about tenofovir effect on renal function, this regimen is not recommended to persons with renal problems, which should be assessed before prescribing this PEP regimen. The PEPline at 888-448-4911 is available for additional advice and recommendations.

Table 12-3

Recommendations for Postexposure Prophylaxis After Precutaneous Injury or Mucous Membrane and Nonintact** Skin Exposures

Exposure Source	Recommendation
HIV-infected	Three (or more) drug PEP
Unknown HIV status	Generally no PEP is warranted. Consider PEP* for source with HIV risk factors; discontinue if source is found to be HIV-uninfected.
Unknown source (e.g., a needle from a sharps disposal container; splash from improperly disposed-of blood)	Generally no PEP is warranted. Consider PEP* in settings where exposure to HIV-infected persons is likely.
Not HIV infected	No PEP is warranted.

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix.

*"Consider PEP" indicates that PEP is optional and the decision to administer should be made case by case, on the basis of an individualized discussion between the provider and the exposed person. Higher risk source patients include injection drug users who have shared needles, sex workers, men who have unprotected sex with multiple male partners, and people who have been incarcerated.

*Followup is indicated only if there is evidence of compromised skin integrity (e.g., dermatitis, abrasion, open wound).

Source: *Infect Control Hosp Epidemiol* 2013;34(9):875–892

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PEP regimens: Current options for PEP, along with recommended toxicity monitoring, are listed in Table 12-4.

Table 12-4
Human Immunodeficiency Virus (HIV) Postexposure Prophylaxis (PEP) Regimens (all given for one month)

Preferred HIV PEP Regimen

RAL 400 mg PO twice daily
Plus
TDF/FTC 300/200 mg (Truvada) once daily

Alternative Regimens

(May combine 1 drug or drug pair from the left column with 1 pair of nucleoside/nucleotide reverse-transcriptase inhibitors from the right column)

RAL	TDF/FTC
DRV/r	TDF + 3TC
ETR	ZDV/3TC
RPV	ZDV + FTC
ATV/r	
LPV/r	

The following alternative is a complete fixed-dose combination regimen, and no additional antiretrovirals are needed: EVG/COBI/TDF/FTC

Alternative Antiretroviral Agents for Use as PEP Only with Expert Consultation
ABC
EFV
T20
FPV
MVC
SQV
d4T

Antiretroviral Agents Generally Not Recommended for Use as PEP
ddI
NFV
TPV

Antiretroviral Agents Contraindicated as PEP
NVP

Note: Laboratory monitoring for drug toxicity should occur at baseline and 2 weeks after starting PEP and should minimally include CBC, renal and hepatic tests.

Source: Updated US Public Health Service Guidelines for the Management of Occupational Exposures to Human Immunodeficiency Virus and Recommendations for Postexposure Prophylaxis. *Infect Control Hosp Epidemiol* 2013;34(9):875.

Resistances

Important factors that should increase suspicion of resistance include (1) history of problems with medication adherence, (2) failure to achieve undetectable viral load on ARV medications, (3) development of detectable viral load after previously undetectable levels while on ARV medications, and (4) previous genotypic or phenotypic test results demonstrating resistance to one or more ARV drugs. If resistance is suspected, consultation with an HIV expert is recommended, but this should not delay initiation of PEP. In instances of known or suspected exposure use of ARV agents to which the patient is unlikely to be resistant is recommended for PEP.

Drug–Drug Interactions

Interactions between drugs in the PEP regimen and the exposed person's current medications may be a problem, and expert consultation may be indicated, especially when an expanded regimen is chosen. Most commonly, interactions involve the protease inhibitor component, such as LPV/r, DRV/r, and ATV/r. Table 12-5 lists several common drug–drug interactions. See also Tables 13-8 to 13-9, pp. 500–512.

Table 12-5

Commonly Prescribed Drugs and Interactions With Concurrent Use of Protease Inhibitors		
Medication	**Effects of Concurrent Use With PIs**	**Options and Recommendations**
Acid reducers		
Antacids	ATV levels ↓	Use another PI or d/c antacids.
H_2 blocker(s)	ATV levels ↓	Use another PI if continuing H_2 blocker treatment or d/c H_2 blocker; may also space dosing of H_2 blocker 12 h apart from PEP administration.
PPIs	ATV levels ↓	Use another PI if continuing PPI treatment or d/c PPIs.
Anticoagulants		
Warfarin	Warfarin levels ↓	Monitor INR closely.
Anticonvulsants		
	Antiseizure medication levels may be altered to supra- or subtherapeutic levels	Use RAL as alternative to PIs.
Antidepressants		
SSRIs	SSRI levels ↓	Titrate dose to clinical efficacy if needed.
Tricyclic antidepressants	Tricyclic levels ↑	Toxicity monitoring is advised.

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Table 12-5 *continued*

Commonly Prescribed Drugs and Interactions With Concurrent Use of Protease Inhibitors

Medication	Effects of Concurrent Use With PIs	Options and Recommendations
Antipsychotics		
	Antipsychotics ↓ to subtherapeutic levels	Titrate dose as needed; use RAL as alternative to PIs.
Antimycobacterials		
Rifabutin	RBT levels ↑	Adjust RBT dose; consult expert.
Rifamycin	PI ↓ to subtherapeutic levels	Contraindicated with all PIs; use RAL as alternative to PIs.
Benzodiazepines		
	Midazolam and triazolam levels ↑	Contraindicated with PIs; use RAL as alternative to PIs.
Cardiac medications		
Calcium channel blockers	Calcium channel blocker levels ↑	Use RAL as alternative to PIs.
Corticosteroid		
Fluticasone	Fluticasone levels ↑	Contraindicated with PIs; use RAL as alternative to PIs.
Herbal remedy		
St. John's wort	↓ PI to subtherapeutic levels.	Contraindicated with PIs.*
Hormonal contraceptives		
Combined oral contraceptives	Ethinyl estradiol and progestin levels ↓ with certain PIs	Use backup barrier method.
Lipid-lowering drugs		
Statins	Statin levels ↑	Lovastatin and simvastatin are contraindicated; caution is advised with other statins. Consider time-limited d/c of statins for duration of PEP; use RAL as alternative to PIs.
Narcotics/Treatment for opioid dependence		
Methadone	Methadone levels ↓	Monitor for opiate withdrawal; titrate methadone dose if necessary.

Note: ↑ = increase; ↓ = decrease. Other abbreviations are defined in the list of Abbreviations and Acronyms, p. ix.

Adverse Drug Reactions and Symptom Management

Potential for PEP interference: Side effects can be a limiting factor in PEP adherence. They generally decrease after the first few days but sometimes can last the duration of the 28-day PEP course. Gastrointestinal side effects (nausea, vomiting, diarrhea) are most common, especially with expanded regimens that include a PI. Zidovudine/lamivudine (Combivir) can cause headache, fatigue, and nausea. Tenofovir/emtricitabine (Truvada) is much better tolerated than Combivir and is given as once daily dosing. Antiemetic and antidiarrheal medications can be prescribed to help with PEP adherence. If side effects are severe, consider changing to a better tolerated regimen. With the current preferred PEP regimens, toxicities are rare, generally not life threatening, and reversible.

Pregnancy

Not a contraindication for PEP: Indications for PEP are the same for pregnant and nonpregnant women. Acute HIV infection during pregnancy carries a particularly high risk for perinatal transmission because of high viral loads in early infection. When deciding whether to administer PEP and choosing the specific drug regimen, the risk of ARV exposure to the fetus and the potential adverse effects for the pregnant woman should be weighed against the benefit of decreased risk of HIV transmission to the mother and the fetus.

PEP regimens for pregnant women: Information about the use of newer antiretroviral agents administered as PEP to HIV-uninfected pregnant women is limited. Expert consultation is recommended. EFV is not recommended as part of a PEP regimen in the first trimester. If EFV-based PEP is used in women, a pregnancy test should be done to rule out early pregnancy and nonpregnant women receiving EFV-based PEP should be counseled to avoid pregnancy until after PEP is completed.

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Breastfeeding

Weigh risks and benefits: Both HIV itself and ARV medications can be found in breast milk. Some guidelines recommend that breastfeeding be avoided for 6 months postexposure. This recommendation is to prevent infant exposure to HIV should transmission occur and to avoid potential PEP drug toxicities in the infant. However, because breastfeeding offers significant benefits and because HIV is rarely transmitted to an exposed person (particularly when PEP is administered), the PEPline advises that mothers be informed of the potential risks and make their own decisions regarding breastfeeding. Because most transmissions are diagnosed by 6 weeks postexposure and almost all are detected by 3 months, a reasonable choice for some women may be to pump and discard breast milk initially and then reinitiate breastfeeding when they have reached a point at which no transmission can be safely assumed.

Follow-Up Postexposure Laboratory Monitoring

Following an exposure, laboratory followup is recommended for up to 6 months. If HCV transmission has occurred or if the exposed person is already HCV positive, followup is extended to 12 months, because rare instances of HIV transmission have not been captured until then [*MMWR* 2005;54(No. RR-9)].

Recommended postexposure laboratory monitoring includes the following:

- **6 weeks:** HIV Ab; HCV RNA PCR
- **3 months:** HIV Ab; HCV Ab
- **6 months:** HIV Ab; HCV Ab
- **12 months:** HIV Ab when concurrent HCV infection is present in the exposed person

Use of 4th generation HIV Ag/Ab combination tests allows for earlier detection of HIV infection. If these tests are used, HIV follow-up testing may be concluded 4 mo after exposure.

HIV RNA PCR is not recommended for follow-up testing unless the exposed person presents within 4 to 6 weeks postexposure with symptoms consistent with acute HIV infection, because false positives (usually at low levels of virus, i.e., <10,000 copies/mL) occur and can cause diagnostic dilemmas and unnecessary anxiety.

Hepatitis B and C Postexposure Management

Hepatitis B

Although widely utilized HIV PEP has been effective in decreasing HIV transmission to healthcare workers, the decrease in HBV transmission is attributed primarily to immunization of healthcare workers. Among nonimmunized healthcare workers, HBV confers a significant risk of transmission—as many as 2–3 infections per 5 needlestick exposures from HBV-infected individuals. As a result, HBV vaccination and documentation of immunity for healthcare workers has become a pre-employment requirement in most U.S healthcare settings. Immunization has helped to decrease transmission rates substantially and has virtually eliminated the need for HBV follow-up testing. However, some healthcare workers may not have received the full vaccination series or may not have responded adequately to vaccination.

Guidelines for HBV PEP: When a healthcare worker does not have documentation of adequate immunity (evidenced by HBsAb titer of >10 mIU/mL at any point in the past), specific guidelines for HBV PEP and follow-up, specified in Table 12-6, should be followed.

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Table 12-6

Recommendations for Postexposure Prophylaxis After Exposure to HBV

Source Status	Unvaccinated Exposed Person	Previously Vaccinated Exposed Person*		
		Known Responder†	Known Nonresponder‡	Antibody Response Not Known
HBsAg positive	HBIG† x 1 and initiate HBV vaccine series immediately	No treatment	HBIG† x 1 and initiate revaccination or HBIG x 2 with second dose separated from first by 4 wk‖	Test exposed person for HBsAb; if response is adequate,‡ no treatment is necessary. If response is inadequate,§ administer HBIG† x 1 and vaccine booster; recheck HBsAb titer in 3–4 mo. If titer is still inadequate§ for immunity, complete full second series of vaccinations.
HBsAg negative	Initiate HBV vaccine series	No treatment	No treatment	No treatment
Unknown or not available for testing	Initiate HBV vaccine series. If known high-risk source, may treat as if source were HBsAg positive.	No treatment	If known high-risk source, treat as if source were HBsAg positive.	Test exposed person for HBsAb; if response is adequate,‡ no treatment is necessary. If response is inadequate,§ administer vaccine booster and recheck HBsAb titer in 1–2 mo. If titer is still inadequate§ for immunity, complete full second series of vaccinations.

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

* People who have previously been infected with HBV are not at risk of reinfection and do not require PEP.

† HBIG (dose = 0.06 mL/kg intramuscularly).

‡ Responder = documented adequate levels of HBsAb (≥10 mIU/mL).

§ Nonresponder = inadequate levels of HBsAb (<10 mIU/mL).

‖ The option of giving 1 dose of HBIG and reinitiating the vaccine series is preferred for nonresponders who have not completed a second 3-dose vaccine series. Two doses of HBIG are preferred for people who have completed a second vaccine series but have failed to respond.

Source: *MMWR Recomm Rep* 2001;50(RR-11):1

Hepatitis C

Postexposure management: When a source patient is HCV infected, the risk of transmission following needlestick exposure is about 1 in 50. No PEP is available for HCV exposure, but early follow-up to identify transmitted infection and, when indicated, to offer early treatment is recommended. Direct viral testing with HCV RNA PCR at 6 weeks, before HCV Ab seroconversion has occurred, allows early identification of transmission and subsequent referral for evaluation and potential treatment. The rate of spontaneous clearance of HCV infection is about 25% in otherwise healthy people; however, with early diagnosis and treatment, HCV clearance can be increased to 90% or greater.

HIV Infected Healthcare Providers

No national standards limit clinical practice for HIV infected healthcare providers. The 1991 guidance (published before availability of effective combination ART) on prevention of HIV and HBV to patients during exposure-prone invasive procedures states that infected healthcare workers "should not perform exposure-prone procedures unless they have sought counsel from an expert panel and notify prospective patients of healthcare worker's seropositivity prior to undergoing an exposure-prone procedure" (*MMWR* 1991;40(RR-8)). However, States vary in implementation of this guidance (*JAMA* 2000;284:1965). Mandatory testing of healthcare workers is not recommended. Other organizations have published safe practice guidance for healthcare professionals who are involved in invasive procedures (*CID* 2005;40:1665), but no universally accepted guidelines exist for specific limitations.

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Chapter 14:
Quality Management

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Chapter 14: Quality Management

Chapter 14 at a Glance

Quality Management

Improved Patient Care

A structured approach: Improved patient outcomes are a goal toward which all clinicians strive. Without a formal process to measure and evaluate the effectiveness of care, however, a clinician cannot be certain that a goal is being met. *Quality management (QM)* is a process designed to identify meaningful goals, establish and implement a plan for achieving them, measure outcomes and, in the clinical setting, realize improved patient outcomes. For the purposes of this guide, QM refers to an overarching strategy encompassing quality improvement (QI) activities and a formalized structure for assessing the quality of care in any setting and with any patient population. Table 14-1 provides a brief glossary of terms essential to any discussion of QM.

Table 14-1

Brief Glossary of Quality Management Terms

Term	Definition
Indicator also known as process indicator, performance measure, or outcome measure	An operational definition of a specific quality characteristic that can be measured. Indicators typically conform to widely accepted guidelines or standards of care. Of note, "outcome" refers more specifically to benefits or results for patients that accrue as a result of QI activity. Results may be positive or negative, and outcome may be measured on the patient or system level. Regardless of the term used, all refer to a measureable indication of an organization's performance in relation to a specified QI process.
Quality assurance	QA refers to a formal set of activities to review and safeguard the quality of services provided. QA includes quality assessment and implementation of corrective actions to address deficiencies. It is focused on ensuring that standards are adhered to, problems are identified, and discrete quality issues are resolved. Resolution focuses most often on a responsible individual. QA is more commonly used in a regulatory environment.
Quality improvement also known as continuous quality improvement or performance improvement	QI is an organizational approach to improving quality of care and services that relies on established principles and methodologies. To be successful, QI requires committed leadership; resources; staff involvement; stakeholder involvement; and a patient-oriented, cross-functional team approach. QI is a continual process of improvement activities and performance measurements.
Quality management	QM refers to an overarching strategy that encompasses both QI activities and a formalized structure for assessing quality of care in any setting or with any patient population.

Table 14-1 continues on the next page

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Table 14-1	*continued*

Brief Glossary of Quality Management Terms

Term	Definition
Root cause analysis	Root cause analysis is the first step toward developing permanent solutions to problems. It first entails identifying all the contributing or underlying causes of a problem; results of this analysis are often organized into a "fishbone diagram." The results provide a way to approach solutions in the different domains identified.
Total quality management	TQM is a strategic approach to management that aims to embed awareness of quality in all organizational processes. TQM encompasses all QI activities as well as management of systems that foster QI, including communications, education, and resource allocation.

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

QM can be applied to accomplish a wide variety of goals, such as enhancing clinical care for a specific population, assessing population-specific needs, understanding and correcting system inefficiencies, measuring outcomes, and identifying lessons learned. This chapter focuses on ways in which care of women with HIV can be improved in the face of everyday challenges confronting them and their HIV care providers.

Elements of a Quality Management Program

A QM program comprises all program-specific quality activities. To be successful, a QM program should have three key elements: (1) a quality infrastructure, (2) performance measurement, and (3) QI activities.

Infrastructure

The QM infrastructure, which provides the foundation and support for a QM program, has five essential components: (1) vision and planning, (2) oversight, (3) formalized structure, (4) resources, and (5) evaluation. These components are described in Table 14-2.

Table 14-2	
Components of Quality Management Infrastructure	
Component	**Key Tasks**
Vision and planning	• Quality vision is established and articulated.
	• Annual planning process is implemented.
	• Written QM plan is developed that includes defined responsibilities, accountability, performance measures, QI activities, and timetable.
Oversight	• Performance data, findings, and accomplishments are shared frequently, both internally and externally.
	• Progress on QM plan is reviewed routinely.
	• QM infrastructure and planned activities are actively supported by senior leaders.
Formalized structure	• QM committee with appropriate membership is established.
	• Senior leaders, key providers, and stakeholders are actively involved in QM committee.
	• Priorities are established, and recommendations for current and future QM activities are solicited by QM committee.
	• Meetings are held regularly; reporting mechanisms are defined, and meeting minutes are maintained.
	• Mechanisms for interface with QI project teams are clearly defined.
	• Membership is reviewed and updated annually.
Resources	• Key staff with QM activities are identified.
	• Dedicated time is allocated for QM activities.
	• Meeting space, training, materials, and other resources are provided.
	• Mechanisms to collect, aggregate and synthesize data.
Evaluation	• QM program effectiveness in meeting organizational needs is assessed annually.
	• Stakeholders inform all intended results.
	• Accomplishments are recognized.
	• Areas for continued improvement are identified using performance data.

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

Performance Measurement

Formalized performance measures are used to assess quality of care, determine progress over time, and confirm that changes made through the QI process actually have improved patient outcomes. Perceptions of care providers may be helpful in identifying areas for QI focus, but individual assumptions and perceptions may not align with documented clinical measures and trend data. Figure 14-1 illustrates such a discrepancy between a care provider's assumption—that patients in her clinical practice were receiving regular Pap smears—and the reality made clear by clinical documentation.

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As part of QM activities, goals for each element of care should be established so that care providers are able to assess their performance. If the goals are not met in certain areas, these areas may be enhanced through a QI project. Regular review of data is critical, and additional analysis may be required for data that may indicate the existence of problems.

Figure 14-1
Provider Perception Versus Documented Reality

Assumption
Provider A believes that at least 75% of women in her clinical practice received a Pap smear within the past 12 months.

Reality
Electronic medical records indicate that only 42% of patients received a Pap smear in the past year.
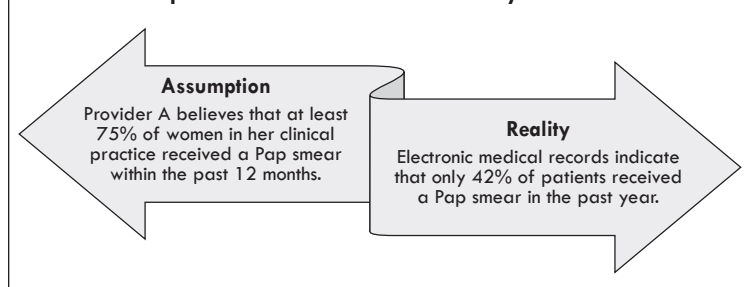
Creating a performance measurement plan: Establishing a performance measurement plan entails defining and selecting performance measures that are relevant to a specific program or population and then identifying appropriate data sources. The data that are collected must reflect the services and quality of care being provided. Finally, data must be collected at regular, defined intervals.

Standardized HIV care performance measures: Standardized performance measures for HIV care, including performance measures specific to OB-GYN care, have been established by several national entities: The Health Resources and Services Administration HIV/AIDS Bureau (HAB), the National Quality Forum (NQF), and the New York State Department of Health AIDS Institute National Quality Center (NQC) in partnership with HRSA HAB. The HAB performance measures have been developed specifically for use by programs funded by the Ryan White HIV/AIDS Treatment Extension Act of 2009. The performance measures endorsed by the NQF can be used across all service delivery systems, including private practices and large HMOs. Performance measures developed by the NQC were derived from established HIV clinical guideline panels to reflect the comprehensive package of services important to provide the best possible care to patients with HIV. The NQC performance measures include several specific to OB-GYN care.

Table 14-3 includes performance measures specific to care of women with HIV, sampled from the three resources noted in the previous paragraph. The measures are expressed in a standard format (i.e., a specific aspect of patient care accompanied by a quantitative measure designed to assess the quality of that care). Table 14-4 categorizes the same measures into three target groups: (1) pregnant women; (2) nonpregnant, sexually active women who want conception; and (3) all sexually active women.

Table 14-3

Performance Measures Specific to Care of Women with HIV

Source	Performance Measure	Numerator	Denominator
HRSA/ HAB	% of women with HIV who have a Pap smear in MY	No. of HIV infected female patients who had Pap smear results documented in MY	No. of HIV-infected female patients who were >18 yr old in MY or reported history of sexual activity and had a medical visit with a provider at least 1x in MY
			Exclusions: Patients who (1) were <18 yr old and denied history of sexual activity or (2) had hysterectomy for nondysplasia or nonmalignant indications
HRSA/ HAB	% of pregnant women with HIV infection prescribed ART	No. of HIV infected pregnant women who were prescribed ART during 2nd and 3rd trimester	No. of HIV infected pregnant women who had a medical visit with a provider with prescribing privileges at least once in MY
			Exclusions: (1) Patients with terminated pregnancy; (2) pregnant patients in 1st trimester and newly enrolled in care during last 3 mo of MY
HRSA	% of pregnant women who were screened for HIV infection during the 1st or 2nd prenatal care visit	No. of pregnant women who were screened for HIV infection during the 1st or 2nd prenatal care visit	No. of pregnant women seen for 2 prenatal visits during MY
NQC	% of women with HIV who receive preconception care and counseling	No. of HIV infected women who received counseling about importance and use of male or female condoms	No. of sexually active HIV infected women
NQC	% of women with HIV contemplating pregnancy who receive preconception care and counseling	No. of HIV infected women receiving preconception counseling	No. of sexually active HIV infected women contemplating pregnancy
NQC	% of pregnant women with HIV who received CD4+ count and viral load each trimester of pregnancy	No. of HIV infected patients for whom CD4+ count and viral load were measured each trimester of pregnancy	No. of HIV infected pregnant women

Table 14-1 continues on the next page

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Table 14-3	*continued*		

Performance Measures Specific to Care of Women with HIV

Source	Performance Measure	Numerator	Denominator
NQC	% of pregnant women with HIV who had HIV RNA measured at 34–36 wk gestation	No. of patients who had HIV RNA measured at 34–36 wk for mode of delivery assessment	No. of HIV infected patients for whom CD4+ count and viral load were measured each trimester of pregnancy
NQC	% of pregnant women with HIV who received counseling to avoid breastfeeding	No. of HIV infected pregnant women who received counseling to avoid breastfeeding	No. of HIV infected pregnant women who delivered a live-born infant within the time period of study
NQC	% of pregnant women with HIV who received intrapartum zidovudine	No. of HIV infected pregnant women who received administration of IV zidovudine during labor or prior to scheduled cesarean delivery alone or in combination with other ARV drugs	No. of HIV infected pregnant women within the time period of study who have delivered a live-born infant
NQC	% of postpartum women who received maternal postpartum follow-up	No. of HIV infected women who received documented maternal postpartum follow-up including monitoring of HIV infection with CD4+ counts and viral load tests	No. of HIV infected postpartum women

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

Performance measures are subject to ongoing change and revision. Readers are directed to the URLs below for the most up-to-date versions. Additional performance measures targeted for HIV infected patients, regardless of gender, can also be found at the following websites:

HRSA/HAB measures: http://hab.hrsa.gov/deliverhivaidscare/habperformmeasures.html

HRSA measures: http://www.hrsa.gov/healthit/coremeasures.html

NQC measures: http://www.nationalqualitycenter.org/index.cfm/5659

NQF measures: http://www.qualityforum.org

Table 14-4			
Performance Measure by Target Population			
Measure	**Population**		
	Pregnant Women	Nonpregnant, Sexually Active, Wants Conception	All Sexually Active Women
Pap smear	X	X	X
Preconception counseling		X	
HIV screening	X	X	X
Prescribed ART	X		
CD4+ and viral load each trimester	X		
HIV RNA @ 34–36 wk	X		
Breastfeeding counseling	X		
Intrapartum zidovudine	X		
Maternal follow-up	X		

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

Use of measures: Performance measurement data can be used to identify potential problems and areas in need of improvement; these areas can be examined further through the implementation of QI projects. Note that performance measurement is just one component of a QM strategy and is not an end in itself. Data analysis and subanalysis can be conducted to determine differences in clinical outcomes on the basis of any number of factors (e.g., gender, race, location, language, socioeconomic status, presence of children). Table 14-5 illustrates the results of subanalysis performed to determine gender differences in provision of CD4+ cell counts. In this example, 85.5% of all clients with HIV infection had 2 or more CD4+ cell counts performed during the measurement year. However, subpopulation analysis revealed that this level was reached for a lower percentage of female patients (71.4%), and further analysis revealed that among female patients, the standard was achieved most often for Latina patients and least often for African-American patients. Had this information been aggregated, resources used to address the actual observed disparity may not have had an appreciable impact because the largest gain would have been realized by focusing on the African-American women. When presenting data, program staff should keep in mind that data, charts, graphs, and other visual depictions of results can often relay messages or emphasize key points or trends more effectively than words.

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Table 14-5

Sample Performance Measure Subanalysis: Percentage of Patients with HIV Infection Who Had ≥2 CD4+ Cell Counts Performed in Measurement Year

Eligible Population	Numerator	Denominator	Percentage
Patients With HIV Infection	*No. Who Had ≥2 CD4+ Cell Counts Performed*	*No. Who Had ≥1 Medical Visit*	*Numerator ÷ Denominator x 100*
All patients (N = 425)	342	400	85.5
Male (n = 295)	257	281	91.5
Female (n = 130)	85	119	71.4
African-American female (n = 78)	44	70	62.9
Latina female (n = 14)	11	12	91.7
Caucasian female (n = 38)	30	37	81.1

Quality Improvement

Well-selected performance data can provide information about how well a system or program is functioning and identify potential problems. Table 14-6 provides an example. Analysis of performance measure data indicate that Agency A appears to be doing well with ART for pregnant women, medical visits, and *Pneumocystis carinii* pneumonia (PCP) prophylaxis. For each measure, baseline rates have been maintained or have improved over time. Although hepatitis B (HBV) vaccination and cervical cancer screening rates remain low, notable improvement has been made in comparison to baseline data. However, rates of TB screening and CD4+ cell counts have declined. Of particular interest is the difference in rates of CD4+ cell count monitoring and medical visits: Although the majority of patients (94%) had ≥1 medical visit during the measurement period, only 76% had ≥2 CD4+ cell counts during the same time frame.

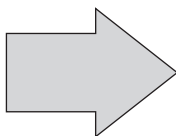| Table 14-6					
Example of Annual Quality Review Results (Agency A)					
Indicator	**Performance (%)**		**Indicator**	**Performance (%)**	
	Baseline	Current		Baseline	Current
Medical visits	91	94	Cervical cancer screening	53	68
ART	78	82	Adherence counseling	73	78
CD4+ cell count	84	76	TB screening	66	62
PCP prophylaxis (if indicated)	90	91	Syphilis screening	59	77
ART for pregnant women	95	98	HBV vaccine completed	45	54

Note: All abbreviations are defined in the list of Abbreviations and Acronyms, p. ix

Goals: Goals for each indicator should be set based on best practices. Any downward trend or measure that did not meet a defined goal can be further explored as a QI project. Once a process or issue is identified, a QI team should be convened. A QI team is a working group constituted to address one specific opportunity for improvement. The team should consist of the people who have regular involvement in the process and should have a leader, facilitator, or both. In this example, given the data presented above, the QI project could examine the rate of CD4+ cell count testing (Figure 14-2).

Figure 14-2
Quality Improvement Problem and Goal

| **Problem**	**Goal**
In 2010, the percentage of CD4+ cell counts conducted at least every 6 months decreased to 76%.	Increase the percentage of CD4+ cell counts completed at least every 6 months for HIV infected patients to 90%.

For each QI project, the specific problem should be identified, baseline data should be collected, and a clearly defined goal should be established. Various strategies can be used to understand the issue at hand and identify potential change strategies that can be implemented to reach the goal. In these processes, such tools as fishbone diagrams, flowcharts, and force field analysis can be useful.

Another useful tool is the Model for Improvement (Figure 14-3), which poses three questions to help guide a QI project: (1) What are we trying accomplish? (2) How will we know that a change is an improvement? (3) What changes can we make that will result in improvement?
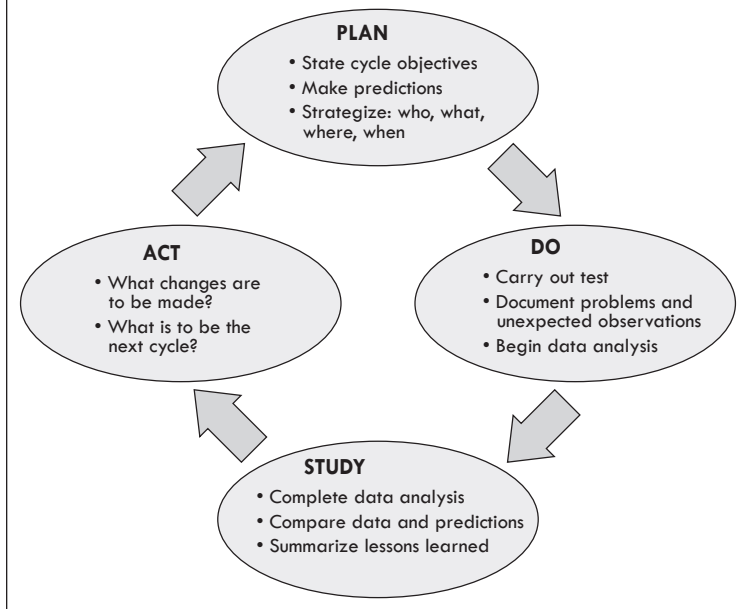
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Figure 14-3
Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What changes can we make that will result in improvement?

ACT | PLAN
STUDY | DO
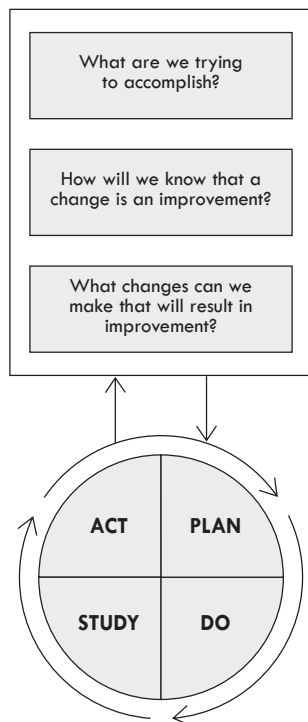
Source: © *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance,* 2nd ed. 2009. San Francisco, CA: Jossey-Bass. Reproduced with permission of John Wiley & Sons, Inc.

Plan–Do–Study–Act: By understanding a problem and implementing tests of change, performance rates can improve. However, not all change results in an improvement. To ensure that positive change is being made, performance must be measured. Plan–Do–Study–Act (PDSA) cycles (Figure 14-4) prompt a QI team to engage in continuous efforts to make change and measure its effect on patient outcomes. Multiple PDSA cycles are required to implement change that is sustainable over time. The most effective QI teams regularly communicate their progress with a QM committee. Senior leadership can be used to minimize or remove barriers, allocate resources, and provide guidance and support.

Figure 14-4
Elements of Plan–Do–Study–Act Cycle

PLAN
- State cycle objectives
- Make predictions
- Strategize: who, what, where, when

DO
- Carry out test
- Document problems and unexpected observations
- Begin data analysis

STUDY
- Complete data analysis
- Compare data and predictions
- Summarize lessons learned

ACT
- What changes are to be made?
- What is to be the next cycle?

Case Study: Quality Improvement In Action

The case study that follows illustrates components of QM program as implemented in an urban, hospital-based HIV clinic.

Quality Management Infrastructure

The HIV program's QM committee was established to support and guide all quality-related initiatives for the HIV program. The QM Committee, which met monthly, included the following members: medical director, nurse practitioner from each site, program director, site managers, QA manager, policy and procedure manager, pharmacist, and peer educator.

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Performance Measurement

The QM Committee was charged with identifying and monitoring performance measures that addressed a range of clinical issues. When the committee examined the measures, it was clear that systems needed to be enhanced to improve the clinic's Pap smear rate. Patient data indicated the following information, which prompted initiation of a QI project:

- Visit adherence: 75%

- Patients on ART: 88%

- Viral load <48 c/mL: 57%

- Annual Rapid Plasma Reagin (RPR): 94%

- Women with annual Pap: 13%

Problem identified: Pap smear completion rate varied across clinic sites. Key baseline data indicated the following:

- 13% of women referred for routine OB-GYN care kept their appointments and had documented results.

- 35% of tests returned abnormal results.

- 100% of women with abnormal results were scheduled for further evaluation, but only 25% kept their appointments.

Goal: Within 12 months, improve the annual Pap smear rate for women infected with HIV to 75%. The overarching goal was for 100% of women to receive an annual Pap smear and 90% of the women with abnormal results to receive appropriate treatment.

Understanding the problem: Data indicated that, despite a clinician's vigilance in making referrals, female patients in the HIV clinics were not keeping appointments for yearly OB-GYN exams. In response, the team implemented a series of change strategies.

Quality Management Phase 1

Strategies: A series of change ideas were implemented to increase the Pap smear completion rate:

- Phone calls to remind HIV clinic patients of scheduled appointments in the OB-GYN clinic

- Assignment of HIV clinic staff members to meet patients in the OB-GYN clinic to help ease the transition to a new setting and new care providers and to address fears

- Provision of child care for patients who kept their OB-GYN clinic appointments

- Designation of the HIV clinic nurse as a single point of contact and the person with responsibility for scheduling appointments and making follow-up phone calls.

Results: The rate of completion rose to only 42%. Of those patients with abnormal Pap smear results, only 36% received appropriate follow-up. Patient satisfaction surveys and information relayed from peer educators and the Patient Advisory Group indicated that the best way to meet this growing need was to provide onsite Pap smears during clinic visits and to build a women's clinic nested within the HIV clinic.

Quality Management Phase 2

Strategies: On the basis of data collected after the first phase, several additional change ideas were tested:

- Patients were routed to a female nurse practitioner, who conducted Pap smears as part of routine HIV care.

- Reminder tags were placed on charts to indicate when patients were due for OB-GYN care.

- Performance data were reviewed more closely to ensure that every patient was assessed to identify need for OB-GYN care.

Results: Data monitoring provided evidence that the nested approach yielded a higher percentage (60%) of completed Pap smears. To build on these results, several additional services were established:

- On-site follow-up for women with abnormal Pap smear results

- On-site colposcopy, cervical biopsies, and loop electrosurgical excision procedure (LEEP), using equipment obtained from the women's health clinic

- Training and certification in colposcopy for nurse practitioners in the HIV clinic

- One morning per week designated specifically for follow-up visits for women with abnormal results, with a primary care nurse assigned to coordinate appointments

End Results

The QI project was successful in providing patients with easy access to comprehensive care and follow-up. As a result, 57% of women had annual Pap (up from 13%), 84% of all abnormal Pap smears were followed up appropriately, and 100% of all pregnant women received ART prophylaxis for prevention of mother-to-child transmission. Another success was a reduction in missed appointments for onsite OB-GYN care, such that 88% of women adhered to scheduled appointments following completion of the QI initiative.

14

Sustaining Change and Spreading Ideas
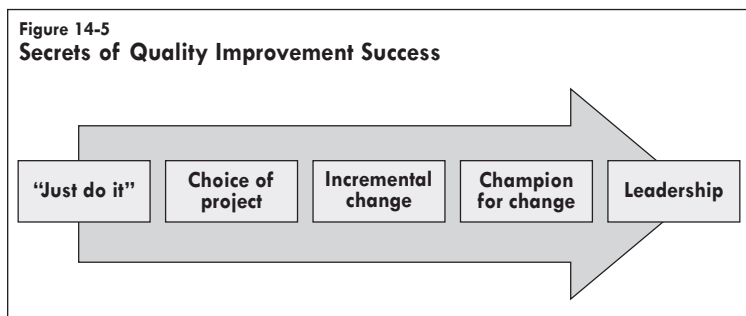
No Improvement Without Change

Clinicians and staff who initiate change must look at who and what the change will affect and select the changes that will bring about the best clinical outcomes for patients. Often, a needed change is obvious, but the resources or conditions are not readily available to support the effort needed to make change happen.

A dynamic process: Once changes have been made, progress must be monitored over time to ensure that improvements are sustained. Successful change ideas can be spread to other clinical sites and practices. Through the use of repeated PDSA cycles, ideas for change can be tested in new settings and modified as needed. As part of the change strategy, policies and procedures may have to be revised, and staff may have to be retrained or cross-trained to be able to implement new policies and practices.

Not all change = improvement: Improvement requires change, but not every change is an improvement. Purposeful change will alter an existing system in a positive way or create something new that is also improved. Only upon analysis of data and outcomes can it be determined whether a specific change led to a desired improvement.

Keys to QI success: The most important step in any QI project may be simply to get started (i.e., "just do it"; Figure 14-5). Also crucial is the selection of project: It's best to begin with a project that has a good chance of success and that will interest and engage others. Start small and aim for incremental improvement in outcomes by making and testing small changes over short periods of time. Identify and engage or involve a champion for change early on to initiate rapid PDSA cycles that will produce data demonstrating early successes. Include all levels of the system to elicit diverse ideas and buy-in for improvement. Finally, ensure effective leadership, which is essential to the success of any QM program.

Figure 14-5
Secrets of Quality Improvement Success

"Just do it"	Choice of project	Incremental change	Champion for change	Leadership

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