

MODULE TWO

Integrating Primary and Behavioral Health Care

A. The Context of Primary HIV Health Care

1. Underserved Populations and Access to Care

- Demographic changes in the HIV/AIDS epidemic – increases in reported cases among women, teenagers, injection drug users and their sexual partners, homeless people, the chronically mentally ill, and minority populations – have required changes in planning, organization, and delivery of care for individuals and families with HIV
- In recent years, the highest incidence of HIV has occurred in medically underserved populations who lack financial resources, insurance, may not speak English or be comfortable with Western health care, and have numerous survival needs that are major barriers to pursuing care
- For many, living with HIV disease is just one problem among many others such as diabetes, asthma, and hypertension; emotional disturbances and chronic mental illness; substance abuse and dependence; and, chaotic and/or violent living situations, and economic challenges.
- For most, medical needs take priority over mental health issues. Even if the need for mental health assistance is recognized, many lack the energy to negotiate yet another treatment system
- Most patients see themselves, as being physically ill, not emotionally disturbed. They fear being labeled as crazy, being condemned if their lifestyles are known, or being isolated or discriminated against if their diagnoses are disclosed.
- Lack of stable housing, child care, transportation, and financial resources all act as barriers to care.
- Poor urban women with HIV delay seeking medical treatment because as caretakers for their children and partners, they often put their own needs last. Another reason for not seeking help is the fear that they might be judged on their childbearing decisions or lose custody of their children.
- Differential access to, or acceptance of, treatment accounts for most of the differences between men and women in terms of survival rate with HIV/AIDS (Kitahata et al., 1996). In an atmosphere of increased hope there is an ever-widening gap in AIDS care between the ‘haves’ and

'have-nots' in the AIDS epidemic. Although access to care is not a new issue in AIDS treatment, it has been exacerbated by the cost of combination therapies.

- People living with HIV who also have substance abuse and mental health problems are often caught in a fragmented system of care composed of providers with different treatment priorities and philosophies.
- Medical providers are concerned about "medical compliance" issues and they worry about being ripped off by substance users who sell prescription drugs or obtain them to get high. Substance abuse treatment professionals often prioritize substance abuse detoxification and rehabilitation as the basis for any other treatment. Some mental health providers are hesitant to treat substance abusers because they feel unqualified and because they doubt the efficacy of mental health treatment undertaken before substance abuse problems have been addressed. Others subscribe to the notion of harm reduction and are willing to assist active users in preparing to change. Differences in perspectives among treatment providers can lead to struggles about who "owns" the patient and about which goals come first.
- Being female and having a child in the household is associated with delaying care. Those living with other HIV-positive people are also more likely to put off care than those who do not. These findings highlight the need to arrange supportive services for HIV-infected women, including free or low-cost child care, preferably on-site within medical settings, as well as services for caregivers in general who are themselves infected and in need of medical care even at the earliest stages of disease (Stein et al., 2000).
- Once people do seek treatment, there is no guarantee that they will receive it. Access to care for those with HIV has improved since 1996, but it remains sub-optimal. Inferior patterns of care have been observed for African-Americans and Hispanics compared to whites, the uninsured and Medicaid-insured compared to those who have private insurance, women compared with men, and other risk and/or exposure groups versus men who have sex with men (Shapiro et al., 1999).
- Palacio, Kahn, Richards, and Morin (2002) performed a systematic and critical review of published studies investigating potential associations between race and/or ethnicity and use of HIV-related medications. The authors found that there is a preponderance of evidence across time and across subpopulations that HIV-infected people of color in the United States have experienced a lower rate of utilization of antiretroviral medications than HIV-infected white people. While there was some evidence to suggest non-whites are also at risk for a lower rate of use of

prophylaxis against opportunistic infections, the strength of the evidence is not as strong as it was for antiretroviral use.

- What can be done to improve access to care? For current and former injecting drug users (IDUs) living with HIV, as an example, programs linking substance abuse treatment, case management, and medical services may help to facilitate the delivery of HIV primary care (Knowlton et al., 2001).
- Katz and colleagues (2000) found high levels of need for supportive care in a national survey of HIV-infected adults. In the six months preceding the study, 67% of these individuals had experienced a need for at least one supportive service and 27% had experienced an *unmet* need for at least one service. Unmet need was most common for *benefits advocacy*, *substance abuse treatment*, and *emotional counseling*. According to the authors, the availability and use of case management services is associated with fewer unmet needs among people living with HIV.

2. **Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act**

- This categorical HIV/AIDS care program was created in 1990 by Congress. It is meant to address and remedy disparities in access to health care, particularly for vulnerable populations. Prior to the C.A.R.E. Act, people with HIV were filling hospitals and emergency rooms when they should have been treated elsewhere and should have been diagnosed and treated earlier rather than in the later stages of illness.
- By 1995, 15 percent of the cost of care for all people at all stages of HIV infection was covered by C.A.R.E. Act funds. Spending priorities for these resources are determined by locally constituted planning councils.
- Of critical importance is the fact that the funds can be used for necessary non-medical services such as mental health, to recruit and retain providers, and to deal with problems of daily life such as transportation, day/child care, home care, housing, and hospice care. Equally important is the legislatively mandated process requiring local assessment of gaps in care, prioritization of the uses of the funds, and preparation of a plan for coordinated, comprehensive community services for diverse populations of people with HIV/AIDS.
- The CARE Act's holistic approach is based on a behavioral model of health care utilization that posits that certain population characteristics and system features determine health service use. Elements of the model include *predisposing factors*, mostly clients' sociodemographic characteristics; *enabling factors* such as family and community characteristics and resources; and *system characteristics*; including

insurance benefits, funding sources, provider type and training, and the distribution and location of facilities (Andersen & Newman, 1973).

- At the *predisposing* level, many newly infected people with HIV disease have no history of regular access to primary care. The stigma attached to certain transmission modes, particularly same-sex contact and injection drug use, deter people from seeking both testing and services for HIV. Many mainstream health care providers have little experience with people who have histories of drug use and mental illness.
- At the *enabling* level, ethnic minorities, especially recent immigrants, may pose challenges arising out of preferences for traditional modalities of care, unfamiliarity with the health care system in the USA, and needs for culturally appropriate food, housing, and mental health counseling services (Pounds et al., 2002).
- At the *systems* level, providing ancillary care for mental health and substance abuse services can ameliorate fragmented care systems for multiply-diagnosed patients. Co-locating services, coordinating appointments and promoting communication among clinicians can improve the ability of patients who have limited education and resources to keep appointments and receive appropriate and regular care.
- Case management, mental health service, substance abuse treatment, transportation, housing assistance, food and nutrition service, legal assistance, drug assistance, and complementary therapy programs coordinated and funded through Ryan White C.A.R.E. Act grantees have been successful in improving access to primary care, increasing primary care retention and the availability of diverse types of services, substantially increasing the numbers and the diversity of underserved people in outpatient primary care, and keeping people out of inappropriate care in emergency rooms and acute care hospitals (Conviser & Pounds, 2002).
- Lessons learned from the programs funded by the CARE Act indicate that even in systems with comprehensive arrays of services, coordination among them may be lacking, making it difficult for providers to make effective client referrals. One way in which systems can coordinate services is to develop formal agreements among providers; this can be characterized as *systems integration*. Another way is to have case managers who coordinate care and link clients with needed services. Although effective case management can overcome poor system integration, in many jurisdictions case managers are lacking or non-existent. In such cases, mental health providers must assume that role in order to ensure quality and coordinated care.

- It is important to note that the Ryan White C.A.R.E. Act and the availability of federal funds to plan and carry out locally responsive care programs came about because of political advocacy and the use of political power by the gay, minority, and other communities and a variety of local, regional, and national organizations working in coordination with public and government advocates. The future of health programs targeted to specific medical conditions will depend on such organized advocacy and political action.

3. Health Care Financing

- In FY 2002, U.S. federal spending on HIV/AIDS totaled approximately \$14.7 billion. Of this total, 18% went to research, 7% to prevention, 59% to care (health care and support services), 11% to cash and housing assistance, and 6% to combating the international epidemic.
- Some of the key programs that provide health insurance coverage, care, and support to people with HIV/AIDS in the U.S. are Medicaid, Medicare, and the Ryan White CARE Act. A variety of federally and state-supported prevention services are provided by state and local health departments and community planning groups.
- Currently, there is no comprehensive way to finance access to comprehensive care for all people with HIV/AIDS who do not have insurance.
- Medicaid covers some of the costs of care but the percentage of care covered, the eligibility criteria, the types of services covered, and the levels of reimbursement to health care providers vary from state to state. Many states have recently cut back on Medicaid benefits thereby increasing pressure on the use of Ryan White funds.
- To receive Medicare, one has to have been receiving Social Security disability benefits for 24 months, which, if one includes the five-month initial wait for those benefits, means a delay of 29 months after a determination of an AIDS-related SSI disability has been made before Medicare kicks in.
- Congressional and state action to cut spending on Medicaid and Medicare has resulted in the movement of more clients with HIV into managed care arrangements. Managed care management practices include allowing access only to “in-network” providers or to salaried employees and facilities of the health maintenance organization (HMO); pre-approval requirements for access to specialists and specialized therapies; pre-approved but possibly limited pharmacy formularies; utilization review; capitation; profit sharing for providers; limited mental health and

substance abuse treatment benefits; lack of social services; and limited or no access to clinical trials.

- In some areas, HIV treatment and behavioral medicine (substance abuse treatment and mental health services) carve-outs have been developed in which managed care clients receive specialized services from a group of providers who specialize in those areas. Behavioral medicine and care for special populations such as people with HIV will be increasingly carved out in high-population-density areas or in areas where these conditions are especially prevalent and where groups of capable and interested specialty providers are available. In rural and less population-dense areas or where conditions such as HIV are rare or of low prevalence, care will be provided by generalist physicians or regional specialists and will not be carved out.
- In the current health care environment, mental health providers often need to be advocates for their clients to help them obtain the services they need and to alter benefits packages as needed in order to offer optimal cost-effective care to their clients and families.

4. Emerging Models of Collaboration between Primary and Behavioral Health Care Providers

- Medical/primary care settings have diversified from the existing traditional office practice to include community based health clinics, HIV specific group practices and county/city based ambulatory models of care for the uninsured.
- The multiple emotional and behavioral factors associated with HIV infection necessitates ongoing collaboration with HIV primary care providers has become a clinical necessity or standard of care
- For patients with co-occurring mental health and/or substance abuse disorders, integrated models of care within HIV primary care settings are beginning to form.
- This integrated approach usually involves the delivery of mental health services on a “levels of care” continuum. The first line of intervention for a primary care patient who has behavioral health needs is done through a general consultation service delivery system. This “first-line” system utilizes on-site behavioral consultants with a set consultation schedule whose services are brief (15-30 minutes) and time-limited (1-3 visits).
- Patients with more complicated behavioral health needs receive services in “critical pathways”, based in the *vertical integration* approach. *Vertical integration* involves providing targeted, more specialized

behavioral health services to a well-defined, circumscribed group of HIV patients such as those with major depression, anxiety disorders, adherence issues, or problems with substance abuse. These specialized health services typically involve a highly condensed behavioral treatment package that involves a structured program of education, skill-building, skills practice, and feedback.

- Patients who do not respond to either the first-line or critical pathways approach are referred to traditional mental health care.

B. Barriers to Collaboration and Strategies for Overcoming Them

1. Reimbursement

- Under most existing systems, physicians are reimbursed for procedures whereas behavioral health providers are reimbursed for time. Thus, mental health providers can get paid for “therapy” services but not as readily paid for such services as consultation to primary care providers, or briefly seeing a patient conjointly with primary care physicians.
- Some mental health providers have developed relationships with administrative and billing staffs of primary care providers to determine the best ways of framing consultative services to ensure reimbursement. Consultative services may be offered at the behavioral health provider’s office, at the primary provider’s office, or done through phone consultation. The most successful services are those in which the behavioral health care specialist has designated hours for consultation at or near the primary care provider’s office.
- Other mental health providers are working in primary care settings as a staff member of the HMO, hospital, or clinic.
- Some mental health providers have joined with primary care providers to develop fully integrated behavioral health care systems.

2. Little Time

- Mental health providers and primary care physicians often operate on different time frames. No matter how extensive the primary care provider’s training and skills, when that primary care provider is seeing 35 to 40 patients a day, opening up mental health issues may be viewed as a potential Pandora’s Box. Every primary care provider has had the experience of asking a small question and seeing the patient dissolve into tears and emotional turmoil while the waiting room is filled with patients both with and without appointment. A few painful experiences such as this will render most primary care providers “gun shy”, resulting in the unconscious overlooking of emotional signs.

- Primary care providers need behavioral consultants to come up with quick assessments and practical management recommendations. Because primary care providers continue to see the patients they refer and they want to be involved, they want to know how to meaningfully assess, monitor, and intervene in their patients' mental, emotional, and chemical dependency problems without putting themselves in a position where they can't close Pandora's Box. Although primary care providers may refer to behavioral consultants for treatment, they want to know practical strategies that they can employ in the context of short primary care visits.
- Consultation reports of more than one page generally will not be read. Primary care physicians will be more impressed by your capacity to be practical and succinct than by your capacity to be comprehensive.

3. Few Opportunities for Contact

- Lack of proximity and regular settings for contact are major components that hinder referrals. In many cases it takes a special effort to develop the relationship, and it is necessary to have a regular setting or routine for continuing the collaboration.
- Regular contact can be established through scheduled telephone contacts, lunch or breakfast appointments, use of FAX or email for referrals and consultation reports, and shared hospital rounds.

4. Cultural Differences

- Potential conflicts between the professional culture of mental health providers and physicians need to be worked out for a successful collaboration. For example, physicians talk openly about their patients and would consider it unusual for a consultant not to report back what they have learned about the patient and how they are doing. When physicians refer a patient to a mental health worker, they don't view it as farming out the work. They expect to know about the treatment and the patient's progress.
- Mental health providers need to tell their patients that their assessment, treatment plan, and treatment progress will be discussed with their primary care physician. When mental health workers explain to their patients that they will not disclose intimate details, most patients are happy that their mental health provider and physician are working together.
- Physicians tend to be action-oriented. Psychologists and other mental health providers place emphasis on developing a thorough understanding

of the issues and helping their patients explore those issues and the implications for their lives. It is generally not helpful for mental health providers to respond to questions from physicians with discussions about issues. Physicians simply want to know *what to do*.

5. Language

- Differences in terminology and jargon create barriers to communication.
- Whenever possible, mental health providers should learn the common language, acronyms, and abbreviations used in charts by physicians involved with HIV care.
- Mental health providers should avoid using terminology or jargon that will not be understood by those who are not mental health providers. For example, do not say, "Patient overuses the defense mechanisms of repression and denial." Say instead, "Patient doesn't want to admit this to himself."

6. Problems with Referrals

- It is not uncommon to receive vague, poorly defined consultation requests. Many physicians and other referral sources are still unclear as to what services behavioral health consultants can provide and what kinds of information are helpful when making a consultation request. As a result, assessment questions are often ambiguous, unclear, too specific, untimely, or inappropriate.
- It is helpful to provide physicians with a list of things that would be appropriate to trigger a referral. For example,
 1. Complaints seem out of proportion.
 2. Unusual symptoms arise as old symptoms resolve.
 3. The patient repeatedly raises issues/questions that are already addressed.
 4. The patient does not adhere to prescribed medications.
 5. The patient takes anxiolytic, sleep, or analgesic medication for a longer period of time than appropriate.
 6. The patient exhibits a great deal of emotional distress.
 7. The patient reports significant family problems dealing with illness.
 8. The patient overuses alcohol or other psychoactive drugs.
- Physicians may need help in phrasing referrals. The following phrases may be more palatable to patients.

"I would like to make a referral...

 1. for stress management."

2. for a special symptom-management program."
 3. to help prepare you to be successful with this difficult medication regimen."
 4. to assist with the stress that this condition has caused you and your family (partner, friends, etc.)."
- Identifying the patient or problem may be an issue. For example, a referral request might read: "patient appropriate for antiretroviral combination therapies but refuses". One could guess that the referring physician is frustrated by the patient's refusal to take medication and wants the behavioral health consultant to convince the patient otherwise. In this type of case, it is essential to garner additional information from a variety of sources, especially the consultee, before actually speaking with the patient. This consultation might reflect conflict between the value systems of the patient and the health care team. Assessment needs to be directed toward both the patient and the staff.
 - "Dumping" and "turking" are two terms that represent assessment and intervention requests for patients for which other professionals no longer wish to be responsible. Occasionally, patients are referred because of the physician's inability to satisfy the patient. It is often unfortunately assumed that if the patient is still complaining, the patient must be psychologically ill.

C. Common Roles of the Mental Health Provider in Assisting HIV/AIDS Patients to Better Utilize Primary Care

1. Assist with Patient Empowerment

- Many patients with HIV/AIDS come from disenfranchised and marginalized communities. As a result of multigenerational experiences with poverty, racism, and stigma, many have internalized the oppression they have experienced. This internalized oppression, combined with lower levels of education and resources, can result in beliefs that one has little power to impact the course of one's illness or care. For many, basic issues associated with identity, culturally-proscribed ways of relating to Caucasian authority figures, and internalized oppression must be dealt with before it is possible to learn the skills of patient assertiveness and being active on one's own behalf.

2. Assist with Identifying and Articulating Expectations of Health Care Team

- Some people prefer a collaborative partnership with their health care team. Others want a health care team that instills confidence by being definitive and directive. Some patients want the opportunity to discuss

psychosocial issues with their health care team. Others want to stick to the medical stuff. Some patients want their health care team to embrace and encourage alternative or complimentary therapies. Others want to hear about only those treatments with demonstrated efficacy. Mental health providers can assist patients to identify their expectations of providers and then support them as they seek providers who have treatment philosophies similar to their own.

3. Assist Patient in Building Relationships with the Health Care Team

- Some patients are unaccustomed to the notion of building relationships with providers in order to ensure higher quality care. Many patients have difficulty building relationships in the face of the inherent power differential between the patient and the provider. This power differential dynamic can lead to patient interaction styles that vacillate between humble gratefulness, a sullen passivity, and angry outbursts.
- The mental health provider can assist the patient to identify critical gatekeepers (e.g., receptionists, billing clerks, case managers, etc.) and key providers (e.g., nurses, nurse practitioners, social workers, etc.) who can assist them in negotiating complex health care systems and in getting the best care possible.

4. Facilitating Communication with Health Care Providers

- Assisting the patient in developing effective styles of communication for getting their needs met can be an important goal of psychotherapy.
- At times, the mental health provider may participate in discussion with the patient and his/her health care team in order to facilitate discussion and lend support to the patient's position.

5. Exploring Patients' Understanding of Medical Conditions and Treatments

- Because of the pressured demands on health care providers in our current system of care, patients are often bombarded with information during their doctor visits and given little time to process what they have learned, ask questions, and consider implications for their personal lives. After providing patients with explanations, providers often ask – do you understand? Typically, patients shake their heads affirmatively and there is no attempt on the part of providers to check out what patients truly understand and what they think it means for their lives.

6. Work with patients to be better observers and communicators of symptoms and side effects so they can better assist the physician

- Mental health providers can play a crucial role in assisting patients to find an optimal balance between the extremes of avoidance and hypervigilance about their symptoms and side effects.

7. Exploring Patient's Personal Meanings of Illness, Symptoms & Treatments

- Medical conditions, symptoms, treatments, and treatment side effects all carry symbolic and idiosyncratic meanings for the patient. Often, primary health care providers do not have the time or inclination to explore and understand these meanings. It is critical for these meanings to be understood and responded to if the patient is to develop a strong alliance with the treatment regimen and a solid partnership with the health care team.
- For example, a doctor may prescribe a medication that causes extremely dry skin in a patient who has always prided herself in having smooth, soft skin. Poor adherence to the treatment regimen may develop and the physician may not know why because the patient is unlikely to bring it up for fear of appearing silly or unappreciative.
- For some, a particular symptom or side effect may be mildly irritating while others may find the same symptom or side effect overwhelming. Often, these individual differences have to do with elements of personal history that can be understood and worked through.

8. Prepare patients for difficult medical procedures

- Many patients have heard the following phrases about unpleasant or painful medical procedures from doctors – it's no big deal; just some mild discomfort; nothing to worry about...
- Prior experiences in which there have been disparities between what they have been told and what they experience lead many patients to be distrustful about what they are told about medical procedures.
- Helping patients to gather information about anticipated procedures and control elements of the experience that *they can* control is another critical role of the mental health provider.

9. Assist patient and treatment team in communicating with family about medical condition, treatments and their role in process. (How they can help.)

- Families and friends of patients are often in key positions either to support or sabotage a patient's movement toward health. Mental health

providers can assist nurses and social workers in informing family and friends about conditions and treatments; in exploring the possible implications for the lives of the patient, family, and friends; in identifying potential sources of conflict as the family and social support system adjusts to the changes; and in developing strategies for working together and sharing the load.

10. Help patients cope with side effects of treatment

- Cognitive restructuring, relaxation training, and guided imagery have all proven to be effective for assisting patients to cope with nausea and vomiting and for reducing anxiety associated with treatments and the onset of side effects. Patients may be instructed to practice these techniques before and after administering medications to gain a sense of control and to distract their attention from potential side effects.

11. Assist Patients with Adherence to Medication Regimens

- Individuals struggling with adherence to antiretroviral regimens clearly benefit from social support. Mental health providers should encourage patients to seek the support of partners, families and friends in their adherence efforts.
- It is important to help patients establish routines so the act of taking medication can be tied to specific events or times of the day.
- Strategies for handling situations in which routines are broken should also be established because such times are often occasions of non-adherence. The use of beepers or electronic timers has proven to be effective for many patients.
- Patients should be encouraged to identify foods (if appropriate depending on specific, individual drug requirements) that make taking medications easier in terms of swallowing or taste.
- Mental health providers can perform a useful educational role in helping patients and families understand why adherence to medications is so important.
- It is often helpful to assist patients in developing strategies for taking medications in awkward social situations.
- Whenever possible, patients should be encouraged to have medication on reserve; ideally one extra month of medication should be available.

- For patients who spend time in a workplace or in more than one home, medication should be available in all these locations; a supply of all medications should be kept in places where the individual spends his/her day.
- Motivational Interviewing and Cognitive Behavioral Skills Training are two approaches that hold promise in terms of improving medication adherence among those with HIV.
- Motivation is a key to treatment success because clients are more likely to be committed to a behavior change plan when their ambivalence about change is addressed and when they perceive the behavior change plan as their own.
- Researchers generally recommend that comprehensive interventions include skills-training and motivational enhancement (Baer, Kivlahan, & Donovan, 1999; Ickovics & Meisler, 1997). Researchers have suggested that the two approaches be sequenced such that motivational and goal setting precedes skills building (Annis, Schober, & Kelly, 1996; Sobell & Sobell, 1993). Most interventions that have been shown to improve adherence for non-HIV medication regimens have included multiple components, including education, motivation enhancement, social support enhancement, and the development of cognitive-behavioral skills (Dunbar-Jacob, Dwyer, & Dunning, 1991; Turk & Meichenbaum, 1991).
- Motivational Interviewing can be utilized to increase the person's readiness for adherence. Through the use of such techniques as reflective listening, asking open-ended questions, affirmation, summarizing, and eliciting self-motivational statements, providers can be client-centered in the approach and work with clients at varying levels of readiness for change. Providers can work with clients on the development of a personalized goal change plan and they can help clients to identify their own barriers and facilitators to medication adherence, thus enhancing their motivation for change.
- For some clients, enhanced motivation may be sufficient to promote acceptable rates of adherence. For many clients however, additional skills will be necessary. The use of Cognitive-Behavioral Skills Training is used to enhance the skills most relevant to the client's unique needs. A functional analysis, by which the counselor and client work together to identify triggers for non-adherence, can be helpful in identifying particular areas in which skills-building can be most useful.
- For example, if a functional analysis were to reveal that a client is most tempted to miss doses when he doesn't feel confident in his ability to stick to the regimen or when he worried about side effects, the provider could focus on enhancing self-efficacy and managing side effects. Further,

Cognitive-Behavioral Skills Training can be used to improve patient-provider communication or facilitate a client's ability to obtain additional sources of social support.

12. Assist Patients with Emotional Reactions to Medical Decision-Making

- The rapid and dramatic advances in HIV treatment during the past few years have created a period of pervasive uncertainty for those living with HIV. In the early days of HAART, medical researchers and practitioners advanced a “hit early, hit hard” treatment philosophy based on the assumption that infected people would fare better if they started taking combination therapies early. Subsequent research demonstrated that combination therapies may diminish in their effectiveness over time and long-term side effects and/or medical complications may be potentially serious.
- In response to this data, a “wait and see” treatment philosophy began to emerge. In 1998, the U.S. Department of Health and Human Services (HHS) changed its “Guidelines for the Use of Antiretroviral Agents in HIV Infected Adults and Adolescents” to recommend initiation of HAART for patients with 500 or fewer CD4 cells or viral loads above 20,000 copies per milliliter of blood (73). In 2001, these guidelines were changed to an even more conservative approach that recommended treatment for patients with at 350 CD4s or viral loads higher than 55,000.
- The controversy over when to initiate HAART still exists and the guidelines will likely change again as new findings emerge. Thus, unlike treatment decisions facing persons with other chronic illnesses that have more stable treatment protocols, patients with HIV/AIDS and their providers must remain vigilant to an ever-changing treatment environment. Because of this general context of uncertainty, decisions about treatment often trigger anxiety and concerns about death and dying. At such times, clients may need an abundance of support and reassurance.
- Despite the success of combination therapies in treating many with HIV, between 15% and 35% of participants in clinical trials testing combination antiretroviral therapies do not demonstrate clinical benefits, and the results appear even worse for people treated outside research protocols.
- Treatment failures occur when combination therapies do not produce meaningful reductions in viral load, when effectiveness diminishes over time, and when side effects become intolerable. Rabkin and Ferrando (1997) described the psychological ramifications of each of these possible ways in which treatments fail.

- According to these authors, failing to respond when combination therapies are initiated may lead to feelings of personal injustice, being cheated, or a sense of betrayal. Discontinuation of treatment due to side effects may lead to self-blame for not being able to tolerate a potentially effective treatment. Finally, treatments that diminish in effectiveness over time may be interpreted as another false promise about the effectiveness of HIV treatments and this interpretation can create a sense of hopelessness and unwillingness to try new therapies.
- It is not difficult to see how the reactions described by Rabkin and Ferrando could lead to more generalized doubts about being able to cope with the disease as well as death-related anxiety.
- When a particular combination treatment fails, people with HIV and their providers are faced with several additional layers of uncertainty that could increase the likelihood of triggering an episode of anxiety. If the HIV-infected client and his or her provider decide to switch to another combination therapy, they are faced with a myriad choices. In the United States there are now 16 anti-HIV drugs on the market and more are in the pipeline. However, the choice of drugs is not the only decision. There is the question of whether or not it would be better to discontinue treatment for a period of time. If the decision is made to discontinue treatment, then the question becomes how long should that discontinuation last.
- With each successive switch to a different medication cocktail, HAART works for shorter periods before another switch is required. This limitation of HAART has led to experimentation with carefully monitored drug holidays known as structured treatment interruptions (STIs). At present, the value of STIs for chronically infected people remains controversial and yet people with HIV are faced with the daunting challenge of sorting through the controversy with their life potentially on the line.
- Psychological reactions to treatment failures are influenced by prior treatment history. Having had more extensive experiences with antiretroviral therapies will mean that a person has been through the ups and downs of treatments tried and treatments failed. Unfortunately, drug resistance is also more likely to develop for people with more extensive treatment histories, so the expectations for success will differ. Thus, greater experience with treatments may psychologically prepare people for unsuccessful treatments, while creating a greater fear of failure since other available treatment options are few or nonexistent.
- The emotional aftermath of treatment failures can be limited by communicating the realistic expectations for combination therapies. Guarding against overoptimism must be balanced with the realistic

optimism that is necessary to sustain adherence to these difficult treatment regimens. It is also important to deal with the potential guilt of treatment failure, particularly when drug resistance develops (Rabkin & Ferrando, 1977). Having decided to start treatment early or not having perfectly adhered to a treatment regimen can fuel self-blame for treatment failures.

- Mourning the loss of hope as well as the loss resulting from not being a part of widely proclaimed treatment breakthroughs should be facilitated in counseling. Expressing anger, guilt, resentment, and grief should be encouraged. However, clients should be reminded of the astonishing pace of new treatments and opportunities to participate in clinical trials. The goal of grief work should be mobilizing the client to move on, and in the case of failed treatments moving on may mean trying new treatment opportunities as they become available.
- It is important to consider how individual difference variables can affect medical decision-making. For example, optimistic people may see new drugs as a motivation to start therapy early, believing that new, non-cross resistant drugs will be available in future should they eventually develop resistance to currently available agents. Pessimists may choose to wait until there are newer drugs available before risking failure on the current drugs.
- Miller (1987) described other individual difference variables that have the potential to affect medical decision-making. He examined two general styles of coping with stressful events; information seekers, who monitor stressful situations and information avoiders, who are less inclined to monitor such situations. People who are high in monitoring are more likely to report illness symptoms than those low in monitoring are.
- High monitoring is also associated with requesting more medical tests and demanding more information about their medical condition (Miller & Mangan, 1983; Miller, Brody, & Summerton, 1988). Therefore, people who are information seekers may be more closely in tune with their condition and more desirous of being involved in their treatment decisions. Although these relationships have not been observed in people living with HIV/AIDS, they are likely to affect HIV treatment decisions.