The Adherence Conundrum

Lisa Cox

King Louis XIV: You have a physician. What does he do?

French Playwright Molière: Sire, we converse. He gives me advice which I do not follow, and I get better.

—W. Treue, Doctor at Court (1958, p. 41)

Historical Significance of Medication Adherence

Prior to the 1981 discovery of the human immunodeficiency virus (HIV), healthcare providers, including social workers, practiced in a world without HIV and the acquired immune deficiency syndrome (AIDS). In 1981, as epidemiologists and physicians were watching people die from pneumocystis carinii pneumonia (PCP), Kaposi sarcoma (KS), and toxoplasmosis, there were no medication protocols to which to adhere. Only in 1987 was the first antiretroviral (ARV) medication, named AZT (azidothymidine; also known as zidovudine, or brand name Retrovir), approved for prescription purposes. These early doses of AZT were typically prescribed at 1,200 milligrams, a dosage that caused extreme side effects. Approximately three years later, the AZT dose was cut in half. Consequently, people living with AIDS (PLWA) experienced side effects that were less devastating, and saved money from not having to fill their prescriptions so frequently.

With HIV/AIDS medications available in 1987 clinical drug trials could be implemented and evaluated. AIDS became a chronic manageable disease, generating optimism and hope about the future for HIV-infected people and their loved ones. Spanning the years between 1990 and 2000, when opportunistic infections such as mycobacterium avium complex, cryptococcal meningitis, and cancers were prevalent, numerous HIV-infected people were recruited into both hospital- and
community-based AIDS clinical trials. These methodological assessments helped answer scientific questions regarding the safety and efficacy of new treatments and of new methods for administering existing treatments, and depended on study participants’ continuing committed participation. AIDS clinical trial researchers judged the validity of drug studies conducted by the industry (e.g., pharmaceutical companies) and the National Institutes of Health (NIH) on the ability of those studies to recruit and retain adherent study participants.

Consequently, adherence—the commonly used term for medication compliance, or concordance, as some Australians say—has become part of the everyday lexicon of scientists, social workers, and researchers who help HIV-infected people adjust to a lifetime of taking prescriptions. As HIV disease has morphed from an acute illness to a chronic illness, adherence has evolved as a major and minor lifestyle issue for people living with HIV and AIDS. Some authorities have called treatment adherence the most serious problem facing medical practice. Both simple and complex definitions of adherence abound. In health care, perhaps the most widely accepted definition of adherence is the extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice. This definition emphasizes aspects of dosage and pill taking, both of them aspects of medication adherence. Despite these definitions, what seems most important is what adherence means to the person infected with HIV disease.

In reality, people living with HIV and people living with AIDS must grapple with medication adherence issues amidst the normal stressors of daily living. When health-care providers, including social workers, encourage patients to adhere to strict medication regimen schedules, those patients are often required to make lifestyle changes. For example, vacations require careful forethought because prescriptions must be filled in advance, some medications require refrigeration, and others are affected by the ingestion of grapefruit and some anti-anxiety medications.

Existing literature on adherence is voluminous, sometimes inconclusive, and often controversial. Nevertheless, medical clinicians have been aware of the need for patient adherence for centuries. Haynes (1979) wryly noted that the “first recorded instance of noncompliance took place in the Garden of Eden” (p. 3). An ancient
Greek treatise on physician decorum, attributed to Hippocrates, gives the following advice: “Keep watch also on the faults of patients which makes them lie about the taking of things prescribed” (Jones, 1923, p. 297).

Goals of Medication Adherence for People Living with HIV Disease or Advanced AIDS

Health-care providers often tell their HIV-infected patients that there are at least five good reasons why excellent adherence to their treatment regimen is important. The goals of medication adherence are to decrease viral load, prevent opportunistic infections, enhance the immune system, improve quality of life, and maximize longevity. Professionals who prescribe HIV medications and counsel HIV/AIDS patients about making healthy lifestyle choices realize the importance of education, coaching, and monitoring. Patients must understand the life cycle of HIV and the potential side effects and drug resistance issues that are associated with highly active antiretroviral therapy (HAART). HAART consists of approximately thirty medications for which there is FDA approval. The thirty HAART medications (as of 2012) fall into several drug classifications: nucleotide reverse transcriptase inhibitors (NRTI), nonnucleoside reverse transcriptase inhibitors (NNRTI), protease inhibitors, fusion inhibitors, and entry inhibitors.

Adherence and HIV Outcomes

The human factor is as crucial as the pharmacologic factor in determining therapeutic outcomes. The most potent treatments are useless in the face of poor adherence. In the field of HIV/AIDS, high levels of adherence to ARV therapy have been shown to have significant effects on viral load, immune reconstitution, and mortality. Suboptimal adherence can lead to ARV resistance because of ongoing viral replication in the presence of the selective environmental pressure of ARV medications. So how much adherence is enough?

Health-care providers would like to see their patients achieve perfect adherence to their prescribed medications and lifestyle recommendations, regarding diet and exercise. People living with HIV and people living with AIDS on the other hand, find strict adherence to be challenging, yet most try their best to adhere to their HAART regimen. Realistically, however, people do forget doses or take “drug holidays.” When people miss doses of HIV medications, viral replication
and drug resistance may occur, and HIV may be more readily spread throughout the community.

Genotype and phenotype tests both provide baseline data and help clinicians and patients better understand how HIV is currently acting in the body. A genotypic analysis indicates a given HIV’s genetic resistance to a given drug, and a phenotypic analysis is a virus-culture drug assay. Phenotypic results are easier to interpret than genotypic results because they do not require the expert interpretation of complex mutation patterns. Phenotype testing is very expensive—approximately $1,000 per test. So oftentimes, patients rely on the cheaper and faster (one-week) genotypic testing that costs about $500. Furthermore, most third-party payers do not cover these tests. Specifically, the genotype is the sequences of nucleotide bases that constitute a gene, whereas the phenotype refers to a defined behavior, especially drug susceptibility related to HIV drug resistance. The more advanced phenosense genotype test is also a helpful tool in a clinician’s armamentarium.

Health-care providers have endeavored to manage the challenge of patient adherence for centuries. The medical literature reveals how difficult it is for patients to stick to even the simplest treatment regimens. Factors associated with poor compliance include perceived need of medication, unstable housing, mental illness, and major life crises. Also creating adherence problems are pill burden, pill size, frequency and timing of dose, dietary or water requirements or restrictions, liquid formulations, unpleasant drug taste, adverse events, storage requirements, number of prescriptions, and other factors such as the number of co-payments, refills, and medication bottles (Stine, 2010, p. 97).

Adherence to a drug regimen means taking all the prescribed anti-HIV drugs at the scheduled times and not missing any doses. Whenever people are asked to alter or maintain new behaviors to treat an existing condition or to prevent a threatened one, there is a possibility that they will not comply consistently and correctly with the prescribed activities.

An interesting exercise to highlight the challenges of adherence with HAART might involve the following class adherence experiment. Virologist and textbook author Gerald Stine (2012, p. 95) conceptualized this assignment, and used it with his students at the University of North Florida. Teachers and students should try this so all can better relate to what it must be like for HIV-infected people who must be compliant with their powerfully potent medications.
Theories, Measures, and Models to Understand Adherence

Why do patients miss doses? Do they miss doses because they forgot, they are depressed, they ran out, they are away from home, or because there is a change in their daily routine? Are there other reasons? Most literature reports that adherence rates decline over time. The “pill fatigue” phenomenon is prominent even in the most adherent patients. A clinical research drug trial, known as SMART found evidence that drug holidays are a bad idea for HIV-infected people who are prescribed a complex regimen (Stine, 2009).

What is a complex regimen? Generally, dosing more than two times a day, a large number of pills that require swallowing, food and fluid restrictions, or special medication storage requirements like refrigeration constitute a complex regimen. Fortunately, a wide range of HIV-infected people living in 2012 may have a regimen that requires only three or four pills once a day, or in some cases just one pill a day. Ideally, health-care providers would like to see their patients continue for many years on the first regimen that they prescribe. This is because every regimen after the first one is typically not simple.

Vignettes later in this chapter illustrate the variability and the formidable challenge that both one-pill prescriptions and complex medication regimens have for newly diagnosed HIV-infected patients and those who have been living with HIV/AIDS for some time. Patients’ ability to maintain excellent medication adherence is often challenged when they start on a once-a-day formulation, but because of noncompliance need to move to a more complex regimen.
Clinical trial researchers, community-based research physicians, nurses, and other health-care providers have learned lessons from other chronic illnesses as to why some people comply with their physician's advice and others do not. Researchers have learned that a simple regimen will likely increase adherence behavior and rates. For example, data have shown that 90 percent of people can comply with a simple one-time-a-day treatment regimen. For optimal virologic suppression, clinicians advise that patients with HIV be 95 percent adherent. This means that they cannot miss a dose more than once a month.

Unreliable predictors of adherence have consistently included age, education level, socioeconomic status, sex, race, gender, and previous substance use. To date, no clinical trials specifically related to substance abuse, adherence, and HIV have been done in the United States. Of interest, the drug Sustiva (Efavirenz) typically causes 50 percent of people who take it to have side effects that include very vivid dreams. Patients' dreams may be erotic or give the sensation that they are being pursued. Therefore, health-care providers must counsel and talk patients through potential side effects. Savvy and experienced health-care providers state that they never start their patients on new medications unless the timeframe is such that the patient may contact the provider if problems ensue. Predictors of adherence can involve positive or negative factors.

Negative predictors of adherence include
- Unstable housing
- Mental illness
- Major life crises (e.g., new HIV diagnosis, marriage)
- Active substance use (especially crack cocaine)
- Significant side effects

Positive predictors of adherence include
- Client's belief in ARV regimen
- Experienced medical provider
- Existence of social support
- Clients that are adherent with office visits
- Clients that are employed
Other associated factors are

- Perceived need of medication
- Pill burden and pill size
- Frequency and timing of dose
- Dietary or water requirements or restrictions
- Liquid formulations
- Unpleasant drug taste
- Adverse events
- Storage requirements
- Number of prescriptions
- Number of copayments, refills, and medication bottles

These realities are illustrated by imagining the practice of a community nurse practitioner. She has shared with staff that she wants to see newer or sicker patients once a month. Patients need to come in to see her, to see a case-manager or mental health therapist, or to obtain bus tickets so that they can become disciplined, habituate, and keep their appointments. She has found that this consistency of contact promotes adherence, thereby measurably reducing the development of drug resistance. She knows skipping only a few pills can trigger the emergence of drug-resistant strains of HIV, which could be worse than the initial infection. Then, the situation might be overwhelming to the person taking ARV and anyone else to whom he or she has transmitted the virus.

Social workers in some infectious disease clinic settings are also using innovative strategies to increase adherence with appointments and medications. The utility of social workers’ involvement in nonbillable intake interviews is under study.

Measures of adherence vary. Patient self-reports, provider estimation, pill counts, smart pill bottles (called MEMS caps, or medication event monitoring systems, used in some clinical trials), pharmacy records, and directly observed therapy (such as in methadone maintenance clinics) are examples of measures. Adherence measures are linked to the dosing frequency and pill quantity of the prescribed HIV medications, as well as the monetary and economic resources at the patient’s
disposal. Some physicians have been willing to confidentially bill patients so they
can pay out of pocket rather than submitting insurance paperwork to their current
employers and insurance companies. Medicaid typically gives patients a thirty-day
supply of drugs at a time, but private insurers may approve drug prescriptions for
as much as sixty days.

Adherence behaviors are also indirectly linked to death rates. An important and
significant statistic was reported in the 1997 National Vital Statistics Report with
regard to death rates. This report documented for the first time that deaths related
to HIV disease dropped from 11.1 deaths per 100,000 in 1996 to 5.9 deaths per
100,000 in 1997. In addition, this statistic also showed a significant decrease in the
presence of opportunistic infections for people with HIV. Such statistical data elu-
cidate the role of HIV medications in reducing opportunistic infections and, con-
sequently, in reducing the number of deaths associated with HIV disease or
advanced AIDS.

Financial Realities of Medication Adherence

The Gay Men’s Health Crisis, a nonprofit group in New York City, states that the
per patient cost of drugs to fight HIV/AIDS, excluding a protease inhibitor,
amounts to about $19,000 a year. This amount does not include physician visits or
routine blood tests. A New York Times article estimated that drugs for someone
with symptomatic AIDS cost about $70,000 a year. Others have reported yearly
costs that range from $84,000 to $150,000 if they are using protease inhibitors.
With such exorbitant costs, people with HIV may sometimes forgo rent payments
or food purchases in order to afford medicine. Some have even turned to the des-
perate practice of cashing in life insurance policies or to viatical settlements, where
a portion of another person’s policy is bought or sold.

Existing Resources, Interventions, and Strategies to Enhance Adherence

Because HAART is so expensive, patients require resources to access their medica-
tions and support their lifestyle and well-being. Existing resources such as AIDS
Drug Assistance Programs (ADAP) represent a vital mechanism for HIV-infected
patients to obtain HAART. In some northern states like New Jersey, a single person
can qualify for ADAP medications on the state formulary if they earn less than
$57,000 a year. ADAP also covers hepatitis C and diabetes drugs through the federal
Ryan White CARE Act. By contrast, some southern states such as North Carolina
often have long waiting lists: residents of these states who are living with HIV may
have serious problems readily accessing HIV medications. Social workers and health-care providers must know about the resource that is the Ryan White CARE Act, initially passed and funded in 1990 with its multiple parts (formerly called titles). This Act routinely undergoes Congressional reauthorization and covers care, treatment services, testing, and prevention services in large metropolitan areas where the HIV epidemic is most severe. Since HIV is a name-reportable disease, it behooves states to have an accurate reporting of cases through county health departments for funding purposes. If people living with HIV or AIDS have insurance or access to Ryan White funding, they can access HAART. Therefore, sustained dependence on HAART requires strict adherence strategies for patients and health-care providers alike.

Health-care providers, whether primary care physicians, clinical trial physician investigators or research nurses, or experienced health social workers, should inform HIV-infected patients about the importance of avoiding drug reactions, and the advantages of joining clinical drug trials in an adherent manner. To facilitate adherence health-care providers, in collaboration with their patients, need to:

- Inform client and anticipate side effects
- Simplify food requirements
- Avoid adverse drug reactions
- Reduce dose frequency and overall number of pills
- Make prescription refills accessible

To maximize adherence, social workers of patients or clients with HIV, in collaboration with their physician, need to be responsible for following strategies, such as:

- Establish client readiness to take prescriptions before first prescription is written
- Treat substance abuse and depression before starting medications
- Negotiate treatment plans that the patient understands and commits to
- Take time and multiple encounters to educate and explain therapy goals and need for adherence
- Recruit family and friends to support the treatment plan (e.g., buddies, med coaches)
Develop concrete plans for specific regimen; relate those plans to meals, daily schedules, and side effects

• Provide written schedules and pictures of medications, daily or weekly pillboxes, and alarm clocks
• Develop adherence support groups, or add adherence issues to regular agenda of support groups
• Consider pill trials

Adherence strategies that are essentially the responsibility of the health-care providers are:
• Establish trust
• Educate, inform, support, and monitor on an ongoing basis
• Provide access between visits for questions and problems
• Listen to patient(s)
• Monitor adherence
• Use positive reinforcement: share CD4 cell counts and viral load
• Use entire health-care team, including the front desk staff
• Consider impact of new diagnosis on adherence, depression, liver disease, wasting, and chemical dependency

Health-care-team-related strategies include the following:
• Provide training
• Discern why patient is not adhering to medications: Did patient forget? Is he or she drug intolerant? Are there too many pills?

Health Social Work Practice Involving AIDS and Adherence

The context of how medical care is delivered in the United States has implications for how social workers need to interface with people with HIV. Clients need support for HIV medication adherence, appointment keeping, and lifestyle adjustments. Social workers are often required to advocate for people living with HIV and people living with AIDS so that stigma is decreased and education and access
to resources, including medications, is increased. In the United States, HIV disease has disproportionately affected socially oppressed groups such as gay men, people of color, and intravenous drug users. In many ways, in the field of health care, the constantly changing challenge of HIV/AIDS has affected the shape of social work practice with these groups. For example, social work practitioners do prevention work with people at risk for HIV infection, and they work with people infected with HIV at all stages of the illness, including diagnosis, asymptomatic status, symptomatic status, advanced AIDS, and death (Linsk & Marder, 1992). Social workers affiliated with AIDS clinical trials often work with HIV-infected clients in assessing social support needs, participating in intake processes, helping to obtain medication, and encouraging subsequent adherence.

Historically, medical social work practice was based in the community and primarily addressed public health concerns like syphilis, tuberculosis, and polio. As hospitals became strategic centers of medical practice, the micro and macro system roles of medical social workers evolved. Physicians hired social workers as community liaisons and medication compliance educators to augment physicians’ work. With the advent of HIV disease, social workers were employed in both in-patient and out-patient settings, and had to stay abreast of issues related to economic concerns, demographic trends, family issues, rapidly changing medication therapies, and adherence (Lynch, Lloyd, & Fimbres, 1993; Mancoske, 1996).

Patient compliance is increasingly much researched. By 1984, only 154 articles, letters, and editorials were listed under the title heading for patient compliance in *Index Medicus*, the publication physicians frequently consult during literature searches. Throughout the 1990s, articles on adherence tripled those published up to 1984 (Lloyd, 1996). Therefore, little research on the personal and environmental variables that affected treatment adherence or adaptive coping strategies for HIV-infected people existed before the late 1990s. The public does not realize that the first rigorous research concerning adherence levels appeared in 1943. From 1943 to 1953, effective new medications appeared in the form of broad spectrum antibiotics, anti-tuberculosis drugs, such as streptomycin and isoniazid, and the phenothiazine tranquilizers for treatment of schizophrenia. Before the 1940s, medical practitioners typically regarded noncompliance as a moral issue, thereby shifting the onus of responsibility onto the patient. This cohort of health-care providers saw no indication that noncompliance might be an intriguing pattern of behavior that deserved wider exploration (Cox, 1997).
Throughout the 1970s and 1980s, many adherence study results appeared in the 
*Journal of Compliance in Health Care*. A literature search on the topic of medication 
compliance today yields seventy to one hundred new articles each month, thus 
illustrating the emphasis medical practitioners currently place on adherence. How-
ever, social work researchers were slow to conduct and publish empirical research 
on adherence, especially in the field of HIV/AIDS.

In the twenty-first century, both medical and social work practitioners have con-
ducted and published research on adherence with HAART and adherence behavior 
research continues to be presented at International AIDS conference venues that 
now occur every other year. Typically, literature has measured adherence behaviors 
by looking at assessment of biological effects, monitoring of attendance at appoint-
ments, clinical judgments, measures of drug levels, patient reactivity, patient self-
reports, and pill counts.

**Linkage of Social Support to Adherence**

Empirical studies also have linked features of social support to adherence. For 
example, a 1996 longitudinal observational study of forty-six HIV-infected men 
evaluated the prevalence of and variables associated with ARV therapy adherence 
(Singh, Squier, Sivek, & Wagener, 1996). The findings revealed that depression, psy-
chological stress, mood disturbance, and poor stress management were predictive 
of poor medication adherence.

Morse and colleagues (1991) studied adherence and social support in an experi-
mental anti-HIV drug protocol that sampled forty asymptomatic HIV seropositive 
persons who consented to participate in a double-blind, placebo-controlled trial of 
the effectiveness of AZT. Study participants were surveyed at six-month intervals 
using a self-report instrument and nurse ratings. Morse and colleagues (1991) 
learned that more adherent subjects or study participants reported that they found 
it easier to talk to their assigned study nurse and saw the study nurse as supportive, 
informative, and caring. This study concluded participants identified as “more 
compliant are better able to elicit and receive support from both personal and clin-
ical relationships” (p. 1163).

Cox (1997, 2002, 2009) studied the relative influence of social support on compli-
ance and reported on data from a compliance study embedded into both preven-
tion and treatment HIV study protocols. She found that in the 179 HIV-infected 
study participants, emotional support and being employed emerged as important 
discriminant variables.
An entire published volume of *The Journal of HIV and Social Services* was devoted to HIV adherence issues (2007, volume 6). Additional figures extracted from conference handouts over the past decade visualize the importance of adherence issues with regard to HIV/AIDS. For example, table 13.1 shows a selection of determinants of successful adherence.

**Table 13.1. Determinants of Successful Adherence**

<table>
<thead>
<tr>
<th>Access/Resources</th>
<th>Social Support</th>
<th>Adherence Technique</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistent access to medication and other treatment services</td>
<td>Personal support</td>
<td>Provider/capability building</td>
</tr>
<tr>
<td>Access to support services</td>
<td>Support for caregivers</td>
<td>Engaging client</td>
</tr>
<tr>
<td>Access to mental health and substance abuse treatment</td>
<td>Relationship with health-care provider</td>
<td>Maintaining the relationship</td>
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<tr>
<td>Stable economic resources, including housing</td>
<td>Social care: Case management, psychotherapy</td>
<td>Ensuring client understands implications of adherence</td>
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<tr>
<td></td>
<td>Support groups</td>
<td>Empowering client role in selecting therapies</td>
</tr>
<tr>
<td>Clients' cultural and health beliefs and practices</td>
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</tbody>
</table>

*Source: Linsk & Bonik (2000).*

Figure 13.1 reveals how social workers and peer counselors can effectively assist HIV-infected clients be more adherent.

**Figure 13.1. Adherence Interventions**

- **Social Worker**
  - Referrals to community agencies
  - Psychosocial assessment
  - Social work counseling
  - Transportation vouchers
  - Medication entitlements programs
  - Disseminate educational materials

- **HIV education**
  - Home visits
  - Support groups
  - “Pillboxes”

- **Peer Counselor**
  - Medication reminders
  - Appointment reminders
  - Supportive role modeling
  - Escort to medical appointments
  - Behavior change modeling
  - Escort to Narcotics Anonymous or Alcoholics Anonymous meetings
  - Substance abuse education
  - Peer counseling
Table 13.2 illustrates the multiple challenges to medication adherence, across disease factors, treatment regimen, and individual and family context.

Table 13.2. Challenges to Medication Adherence

<table>
<thead>
<tr>
<th>Disease Factors</th>
<th>Treatment Regimen</th>
<th>Individual and Family Context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronicity of illness</td>
<td>Frequency of dosing</td>
<td>Client cultural and health beliefs</td>
</tr>
<tr>
<td>Presence of symptoms</td>
<td>Convenience or inconvenience</td>
<td>Client-provider relationship</td>
</tr>
<tr>
<td>Changes in symptoms</td>
<td>Complexity or difficulty</td>
<td>Mental health or substance abuse history</td>
</tr>
<tr>
<td></td>
<td>Number of medications prescribed</td>
<td>Life stressors</td>
</tr>
<tr>
<td></td>
<td>Side effects</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Perceived efficacy of drugs</td>
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</table>

The ADHERE model is part of the trainer curriculum developed by and available through the Spectrum: Mental Health Training and Education of Social Workers Project (Tomaszewski, 2005):

Assess client knowledge and readiness

Dialogue about health beliefs

Holistic approach including environment and culture

Empower client to implement action plan

Reinforce strategies and revise as needed

Evaluate progress and resources

Evidence-Based Social Work Practice

Personal Challenges for Social Workers and Their HIV-Infected Clients. The role of the HIV/AIDS social worker who works in health settings, such as a clinical trial consortium, AIDS Service Organization (ASO), or an infectious disease (sometimes referred to as ID) clinic in a hospital or private practice is rather specialized. Infectious disease clinic social workers conduct intake assessments, advocate for clients who must have prescriptions filled, and negotiate complicated paperwork associated with insurance and drug companies and entitlement program systems. Clients present across the entire spectrum of HIV disease. Social workers counsel the newly diagnosed, those who are asymptomatic, and those who suffer with symptoms in the form of cancers, opportunistic infections, dementia,
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or accompanying mental health diagnoses. Clients are mothers, fathers, children, and grandparents. Client demographics cut across all races, ethnicities, and religious beliefs. These clients have contracted HIV through blood, breast milk, or bodily fluids. These clients may be wealthy, employed, homeless, or poor. Real-life stories about how people with HIV disease manage adherence issues may best be appreciated by reading and thinking about case vignettes of people living with HIV and AIDS. Such vignettes are presented later in this chapter.

Cultural Diversity Issues

Giddens, Ka’opua, Kaplan, and Linsk (2009), in conjunction with a RAND Corporation and Oregon State University survey, developed education and training materials related to cultural competence. Using some of their conclusions, the HIV/AIDS Spectrum Project at the National Association of Social Workers (NASW) in Washington, DC, has suggested that in order to be culturally competent social workers should discuss the following with HIV-infected clients:

• Primary cultural beliefs and values
  • Individualism versus collectivism
  • Concept of time
• Their view or conceptualization of disease
  • Their cultural beliefs about the cause and treatment of disease
• A historical context of culture and health care (that may lead to mistrust)
  • For example: Tuskegee syphilis study or refusal of blood banks to accept blood from MSM (men who have sex with men)
  • Belief (e.g., conspiracy theory) that U.S. government created AIDS to eradicate or control African Americans

According to Poindexter (2010, p. 56), in her Handbook of HIV and Social Work, “cultural competence—values, awareness, knowledge, and skills—is complex, difficult to contextualize, and even more difficult to realize in practice.” No one person holds the definitive knowledge of facts about a particular cultural group, or can fully understand the effect of cultural beliefs, values, and experiences on others. Stigma, shame, oppression, social injustice, and resource inequity are closely
related to the experiences of many people living with HIV disease and have altered their life course and viewpoints. The Health Resources and Services Administration (HRSA, a division of the U.S. Department of Health and Human Services, or DHHS) and the National Center for Cultural Competence offer a conceptual model of cultural competence in HIV (Poindexter, 2010, p. 47). The main concepts of this model suggest that practitioners will need to help people living with HIV disease across four interlocking systems: the (1) individual, (2) family, (3) organization(s), and (4) society and community.

HRSA’s (2001) framework offers nine domains to consider in assessing cultural competence: (1) values and attitudes, (2) cultural sensitivity, (3) communication, (4) policies and procedures, (5) training and staff development, (6) facility characteristics, (7) intervention and treatment model features, (8) family and community participation, and (9) monitoring, evaluation, and research. HIV medication adherence as it relates to clear communication between client and worker during social work interventions warrants special consideration.

Cultural sensitivity with respect to stigma across cultures requires special attention. Stigma, defined as a “token of disgrace, dishonor, or infamy,” is a powerful deterrent of individual freedom and self-determination. According to Poindexter (2010, p. 49), “Stigma is experienced as fear, anxiety, shame, disenfranchisement, hostility, ostracism, and a threat to survival, and it is influenced by sociocultural experiences and norms that influence disclosure, self-protection, coping behaviors, and acceptance. Stigma is perceived or experienced not only because of a person’s HIV status, but is further complicated by related issues of accepting one’s own self (sexuality, membership in an oppressed group, level of acculturation), feeling guilty about a specific lifestyle (drugs, sex work), and the need to conform for safety and support.”

Case Examples

**Vignette #1 (Jim): HIV Positive, Insured, Employed, Yet Financially Challenged to Adhere**

One of the biggest struggles HIV/AIDS social workers experience is helping insured clients manage hefty, cumulative copays. For example, a social worker employed at an infectious disease clinic in Virginia shared how she and two additional social workers spent a lot of their time working with Jim, an
employed HIV-infected male client who had ample insurance. However, although Jim had a co-insurance for his high-priced HIV medications, due to his other bills he could not afford his medications on a regular basis.

Unfortunately, Jim’s income made him ineligible for Ryan White funds or any other financial resources to assist with ongoing co-pays. In response to this insured patient’s quandary, multiple social workers spent much time and extra effort making copious phone calls on his behalf. As a result, the social workers discovered that Jim could access a drug savings card through his insurance company. It was a little-known resource that any employee at his workplace was eligible to use. Also, the infectious disease clinic social workers were able to get the sum of his co-insurance fees reduced considerably, so Jim could now afford it. Jim’s copay costs eventually dropped from several thousand dollars to $600 to $700 a month, and eventually to less than $200 a month. So, while the couple hundred dollars a month was still a burden for him with his other expenses, with his income Jim was eventually able to afford his monthly prescribed HIV medications, enabling him to be as adherent and healthy as possible.

Side Story. While the social workers made phone calls to research available options, assess the resources, and broker and advocate for the client, Jim’s physician’s assistant, another health-care team member, changed Jim’s medications to a regimen he thought would be less expensive for the client. Actually, this new prescribed regimen was not cheaper. Serendipitously, this new medication turned out to be a drug that Jim could better tolerate. The lesson learned is that finances can still greatly affect an HIV-infected person’s level of adherence, even if he has medical insurance coverage.

Questions for Reflection

1. How would you assess Jim’s initial perceptions of his health status, efficacy of treatment, and ability to adhere? How about his current perceptions?

2. How might you work with Jim regarding his financial resources?

3. How could you help Jim develop an action plan to prepare for the unexpected?

Assessment:

Skills:

Resources:
Vignette #2 (Dorothy): New HIV-Positive Diagnosis and Readiness to Adhere

Dorothy is a forty-year-old Caucasian woman, newly diagnosed with HIV disease, who was recently admitted to the hospital. Before being hospitalized for community-acquired pneumonia, Dorothy had been very healthy. She was mentally eager to obtain medical care at the infectious disease clinic, but had difficulty in physically crossing the threshold of the clinic door. Eventually, Dorothy kept her two initial clinic appointments and the social workers coached her with encouragement and provided extensive answers to her many questions about HIV. Consequently, Dorothy has remained very compliant keeping appointments and she continues to educate herself about HIV/AIDS. Fortunately, she has insurance, remains employed, and she is doing remarkably well in adhering to her HIV regimen.

Side Story. Dorothy, an example of a recently diagnosed, White, non-drug-using heterosexual client, presented with above-average fear and a lot of shame about being told she has a stigmatizing HIV disease. With proper education and time, she became a relatively low-maintenance and compliant patient after her initial drug regimen was established. The lesson learned is that clients have to be ready to comply not only with prescribed medicines, but also with medical appointments and concomitant lifestyle changes.

Questions for Reflection

1. How would you assess Dorothy’s understanding of drug therapy?
2. How would you be client centered with Dorothy in order to help reduce anxiety?
3. How might you help her appreciate the need for excellent medication adherence and appointment keeping?
4. Taking into consideration the high level of stigma Dorothy is experiencing, what does she need to consider with regard to privacy issues?

Assessment:

Skills:

Resources:
Vignette #3 (Frances): New HIV-Positive Diagnosis

Frances is a highly educated forty-year-old heterosexual Caucasian (White) woman who was recently diagnosed with HIV infection. She currently works as a bookkeeper in an accounting firm. She was formerly married and has a grown daughter and a grandchild. Her family is what keeps her motivated. Frances believes she contracted HIV from her former boyfriend. Currently, her CD4 cell count hovers around 756. Her viral load was at 6,000 the last time she was examined. These results mean that Frances is doing well and is not currently a candidate for HIV-related medications.

Upon initial assessment, the clinic health-care team learned that Frances had a history of depression. Prior to her diagnosis with HIV, her primary care physician had prescribed her some antidepressants. Fortunately, Frances has been regularly seeing a therapist for counseling and she is doing very well with antidepressants. Frances stays up to date on her immunizations, gets an annual flu shot, and complies with well woman exams, such as mammograms and Pap smears.

Side Story. As an educated White woman, Frances is an outlier in some general HIV/AIDS clinic populations, where much larger numbers of gay men and African-American men, who are either homosexual or bisexual (down low), receive care. Frances’ story is also a good example of how a stably employed client who believes in her ARV regimen, has an experienced HIV care provider, and strong social supports will likely be adherent. Frances was compliant not only with taking her meds, but also with keeping up with mental health care, attending infectious disease clinic visits, and getting her prescriptions refilled promptly. The lesson learned is that patients like Frances, when presented with consistently encouraging clinical lab results, will generally tend to be adherent with monthly appointments and health-care recommendations.

Questions for Reflection

1. Will your biopsychosocial assessment address culturally based beliefs? How so? If not, why?
2. How might you help Frances create goals that involve her, her health-care provider(s), her family, and her friends?
3. How could you help Frances identify cues or reminders to help her be adherent? (e.g., trigger the memory with meals, television programs, exercise, etc.)?

Assessment:

Skills:

Resources:

Vignette #4 (Christopher): Long-time HIV-Positive Black Gay Man Who Takes Drug Holidays

Christopher is a fifty-seven-year-old Black gay man who has never married and has been coming to the infectious disease clinic for a long time. Soon after his diagnosis, a male social worker named Mel worked with him with respect to adherence issues, when he first was put on medications. Christopher worked with Mel to address many complex issues. At first, he struggled with medication adherence, but he finally did become compliant and did well. Christopher was one of those clients who believed that his CD4 count was high enough where he could take breaks from his daily pills. He also was part of a clinical drug trial study after he was initially diagnosed. This particular clinical study allowed him to come off HIV medications once his CD4 cell count exceeded a certain point, approximately 800 cells per cubic millimeter of blood. He's now been off medications for about five years. The infectious disease clinic has followed Chris for nearly twelve years. Now he is back on meds, however, because he became sick. Christopher's CD4 count is low, and his viral load has been increasing. He is still working and therefore has medical insurance coverage.

Even though Christopher had been through the medication scenario before taking a drug holiday, he seems to be dragging his feet about starting his medication regimen again. For example, he has not called his insurance company to learn what his medication copays will be. He does not yet know if he can afford the medications the physician has selected for him. Therefore, he does not know if he needs help with securing financial assistance for his copays.

It has taken Chris several months to finally take his financial information to the infectious disease clinic social workers. He repeatedly verbalizes some reluctance to get back on meds. The social worker who sees Christopher doesn't think he wants to face what the news that his HIV disease is progress-
There is an underlying understanding that he has to take medications, otherwise "his numbers will keep dropping" and he will potentially become quite ill.

The clinic staff responded to his reticence by connecting Christopher with an advocate, or adherence coach. The social workers are concerned that Chris will now suffer medication side effects because he has been on a drug holiday for so long. Additionally, restarting a medical protocol is a painful reminder to Christopher that he is HIV positive, even though he tried to forget.

**Side Story.** Christopher’s situation brings up many of his old feelings and fears again, as well as mental health and coping issues. Chris knows he is HIV positive but as long as he was not taking pills, he did not have a constant reminder that he had a dangerous virus lying latent inside him.

In the past decade or two, much has changed on the HIV/AIDS medication front. In the late 1980s, infectious disease health-care providers only had one drug to prescribe: AZT. The next ARV to be used was DDI (didanosine, brand name Videx) followed by combination therapy (AIDS cocktail), and now HAART and many new drug classifications. The lesson learned in Chris’ scenario is that there are many factors that determine when people are started on HIV medication regimens, and on which medications they start. Routinely having one’s CD4 count, viral load, and genotype tested is a lot for an HIV-infected patient to think about.

**Questions for Reflection**

1. How would you outline possible consequences of non-adherence with Christopher?

2. How could you help Christopher see that he, and no one else, is in charge of his medication adherence? How could you use a contract?

3. How helpful might it be to ask Christopher specific questions about adherence and non-adherence? (e.g., “How many doses did you miss in the past day, two days, or week?”)

**Assessment:**

**Skills:**

**Resources:**
Vignette #5 (Mehari and Senayit): Married Couple from Ethiopia

A married couple from Ethiopia, a country in northeastern Africa, has sought services from a social worker in an HIV/AIDS clinic. Their case raises the need for practicing with cultural sensitivity and willingness to adapt interventions based on specific needs of the case. Mehari and Senayit are both HIV-positive. They started on a drug regimen when they were in their home country of Ethiopia, prior to coming to the United States as refugees. After they escaped from duress in Africa, they initiated contact with an infectious disease physician in the United States so they could keep up their drug regimen. The physician who worked with them thought they had been put on a very interesting and peculiar regimen. He decided to change the regimen. Senayit was of childbearing age and expressed to the physician that she wanted to have children. Her new regimen would need to include only medications that would not be harmful to a developing pregnancy. Keeping this in mind, and also in an effort to help the couple stay as compliant as possible, the physician constructed a regimen that they both could be on. Because they would both take the same drugs at the same time, they could support each other and provide extra accountability.

Side Story. There are many factors to consider if a woman with HIV wants to get pregnant. Many couples who are both positive (sero-concordant), or couples where one is positive and one is negative (sero-discordant), successfully give birth to HIV-negative babies. This possibility is not reached without effort, including planning, counseling, and special drug regimens. In some instances where finances are available, sperm washing is practiced if the man is HIV-positive. The lesson learned in working with this Ethiopian couple is that, despite one’s country of origin, patients’ values must be considered and communication must occur about the desire for building a family, despite being diagnosed with the now chronic condition of HIV disease. In 2010, transmission rates from mother to child were greatly reduced through prescription of nevirapine. Currently in the United States, a very small percentage of babies acquire HIV during birth or become HIV-positive through breast feeding by an HIV-positive mother (or other woman, like a wet nurse). While medical professionals in the United States encourage that babies born to HIV-positive mothers be exclusively formula fed, social workers should be aware that due to cultural factors or cost, mothers may insist on short- or long-term breast-feeding, or combination feeding.
Questions for Reflection

1. How can you incorporate ideas from Giddens and colleagues (2009) cultural competency research to assess how this couple is coping with the medication regimen?

2. How can you let the couple know you are there to support them, not judge them? How can you implement the ADHERE model (p. 368)?

3. How can you actively create an environment that encourages the development of cooperative strategies and skill building?

Assessment:

Skills:

Resources:

Vignette# 6 (Joyce): Pregnant Woman Does Not Know Her HIV-Positive Status

Joyce was first seen by health professionals at a point very late in her pregnancy. It was not until this point that she learned she was HIV-positive. She went into labor before she could be started on a medication protocol that included nevirapine. When the baby was born, he was put on triple-drug therapy. This is not typical, but in this case, there was a higher-than-usual risk of transmission. During the delivery, there was a lot of blood present, due to torn membranes. Usually, HIV-positive pregnant women who seek medical help for their pregnancies are put on meds early, to keep their viral load suppressed. Many of the women who comply with their treatment manage to keep their viral loads suppressed so that they can have vaginal deliveries of HIV-negative babies. When born, the newborns are also given medication for a period. Testing is required to make sure they remain HIV negative.

The aforementioned patients captured in each of the vignettes illustrate an array of adherence issues and treatment strategies that depend on both the clients’ stage of HIV infection and their available health insurance benefits and insurance realities. Multiple patient, provider, and contextual factors dictate the type of medications that health-care providers such as physicians prescribe to patients with HIV and how adherent their patients are upon consistent face-to-face or phone monitoring by advocates, research study nurses,
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or social work case managers. Physicians prescribe medicines, yet a supportive team of health-care providers, such as nurses, social workers, and AIDS service organization advocates/buddies/coaches, provide ongoing adherence monitoring.

Assessment:

Skills:

Resources:

Typical Prescriptions Today

As of 2012, physicians can choose from multiple classifications of drugs. For example, Atripla is dosed as one pill, once a day. When the patient disrupts this simple regimen and misses doses, he or she becomes drug resistant. Atripla is usually only given to populations that have proven to be responsible in other aspects of their life. There is an expectation that patients with a track record of continual work or a high level of education will be more adherent. It would not be suitable for a homeless patient to be on this medication, since the likelihood of adherence is low. Unfortunately, a homeless patient would be best prescribed a regimen that is less simple than one pill a day. In addition to Atripla, another frequently prescribed HIV medication is called Truvada, which is also a combination therapy drug. Once-a-day combinations create regimens that patients can easily remember; the future development of HIV/AIDS clinical trials definitely consider this reality.

Future of HIV and Adherence

To truly appreciate the intricacies of medication adherence, one must understand some basic immunology and virology as it applies to the life cycle of the HIV. A retrovirus includes a single strand of RNA that is inserted into a host cell in order to replicate. From a biological standpoint, HIV is classified as a retrovirus. It is one of only three retroviruses that are known to infect humans. Human hosts are required for HIV to replicate, and HIV does so quite differently from other viruses. HIV effectively hijacks people’s immune systems in order to replicate itself.

Sero-conversion is the term used to indicate the development of antibodies in the blood serum as a result of an infection (or immunization). With respect to HIV,
sero-conversion is the term used to describe when the person became HIV positive. If a person of average health is infected with HIV and does not take any ARV medications, he or she can likely live another seven to eleven years after HIV sero-conversion. Clinical manifestations of HIV-related symptoms and illnesses (opportunistic infections, cancers) will continue to emerge and require blood work and monitoring through diagnostic markers such as viral load and CD4 cell counts. Protocols governing when a person should start HIV medications are often amended over time and will likely continue to be an area for debate. The adage, “Hit early, hit hard,” has been challenged and health-care providers must, in concert with their HIV-positive patients, make careful decisions. The regimen of drugs constructed for each patient is dependent on whether they are asymptomatic, are HIV symptomatic, have advanced AIDS, and have other health-related factors.

There are more than thirty FDA-approved HIV ARV medications, classified as nukes (NRTIs), nonnukes (NNRTIs), or protease inhibitors. Researchers continue to study other classes of medication, such as the previously mentioned entry inhibitors, integrase inhibitors, and maturation inhibitors. No matter the drug classification, side effects are inevitable. Physicians should seriously consider prescribing them because they have been shown to have a high impact on a person’s level of adherence. While most people can adapt to short-term side effects, highly adverse events or long-term side effects require serious scrutiny.

Advancements in drug formulations have minimized the number of pills people must take, yet poor medication adherence continues to be a widespread problem. Health-care providers and social workers still need to study and observe multiple biopsychosocial factors that predict medication adherence, such as “socioeconomic status, race, gender, psychiatric conditions and cognitive functioning, family and social support networks, attitudes toward treatment, physician-patient relationships and rapport, and the complexity of treatment regimens” (Poindexter, 2010, p. 20).

Social workers can best help their HIV-infected clients be adherent to medications by being informed, supportive, and real. Clients must realize that they need to take their drugs on time, every time. Missing just a few pills can trigger drug-resistant strains of HIV to emerge, which could create a condition worse than the initial infection. And last, but not least, social workers need to stay current with community resources across federal, state, and local levels.
Web Resources
For Social Work Professionals

NASW: www.socialworkers.org


For HIV/AIDS Treatment Information

AMFAR: The American Foundation for AIDS Research: 1-800-39AMFAR (392-6237)

AIDS Treatment Data Network: 1-800-734-7104

AIDS Treatment News: 1-800-TREAT 1-2 (873-2812)

National HIV Treatment: 1-800-822-7422

For information about HIV/AIDS clinical trials conducted by NIH and the Food and Drug Administration (FDA)—approved efficacy trials, call National AIDS Clinical Trials Information Service (ACTIS): 1-800-TRIALS-A (874-2572).

For information about National HIV/AIDS resources, call AIDS Action Council (1-202-547-3101).

Gay Men’s Health Crisis (1-212-807-6655)

Mothers of AIDS Patients (1-619-234-3432)

National AIDS Information Clearinghouse (1-301-762-5111)

National AIDS Network (1-202-546-2424)

Project Inform (Alternative AIDS info) (1-800-822-7422)

Public Health Service Hotline (1-800-342-2437)

Centers for Disease Control and Prevention (1-404-639-2070)

American Red Cross (1-202-639-3223)

Guide to Social Security and Supplemental Security Income (SSI) Disability (1-800-772-1213)
References


