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Counseling Clients with HIV Disease: Assessment, Intervention, and Prevention, Mary Ann Hoffman

CHAPTER 1

Introduction: Counseling Clients with HIV Disease

> My soul is fighting my body's instinct to live.
> My body requires life; my soul, flight. There
> is no reconciling these two.
> —MENDELSON (1995, p. F1)

What the human immunodeficiency virus (HIV) has clearly shown is that health epidemics are rarely, if ever, just about disease. Epidemics thrust the specter of death, with all of its meanings and implications, into the midst of the living. In this way, diseases such as HIV profoundly affect the psychosocial, cultural, and political aspects of communities and countries. Moreover, the meaning attached to a particular disease, such as HIV, affects how those who are afflicted perceive themselves and are perceived by others. Given the enormity of the impact of HIV, it has become the most intensively studied virus in history (Greene, 1993). This worldwide pandemic has enormous implications for the health and psychosocial well-being of individuals, their family structures, and their community structures, for the delivery of psychosocial and medical services, and responses by governmental agencies. What we learn about the HIV pandemic has the potential to serve as a "blueprint" to guide responses to future health epidemics.

Although many issues that persons living with HIV disease face are similar to those faced by persons with diseases such as cancer, the complex sociocultural aspects of HIV disease and its transmission set it apart. First, HIV is transmitted through behaviors that are usually private and are often associated with norms and values of a subculture. Disclosing one's HIV status can reveal intimate aspects about one's life and can result in stigma and discrimination from others. Second, this disease is the leading cause of death in young adults and appears to be terminal. Many young people are facing a progressive, debilitating disease at the same time that their contemporaries are looking forward to a long future. Third, given the progressive nature of HIV, nearly all aspects of the individual's life are affected, including physical and emotional well-being, social supports, and life roles. Finally, many subcultures and communities have also been profoundly altered as a result of HIV disease.

HIV disease's impact on subcultures and communities in the United States can best be illustrated by examining the demographics of this epidemic. HIV disease was first observed in the United States in 1981, when a small number of gay men became ill with diseases that did not usually occur in young people (e.g., Kaposi's sarcoma) and that did not respond as expected to treatment. Initially, this epidemic primarily affected gay men. Over time, large numbers of injecting drug users also became infected. Presently, the majority of the cumulative cases of AIDS are comprised of injecting drug users and men who have sex with men (Centers for Disease Control and Prevention, 1995).

These statistics tell one story about the impact of HIV disease. Other statistics reflect different aspects of this epidemic. For example, African Americans and Latinos are disproportionately affected in AIDS cases for both men and women. The vast majority of people with AIDS are young (in their 20s to 40s), which has multiple implications about the impact of this epidemic on family structures and on lost years of productivity. Finally, AIDS cases represent just one end of the disease continuum. An additional 1.5 to 2 million Americans are estimated to have HIV disease. Moreover, recent cases of HIV infection show an increasing number of cases of heterosexual transmission (especially among women), which suggests that HIV disease now has a strong foothold in multiple populations. What these statistics show are that HIV disease affects many groups or subcultures of people in the United States, that multicultural factors, such as race and sexual orientation, are important defining variables in this epidemic, and that HIV disease, in terms of who is affected, continues to shift. These factors contribute to the psychosocial impact of HIV disease.

One of the most powerful ways to address the psychosocial aspects of this disease is through counseling interventions. In one review on positive behavior change in persons with HIV, Selwyn (1986) concluded that one predictive theme emerged: the importance of a comprehensive and ongoing counseling component. This is valuable because as HIV disease progression occurs, individuals are also undergoing major changes in numerous aspects of their lives, other than their health. Therefore, it is helpful to view HIV as a disease that has important psychosocial consequences as well as medical consequences. Counseling interventions help clients learn to live with these psychosocial consequences.

What do counseling interventions offer that other forms of support may not? Ferrara (1984), in telling of his own experience with AIDS, describes how his counselor allowed him to express his feelings in a way that his lover and friends could not. Ideally, therapists allow clients with HIV disease the opportunity to transcend the physical realms of their disease by offering an openness to any issue, feeling, or concern that allows clients to freely express and explore aspects of themselves and their lives without worrying about the impact on the therapist. Alleviating distress and helping clients find meaning in their disease by focusing on healing (e.g., emotional or spiritual wholeness), rather than curing, are important roles that counselors play. Counseling also provides a critical source of social support when other supports might be shifting, as well as education, advocacy, and the means to alter attitudes and behaviors.

HIV clinical work challenges therapists in a way that few, if any, other client concerns have done. For example, sexuality and sexual practices, drug practices, declining health and overall functioning, anticipatory grief, spirituality, and death and dying are common concerns of clients who are affected by HIV disease. Although it is not unusual to work with persons who present with concerns in one or more of these areas, what is unique about HIV disease is that many of these issues need to be assessed and addressed with a degree of urgency that does not typically direct clinical work. Because of these differences between HIV disease and other client concerns, I found that the traditional ways I had used to conceptualize client issues and dynamics were often not very effective.

To illustrate, I was trained to assess the client's history and current level of functioning and to identify a presenting concern. What I found with my clients with HIV was that crises often dictated what we addressed and that past ways of responding to stressors often had little to do with current ways of responding. Disequilibrium was common in the lives of my clients, and it frequently carried over into our work. Often, just as we moved forward on an issue, something new and urgent would occur and we would have to address that issue. Many counselors working with persons with HIV (PWHIVs) tell me that they spend much of their time responding to crises, feeling pulled in many directions, thinking about how to "fix" things, or feeling overwhelmed. In other words, they are often reacting in an anxious manner to whatever momentary challenge faces them.

Yet we are trained in our clinical work to begin by developing a therapeutic alliance as we carefully assess our client's life situation, so that we are able to truly understand what is meaningful, as well as distressing, for our client. This allows us to connect empathically with what our client is experiencing. An empathic connection provides the means of gathering accurate clinical data because it allows us access to our client's subjective experience. Often, an empathic connection is difficult to develop when we are anxious about what to ask and say, are hesitant to talk about issues such as sexuality and dying, or feel unable to understand or conceptualize what is happening for our client.

Early in my work with PWHIVs, I found little in the literature to help me in assessing and understanding the enormity of what was happening to my clients and to help me connect with them so that I might intervene in more helpful ways. I began to develop and utilize a conceptual schema to guide me in this important process. My clients truly shaped my view of what was important to explore and understand and of the value of discussing difficult issues, such as stigma, loss, and dying. I then found that the literature on HIV disease fit well with my conceptual schema and this schema eventually evolved into what I refer to now as a psychosocial model of HIV disease (Hoffman, 1991b).

Chapters 3–6 present this model, or conceptual schema, that I have found invaluable in organizing the numerous and complex aspects of the client's life that should be assessed as the first step in helping the PWHIV live the best life possible. Specifically, this model provides a conceptual framework for assessing the resources the HIV-infected person has available to help adapt to or cope with HIV disease. These include material resources, such as money and health insurance; interpersonal resources, such as partners and other family members; and psychological resources, such as self-esteem and coping skills. Although the medical and neurocognitive concerns that accompany HIV disease are important and are discussed in Chapter 2, the focus of the model I have developed is on those areas in which counselors can be most helpful—the psychosocial aspects of HIV. The model has four components: (1) defining characteristics of HIV disease (e.g., stigma, progressive course of HIV), (2) social support, (3) unique life situation (e.g., changes in life roles, emotional stage of disease), and (4) personality and demographic characteristics of the client (e.g., self-efficacy, sexual orientation, race).

Assessment leads to decisions about which interventions will be most helpful in helping clients adapt to HIV disease. Interventions, discussed in Chapters 7–12, facilitate adaptation by alleviating emotional distress and optimizing coping. Although clients adapt to HIV disease in many different ways, I have grouped adaptations into six broad areas.

These chapters explore how counselors can help clients enhance affective, cognitive, and behavioral adaptations to HIV disease, rethink life goals, explore spiritual and religious concerns, and prepare for death and the dying process. Empirical and clinical research about each of these areas is presented and then placed in a psychotherapeutic context through the use of clinical examples and suggested counseling interventions.

Counseling interventions for PWHIVs provide (1) a way to explore and address important HIV-related concerns, such as depression and fears about the dying process; (2) assistance with learning and maintaining self- and other-protective practices; and (3) a means of emotional and social support. Counseling interventions can be delivered through individual, group, family and systems, and community-based modalities.

Adaptations to HIV disease and the counseling interventions discussed in Chapters 7–12 are explored one area or topic at a time. For example, Chapter 12 explores the dying process. Because PWHIVs typically come to counseling with multiple concerns about various aspects of living with HIV disease, Chapter 13 presents comprehensive case examples that illustrate how to integrate assessment and intervention to address these multiple concerns.

Although there are parallels between clinical work with PWHIVs and clients with other concerns, unique challenges are often present. For example, HIV disease challenges us to rethink our views about disease, the dying process, typical therapy goals, the boundaries of the therapeutic relationship, and what constitutes a good therapeutic outcome. It challenges us to rethink what it means to “cure” or bring about therapeutic change. HIV disease also challenges us to consider the role that multicultural variables play in defining the therapeutic context.

Issues that shape and define the psychotherapeutic context are explored in Chapters 14–18. These chapters explore the counseling relationship, multicultural issues, ethical concerns, the counseling needs of formal and informal HIV caregivers, and the HIV-related training needs of counselors and other mental health providers.

The remainder of the book is devoted to prevention. Although the focus of prevention is typically on the uninfected, prevention is also an important aspect of the therapeutic work with PWHIVs. Two issues are pertinent: How did your client become infected, and how does this inform your clinical work? For example, a client who repeatedly took risks that led to acquiring HIV disease may also take risks in other aspects of his or her life. Understanding what this means for your client is important for the therapeutic work. Another goal of understanding risk factors for PWHIVs is helping them prevent the spread of the virus to others.

Prevention is discussed in Chapter 19 by exploring specific behaviors and attitudes that are associated with becoming HIV infected. Next, comprehensive models of prevention that address multiple risk variables are discussed in Chapter 20. Finally, in Chapter 21, prevention is discussed from the perspective of community-based interventions. This topic is included because it is difficult for most individuals to make and maintain HIV-related behavioral changes if their community or environment does not support these changes. Therefore, understanding and changing the individual and environmental contexts in which risky behaviors occur are important goals of prevention efforts.

I have attempted to write a book that is clinically useful for mental health professionals as well as scholarly. It is first and foremost a book inspired by the lives of my clients. They have touched and blessed me in sharing their journey with me and have taught me much about resilience, the will to live, and the indomitable nature of the human spirit. I have also been influenced by the insights of other counselors working with PWHIVs and have used our conversations to deepen my own thinking and understanding. I have carefully researched the empirical and clinical literature on psychosocial aspects of HIV, so that this book is informed by the work of others. The literature on HIV disease is truly interdisciplinary and encompasses the interface of knowledge from multiple fields. I have tried to bring this richness and complexity to what I write. Moreover, I addressed a void in the psychosocial writings on HIV disease by placing research in a clinical context through the use of case examples and counseling interventions. It is my experience that utilizing both research and clinical writings provides a multiple perspective that allows clinicians to be knowledgeable about HIV and its psychosocial consequences, while at the same time allowing them to connect with their clients through the power of empathy, compassion, and the therapeutic alliance.

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