CHAPTER 9:

Counseling Themes & Clinical Considerations

"Will I lose my dignity / Will someone care /
Will I wake tomorrow / From this nightmare?"

These lines from RENT, the Pulitzer prize winning musical by Jonathan Larson, evoke the emotional turbulence often accompanying a diagnosis of HIV disease.

Counseling and psychotherapy sessions may include poignant, harrowing stories filled with anger, sadness, shame, and rejection. During these same sessions, however, people living with HIV can find hope, survival, acceptance, and redemption. When working with HIV-infected persons, it is essential to be present with such pain and hope, whether it is verbalized or not.

It was the experience of the 11 Demonstration projects that certain counseling themes and clinical considerations emerged among all sites. While not an exhaustive list, this chapter highlights the common themes and considerations encountered in the Demonstration projects.

Louis' Story

Louis was in his early forties when he learned of his HIV infection. He had survived a traumatic childhood and adolescence in which he was a victim of family incest that was tolerated since the perpetrator brought money into the family. Multiple oppressions had strangled his self-esteem. He is African American, and he questioned whether his darker complexion was the reason that his mother and grandmother did not love and protect him. Aware of his same-sex sexual attractions, he was confused and troubled following the sexual assaults by his uncle and chose a path of pansexuality and prostitution during which he felt hypervigilant, empty, and vacant. Impoverished, he recalls holidays and birthdays without gifts while watching other children play. Such victimization and lack of nurturance thwarted his ability to trust. Nearing his 45th birthday, he stopped using alcohol and drugs, an addiction since his teens, and began intensive outpatient substance abuse treatment accompanied by psychotherapy—resulting in full-time employment, securing his own apartment, and several years of sobriety.

What arises as the important core issues for clients will vary, depending on their specific life circumstances. For example, clients living with families who are fearful and uninformed about HIV transmission may describe how family members demand that they use only disposable plates and utensils—to "protect" others. Lacking knowledge, the family contributes to a conclusion for the person with HIV that he/she is unclean, thereby promoting isolation and stigma.

The 11 Demonstration projects identified the following counseling themes and clinical considerations common in the provision of mental health services to people living with or affected by HIV: sense of self and self esteem; parenting; fear; disclosure; sexual orientation; loss of loved ones; adherence; Lazarus Syndrome; and spirituality.

SENSE OF SELF AND SELF-ESTEEM

Clients whose sense of self and self-esteem are not strong or fully developed may be especially vulnerable to stigma by family members and friends. For all clients, the sense of stigma and shame related to infection may foster feelings of guilt, anxiety, and self-loathing. They also may contribute to symptoms of depression. For women, there are particularly subversive effects. They may perceive that HIV will mark them as sexually undesirable, cause their partners to leave them, or result in abuse. For those who have survived sexual abuse and assault, infection with HIV further complicates the healing of one's shattered self.

PARENTING

Specifically for parents, complex personal struggles will naturally involve guilt over having become infected, having shortened time with their children, and/or leaving orphaned children—all of which may generate a permissive parenting style that impedes setting limits and discipline. As a result, parents may too readily gratify their children's wants in an effort to assuage their guilt. When HIV-infected parents become ill, it may be more difficult for them to actively parent—to discipline and provide caretaking. In such a situation, children may develop parentified behaviors and assume a caregiver role toward both the parent and younger siblings. When a parent recovers or ultimately dies, a child may find it difficult to relinquish such a role and return to a developmental stage suited to his/her age.

Maria's Story

Maria, a 22-year-old Latina, lost custody of her daughter, due to neglect relating to Maria's addiction to crack cocaine. Maria did not appear to understand the responsibilities of being a parent, but she was intent upon regaining custody of her daughter—even though her worker from Child Protective Services (CPS) thought this highly unlikely. Over the course of three years, Maria, with the help of her therapist, worked diligently on parenting skills, communication with her family, her relationship with CPS, and her substance abuse problem—in both individual and family therapy sessions. Several months ago, Maria was given custody of her daughter, and her CPS case was closed. Maria remains in treatment and currently is working on setting clear and consistent limits with her daughter, as well as issues around returning to school to get her GED.

FEAR

Fear is a reasonable and expected reaction to HIV. Clients may fear the infection and its progression. They also may fear rejection from friends, family, or co-workers when they disclose their status. As a result, they may choose not to disclose their infection, preferring to keep this a secret. This becomes especially complex for families and their children as noted above. A parent may choose to keep his/her children and the family removed from interacting with others in the extended family or in the community to protect this secret and to delay or avoid disclosing his/her status. Parents also may decide to disclose HIV-related information selectively—but only after determining criteria about who will be told.

Families that fear repercussions related to stigma may develop a boundary around the family and limit contact with extended family or the community. Such insularity may deplete the parent as he/she serves as the sole emotional link for the children and limits other potentially supportive contacts for the children. Older children may sense that a secret exists and may become suspicious regarding the nature and reason for the secret—a suspicion that the parent is unwell and has HIV.

...a reasonable and expected reaction...

DISCLOSURE

Disclosure can present its own turbulent struggle. Disclosing one's HIV status may contribute to strong feelings of rejection and isolation, or it may facilitate finding support and lessening one's burden. The risk and complexity of disclosing one's status is especially weighty for those in intimate relationships or those attempting to establish such a connection.

For many, disclosure becomes a complicated dilemma that may best be handled through discussion in counseling sessions. Therapists can encourage clients to discuss their own emotional responses to HIV and their beliefs about reactions from others. This will assist clients in determining if disclosure needs to occur at all. For clients whose boundaries in relationships frequently blur and may become enmeshed with others, there may be benefits if clients can learn to protect their privacy and limit disclosure to prevent emotional upset.

SEXUAL ORIENTATION

Gay, lesbian, or bisexual clients may feel guilt or shame as a result of society's negative and distorted beliefs about homosexuality. Some may even believe that their infection is a "punishment" for being gay. Many people remember when HIV was initially identified as gay-related immunodeficiency disease (GRID), and for some, disclosure of one's HIV-positive status is complicated by whether others will automatically assume they are gay. Many heterosexual individuals do not want to risk what they view as a societal stigma, and many gay individuals are not prepared to publicly acknowledge their sexual orientation. Such reactions may damage the client's sense of self and lead to low self-esteem and isolation. Therapeutic work with issues of sexual orientation requires specific knowledge, sensitivity, an appreciation of the effects of homophobia, and an affirming attitude.

LOSS OF LOVED ONES

In communities where there have been a great number of deaths associated with AIDS, such as in the gay community and now more commonly in impoverished communities of color, there is a toll from the trauma of multiple deaths that complicates grieving. Multiple losses is a common theme for many people living with or affected by HIV. For clients not infected with HIV who belong to communities hard hit by HIV's impact, such as older gay men and long-standing injection drug users, there may be survivor guilt merely from still being alive while close friends and associates have died from AIDS. Work in this area involves an acknowledgment of a client's loss. For HIV-infected persons, the reactions to multiple deaths may be naturally compounded by fear of HIV's progression for themselves.

Alan's Story

Alan had cared for his partner, Jerome, for a year after symptoms of HIV-associated dementia appeared and created drastic changes in Jerome's personality. Alan speaks of how he tenderly cared for Jerome until his death. When faced only a month later with his father's death, he describes how he felt numb and disconnected. Further complicating his grieving was the earlier death of a family member and several deaths of friends. Alan's therapist helped him reflect on his relationship with Jerome and strive for reconciliation. His coping capacity was enhanced after grief work was incorporated into several counseling sessions.

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ADHERENCE

The interplay between adherence to medication and treatment regimes, clients' psychological and emotional state, and their health is critically linked. The greater use of protease inhibitor treatment, for example, has contributed to renewed health for some with advanced HIV infection and a longer period without disease progression for those with asymptomatic HIV infection. Managing the doses and administration of these drugs requires a significant level of commitment from providers and clients as there are risks when medications are not taken properly. Realistic fears about adverse effects, reluctance to acknowledge one's need for medications, and avoidance of HIV itself may affect one's emotional reaction to initiating protease inhibitor treatment. For many to cope, HIV itself needs to be put out of their minds as they continue to live from day-to-day. However, beginning protease inhibitor therapy becomes a frequent reminder of their HIV infection.

LAZARUS SYNDROME

A central psychological theme that accompanies protease inhibitor therapy is the emergence of the "Lazarus Syndrome," in which persons with advanced HIV infection notice a significant improvement in the medical indicators of immune system function and HIV viral load. With improved health, they may experience varying degrees of increased energy and fewer immobilizing symptoms. For many, this is a relief and becomes a welcome opportunity to reconstruct their lives. For others, there may be a sense of existential angst and the development of symptoms of depression, such as lethargy, isolation, and sadness, because they already had prepared to die.

Edward's Story

Edward had begun treatment with protease inhibitors in May of the previous year. His response to the medications was excellent, as his viral load became undetectable and his T-cells increased. Edward had survived the deaths of practically everyone else he knew who had been infected with HIV. When he considered his survival, he was consumed with the question, "Why me?" Diagnosed with an AIDS-defining illness in the 1980s, Edward expected a trend of deterioration and death. However, protease inhibitor treatment revised that assumption. Edward was called upon to confront the task of life reconstruction complicated by survivor guilt and the developmental dysynchrony that comes from not progressing to the next stage he was expecting. Edward seemed ashamed that he was not happier and more pleased by his improved health. Treatment, consisting of both an increase in an anti-depressant medication and insight-oriented psychotherapy with a focus on loss, helped Edward to re-invest himself in life and make a trial return to work.

SPIRITUALITY

Attending to the spiritual aspect of clients' coping may prove helpful in stimulating resources for living, as well as assisting clients to extract and integrate meaning into their experiences of living with HIV. Provider insensitivity to the client's spiritual background and belief system can erect an insurmountable barrier to treatment.

Mental health providers may need to increase their own comfort with religious traditions and spiritual practices as clients may not wish to meet with a separate pastoral counselor. Counselors and therapists may consider integrating spiritual issues into their counseling work by exploring the meaning of faith, as it relates to the client, and the purpose it serves in the client's life. Linked to this is the need for providers to remain open to clients' belief systems—especially when clients' beliefs are not reflective of their own religious traditions (specifically for individuals among recent immigrant groups and communities of color) and utilize the client as a resource.

By incorporating concepts of faith, strength, and redemption (as determined and described by the client) into the therapeutic process, mental health providers may find that this approach offers comfort and solace to clients, especially those experiencing increasing health complications or those facing death. By being willing to explore the topic of spirituality or faith, mental health providers can begin to discuss ways to help clients integrate their spirituality and HIV status into their lives more effectively.