HIV Mental Health for the 21st Century

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Loss and grieving echo throughout the course of HIV/AIDS. For persons infected and for those who care for them, including the mental health provider, one of the greatest challenges is the relationship we are invited to make with loss.

The instant the client receives test results showing infection, the client becomes a participant in an ongoing grieving process. This individual immediately grieves the loss of his or her HIV-negative status. Now he or she is living with HIV, and the future, as previously imagined, is changed forever. Concurrently, the individual has to begin the process of integrating the new status—"HIV-positive”—into his or her psychological world.

As the illness progresses, there is a loss of the previous, healthier identity. Each new set of symptoms forces adaptation to the new identity—"symptomatic," "AIDS patient."

For the provider, too, the feelings of loss begin when we first meet the HIV-positive client. During the course of the therapeutic relationship, we shall always be aware that the client has a chronic, life-threatening illness. The awareness of potential loss will, consciously or unconsciously, prompt memories of our own earlier losses, and sometimes we may act out of these unconscious reverberations. We may offer the client health
education, for example, instead of working toward processing his or her feelings, or we may neglect to follow up with a very sick patient who misses sessions, hiding (perhaps even from ourselves) our feeling of relief that we do not need to be with the person's pain. Later in the client's life, we may avoid hospital visits, rationalizing that we are “too busy.”

Our work with loss and grieving in the area of HIV/AIDS is further complicated by our society's unwillingness to respect feelings of loss and bereavement.

The work described in this chapter is revolutionary to the dominant culture, which focuses on the here and now and denies the reality of death. In the last half of this century Americans have become less familiar with the dying process because it has been removed from their direct experience.

In the first half of the 20th century dying was a family affair. Large extended families helped care for dying family members, relatives bathed the corpse, and wakes were conducted in homes. Technological “advances” and family mobility, however, have changed this. Just as childbirth has been relegated to medical staff in hospital settings, so has dying. Only those who are proactive in their choice to experience birth or death in their homes, or in special care centers set up for these purposes, have access to the full emotional experience that these transitional events can evoke.

Now, from hospital to burial, the dying process is essentially controlled by professional specialists who “spare” those closest to the dying person the pain of attending to him or her in intimate surroundings. Physicians sometimes prescribe tranquilizers to assist family members in coping with the dying and death of their loved ones. Bodies are neatly packaged in funeral homes. Society which deems death an “event,” expects mourners to resolve their feelings quickly and return to normal home and work lives within days or, at most, weeks. (See Nuland [1993] and Mitford [1963] for description and comment on dying and death.)

While we hand over dying-related responsibilities to the medical profession, physicians and other medical providers often mirror society’s death anxiety.

Deidre had signed a Living Will specific to persons with AIDS that included her directive not to be kept alive by machines. When she was brought to an emergency room dying of AIDS and with a collapsed lung, she was immediately intubated because the physician did not read her chart, which was available to him and clearly specified her wishes.
Unfortunately, Deidre’s situation is common. In medicine, as in society, death is considered the enemy. “I’ve lost the patient” is medical jargon that personalizes the death, implying unrealistic control over life. One reason medical providers are uncomfortable with AIDS care is that all clients eventually “don’t make it,” in doctors’ language.

While these practices have evolved from the exigencies of modern life, we pay an emotional price for them. Essential grief work facilitated by active participation in the dying and mourning process is now neglected and lost. When grieving is suppressed or interrupted, the losses are likely to go unmourned, complicating bereavement. More will be said about this later.

**Background Reading**

Many of the pioneers of psychotherapy have considered issues of loss and their effect on personality development.

Freud’s paper *Mourning and Melancholia* (1917/1959) considers the fundamental process in melancholia (depression) to be loss of the early love object and the failure of the person to establish the lost loved object within its ego. Bowlby’s attachment theory (1969) explains that attachments are formed from a need for security and safety. His (1970/1979) work on separation and loss within the family informs us that “many of the troubles we are called upon to treat in our patients are to be traced, at least in part, to a separation or a loss that occurred either recently or at some earlier period in life” (81). Melanie Klein (1934/1948b) considers the infant’s loss of the breast to be “the first fundamental external loss of a real love object” (307), and she states that the infant mourns this loss. In her writings on mourning and depression (1940/1948a) Klein further hypothesizes that “this early mourning is revived whenever grief is experienced in later life” (311).

*The Denial of Death* (1973) describes Becker’s thesis that “the idea of death, the fear of it, haunts the human animal like nothing else; it is a mainspring of human activity — activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man” (ix). It is suggested that readers follow Becker’s book with Yalom’s *Existential Psychotherapy* (1980), which discusses a dynamic approach to focusing on patient’s concerns about existence.

To educate health care professionals to become more familiar with the needs, concerns, and anxieties of individuals who face the end of their
lives, Kubler-Ross wrote *On Death and Dying* (1969). Her five stages of mourning—denial, anger, bargaining, depression and acceptance—were originally thought to be linear, but it is now recognized that people loop around and in and out of these stages as the grief process unfolds. The stages serve as a guide; it is not clinically sound to expect a client to follow any theoretical grief pattern in a predetermined fashion.

Worden (1982) outlines four tasks of mourning: accepting the reality of the loss, experiencing the pain of grief, adjusting to an environment from which the deceased is missing, and withdrawing emotional energy from the person or object of loss in order to reinvest in life.

Rando (1984) describes three psychological reactions to normal grief: avoidance, confrontation, and reestablishment. She states that these reactions are typical yet not universal and that the griever will probably move back and forth among them.

In *Life Is Goodbye, Life Is Hello: Grieving Well Through All Kinds of Loss* (1982), Bozarth-Campbell identifies three stages in the processing of loss: shock, the feeling stages (fear, guilt, rage, sadness), and well-being. While we are typically not taught to grieve well, either by word or example, Bozarth-Campbell’s work normalizes what has become for many the very foreign, frightening work of grieving. She also recognizes that people have different styles of grieving and that some use several styles in different stages of the mourning process.

Lindemann (1944) identified grief as work, describing the emotional and physical energy required to do it. My experience has been that the most emotional presence and investment is in the middle “stages” of grief. Kubler-Ross’s (1969) depression, Worden’s (1982) experiencing the pain of the loss, Rando’s (1984) confrontation, and Bozarth-Campbell’s (1982) feeling stages all make heavy physical, psychological, and spiritual demands. There is a natural tendency for clients and providers to skip over this portion of the grief work, either consciously or unconsciously. Providers must be equipped to notice when this is happening and make the client aware. When the client is experiencing the pain, we need mostly to “just stand there,” as Robert Barret so eloquently describes in his chapter on countertransference.

**My Clinical Work**

For the past four years, I have provided psychotherapy to HIV-infected and affected persons who are clients at a methadone maintenance program
at Montefiore Medical Center in the Bronx. Primary care and mental health services are integrated into the program, on site. The majority of my clients are Latino and African American, and all have histories of injection drug use. Some continue using substances such as alcohol, cocaine, or pills while on methadone.

My work with colleagues in this setting inspired the creation of a comprehensive assessment and treatment model called the Model of Multiple Oppression (Millan & Elia, in press). The model acknowledges the themes of loss, grief, and rage that are predominant in our clients' lives. Multiply oppressed persons with HIV/AIDS have suffered traumatic and abusive childhoods; they are people of color, living in poverty, addicted to drugs, struggling with gender roles and often with their sexual orientations in culturally and familially hostile settings. Most are suffering from chronic posttraumatic stress.

These multiple oppressions render the client multiply stigmatized, which causes self-hatred, pervasive secret keeping, and, often, despair from all of the unexpressed loss. Many clients hide parts of themselves from their families, others are ostracized from them, and some even choose to disassociate from those they love. One of the most therapeutic aspects of group treatment for the multiply oppressed person with HIV/AIDS is the opportunity it offers for the individual to expose all of his or her "labels" and to be whole in a "family" that does not impose judgment.

When Rhonda died of AIDS, several members of her HIV support group attended her funeral. There they were confronted by Rhonda's siblings, who accused them of drawing their sister into the street life and of killing her.

Harold, an African-American bisexual man, never used needles. He knew that when his wife discovered he had AIDS she would also learn about his "double life."

Jose instructed his teenage sons not to tell their friends that their father has AIDS for fear that those friends will abandon them.

These anecdotes, and virtually every story I have heard from my Bronx clients, are about loss and grief, be it expressed or unexpressed.

The provider working with the multiply oppressed person with HIV/AIDS must envision the client's illness within the context of the person's whole life situation. At times the client may not be able to focus on the loss issues relevant to HIV/AIDS because he or she is attending to other life and death concerns, such as a welfare snag, recovery from addiction,
or violence in his or her neighborhood or home. The practitioner who wants to “work on the AIDS issues” may become frustrated. But I have learned that work in one area affects the whole person. The most therapeutic thing we can offer the multiply oppressed person is love and respect. Even the most difficult clients respond favorably to this.

**Tools for Clinical Practice**

I offer these observations on loss and grief in HIV/AIDS clients:

- *The social isolation of our HIV/AIDS clients, which stems mostly from stigma, is a psychological death experience that precedes the physical death.*

  A colleague was explaining our work with HIV-infected injecting drug users to a medical doctor who remarked, “It would be wonderful if these skillful interventions could be used with cancer patients, who would really benefit from them.” The implication of this remark, and other versions of it, is that our patients are unresponsive to and undeserving of quality care. No such judgments are made regarding patients, even those terminally ill, with other conditions, such as cancer. So the remark about AIDS patients reveals unspoken stigmatization: that they come from an underclass or brought the illness upon themselves, that they do not deserve or do not want help with their suffering, and that they are content to have less than meaningful lives or deaths. The truth is that most people welcome compassionate care, and many are open to learning about the benefits of dealing with death more candidly.

  Another stigmatizing factor is fear of contagion, despite knowledge of routes of transmission. Karen had a close relationship with her two nieces, ages three and five, until she told her brother she is HIV-positive. Since then she has been able to talk with them only on the phone. Herbie notices that his mother keeps separate dishes for his HIV-infected cousin when he comes to eat there. These behaviors stigmatize clients even more because their own families seem to be rejecting them.

  Once the feeling of stigma becomes internalized, patients may isolate themselves from others, leaving their apartments only to complete the bare minimum of chores. One patient described feel-
ing like one big germ when she is around family members, who have stopped touching her since learning she is HIV-positive.

Another man, who has ten siblings and dozens of nieces and nephews, spent five days in his apartment without hearing from anyone. He emerged only to express his despair upon realizing he could have been dead and no one would have known.

• **Facing death, clients' behavior varies greatly, ranging from denial or avoidance to direct confrontation and acceptance.**

Most people admit that they do not really know how they would react if suddenly faced with a terminal diagnosis. While much has been written about normal and pathological grief patterns, it is clear that no two people grieve exactly alike. Some clients remain in denial until they are in end-stage AIDS, when they are almost forced to acknowledge directly their approaching deaths. Others talk openly about their fears from the time they first discover they are HIV-positive.

It is necessary for the provider to respect the client's defenses while at the same time helping the person to face the reality of his or her condition in the moment. A client's ability to handle the situation varies considerably, and it is influenced by several factors. These include but are not limited to the client's general coping abilities, sobriety, mental status, developmental stage, sense of shame, and belief system.

Related to this is the subject of disclosure. My experience has been that it is most helpful for clients to disclose their status as early as possible to immediate family members for two main reasons: First, for some clients the diagnosis becomes real only when they share it. Second, it affords everyone involved, including the client, the opportunity to begin the process of anticipatory grieving (see Fulton & Fulton, 1971). Anticipatory grieving offers people the chance to work out unfinished business. While it does not eliminate grief later, it can soften the blow because the process of integrating the loss has occurred gradually.

While the client struggles with whom to tell, the provider's anxiety can be great. Clients in some form of denial about their illnesses may be unable to tell lovers that they have tested positive. While it is tempting to rebuke clients for not being honest about their illnesses, it is not therapeutic. It is, however, imperative to work with the reluctance.
The client's religious or spiritual belief system is an important influence on outlook about death.

Some clients fear death and even punishment for their perceived transgressions against God and humankind. Others may believe in reincarnation, while some practice religions that proclaim the presence of evil spirits within them.

There are many variations on these themes, and we must be open to learning about the client's family belief system from a somewhat historical perspective. It is just as important, though, to assess current "spiritual status" (Elia & Cherry, 1996). An assessment should include these questions:

— What is the client's current view of God, or the transcendent?
— If the childhood religion has been abandoned, how does the client feel about that?
— Has being HIV-positive or having AIDS affected the client's spiritual development? If so, how?

For our part, we must ask how comfortable we are talking about all of this. What effect do our own beliefs have on client care? My experience is that there is a natural gravitation to the spiritual dimension of life for those infected and affected by HIV/AIDS. Providers must be open to exploring this dimension with clients throughout their journey with AIDS. In fact, it is sometimes necessary to raise the topic when clients do not because the clients may believe it is something the provider would not understand. This is especially true when the provider is from a different culture. See the preceding chapter for more information on spirituality.

Mourning is the outward expression of grieving, and mourning practices are heavily influenced by culture and class.

The practitioner must remain open to different mourning patterns and must recognize the validity of different grieving styles. This is especially important for those working cross-culturally. Jacqueline Kennedy was admired for the reserved manner she displayed during the funeral of her assassinated husband. Her Anglo ethnicity and her socioeconomic class helped define this mourning pattern. If she had thrown herself on top of the coffin, sobbing, people would have felt she was "falling apart" or "having a breakdown." In most Latin cultures, however, a more demonstrative display of emotion would have been totally understood.
and fully expected. In some African countries mourners wear white in celebration of the deceased person passing over into a better world, while Italians may wear black for a year to show respect for their dead. A part of mourning is ritual, and people creatively develop rituals as a means of coping. The Bronx has many graffiti-style memorial walls, poignantly expressing the grief of youth who have lost their peers to AIDS and to the streets. Like the AIDS Memorial Quilt or the Vietnam Memorial, these walls are their attempt to display publicly their otherwise disenfranchised grief (Doka, 1989), as society does not really care about the body count of so many young people of color in the inner cities.

• **AIDS-related grief is disenfranchised grief.**

  Disenfranchised grief (Doka, 1989) is grief that is not openly acknowledged by the griever, is not socially sanctioned, and is not publicly mourned. When a gay man loses his lover to AIDS, he cannot always talk openly about the loss because society does not recognize gay and lesbian relationships as valid. If the person has not “come out” to those close to him, such as coworkers or even family members, there is no opportunity to mourn openly. Many in the gay community have described feeling as if they are living in their own private hells, burying friend upon friend, while society at large appears to be oblivious to their holocaust. Similarly, in communities where there is a high percentage of the multiply oppressed infected, whole families are being eliminated by the virus.

  The case of Matilda both illustrates the way to avoid disenfranchised grief in an institutional setting and reveals the role of the practitioner in actually promoting disenfranchised grief.

  Matilda is HIV-positive and is the mother of two daughters, ages one and eight years. I had met with her about a half dozen times when I learned she had become pregnant by her abusive alcoholic boyfriend from whom she was trying to separate. Matilda stopped coming to see me, despite my efforts to contact her, and she decided to keep the baby.

  At five months she went into labor and gave birth to a boy, whom she named Joey, after his father. The baby died within a few minutes after delivery. A week after the baby’s funeral Matilda called for an appointment.

  Upon her arrival, Matilda immediately began to tell her story.
She described having had the opportunity to hold her baby, to baptize her baby, to name her baby, and to bury her baby in a formal funeral service, which she attended alone. She also explained the loss to her older daughter and brought her to visit the gravesite. Fortunately for Matilda, the hospital staff where she delivered her baby was sensitive to the loss that she was experiencing as a mother. The rituals they performed with her from birth to death prevented the loss from becoming disenfranchised. Matilda was encouraged to acknowledge the loss and to mourn it publicly.

I asked Matilda what had kept her away from therapy during the pregnancy. She stated that she felt ashamed and thought that I was disappointed that she became pregnant. She did not want to think about an abortion, and she felt that if we met she would be encouraged to weigh all of her options. Although she said that she didn’t think I would judge her, I believe she knew intuitively that I did not sanction her relationship with her boyfriend or her pregnancy, since she is HIV-positive. As a therapist, it is my job to monitor constantly my feelings toward my clients and to discuss countertransference with a supervisor. Matilda had sensed my judgment, which subtly caused her grief experience with me to become disenfranchised.

• Unmourned loss complicates bereavement.

Old losses that have gone unmourned have an effect on the current grief process of the client. While no one can completely mourn all of his or her losses, bereavement is most apt to become complicated when major losses have not been addressed.

The case of Angela demonstrates the powerful effect that unmourned losses can have on the client’s life choices and establishes the need to document the client’s loss history. At twenty-seven years of age, Angela has been HIV-positive for four years. Though she was raised in foster homes, Angela is certain that she became infected by her biological mother, who died two years ago, since they shared needles. Angela’s two children have been taken away from her, though she is currently working hard at recovery to get them back. Three months ago her sister Maria—“she was like a real mother to me”—died from AIDS.

Angela lives with her boyfriend, Robert, whom she has not told her HIV status, but she thinks “he must know.” Angela tells
me they are thinking about having a child. For the first time she also reveals the existence of a daughter, taken from her at birth twelve years ago and not seen since. Moreover, Angela’s childhood was fraught with early losses that led to substance abuse by the age of nine. Her ability to grieve adequately now is severely limited by this psychosocial history.

My task is to help Angela prioritize her grief work. At the very least she has not mourned her relationship with her mother or the loss of her oldest child. In our sessions she cries often for her younger children in foster care and for her sister Maria. While it will not be possible for Angela to grieve all of her losses completely, it may not be necessary. Her relationship with her mother is the seedbed for much of her pain. My focus will be to help Angela to come to terms with this relationship and to help her make sense out of her seemingly chaotic life choices. Early in the work Angela announced, “Gee, I wonder if the reason I want a baby now is to make up for the one I lost twelve years ago.”

• Because grief work is so hard, many people use and abuse substances in order to self-medicate the feelings that are associated with loss.

It is my belief that the psychological etiology of much drug addiction is unmourned loss. Substance use complicates bereavement because the person’s psychological, emotional, and spiritual development is arrested. Sometimes people are prescribed drugs during the week leading up to and including the funeral of a loved one. This puts the necessary emotional tasks on hold, but it does not eliminate them.

The case of Leslie demonstrates how clients often learn to self-medicate from their families, by observing as children the way painful feelings such as grief are handled.

Leslie was a methadone patient who died from AIDS at age thirty-three, leaving behind a live-in boyfriend who “didn’t know why she was always sick” and two children, a boy, ten, and a girl, eight. Leslie had two brothers and a sister, all of whom had died from AIDS, and she felt unable to tell her children that she was dying. Even when in the hospital bed, having wasted away to eighty pounds, she insisted on telling them that she would be home soon. Having done some work with the family, I was invited to the funeral, where I encountered Leslie’s father, out-
side drinking beer with Leslie’s uncles. Inside, her mother explained that her husband “was taking the death hard.”

- Bereavement overload is an issue for those infected and affected by HIV/AIDS.

Johnny has AIDS and lives in a residential hotel in New York City. It is typical of those facilities that a city agency fills with persons with AIDS. Johnny describes the difficulty of seeing bodies carried out of his hotel on a weekly basis.

Neil is a fifty-year-old Vietnam veteran, who lost many of his friends in the Vietnam War. He is now losing many to the virus. When his cousin Rosie died last month, Neil stated that he simply could not attend any more funerals, including hers.

Irma comes into the clinic looking exhausted and very sad. Three of her four adult children have died of AIDS. She states that she is having trouble sleeping and that she is feeling depressed.

Thomas is a forty-five-year-old gay man who has lost almost his entire friendship circle to AIDS. He is HIV-negative.

All these people are coping with bereavement overload (Kastenbaum, 1969), a term originally coined to describe the plight of the elderly person whose loved ones all die and leave (usually) her behind. AIDS has made the concept applicable to people of all ages. In communities where the epidemic is rampant, infected and affected people have been traumatized by the way AIDS has ravaged their lives. When there is a steady onslaught of fresh loss, the grieving process is constantly interrupted, and it is not possible to grieve each loss completely.

The grieving process requires the client to work on many levels concurrently. In the case of an HIV-infected man who loses his wife to AIDS, his main tasks are to deal with the guilt he has from infecting his wife, to mourn the loss of his wife in order to reestablish himself as a single man, and to organize his emotions around his own terminal condition. There are also myriad secondary losses that will require attention. The person with AIDS is often juggling more than one major life loss simultaneously, and he or she may not understand that the work is naturally overwhelming. Especially in cases like this, I have found it helpful to provide the client with information about the normalcy of what he or she is feeling. This is not false reassurance but instead an effort to help the client to feel “less crazy.”
While some unresolved loss is inevitable, it appears that, with treatment, "healthy enough" resolution is generally possible. In working with clients who are faced with massive bereavement, practitioners can use some of the same clinical skills they apply to survivors of trauma in general: Give clients the opportunity to talk about their feelings in a way that gives them some control of the process, because the profundity of the loss makes them feel so out of control; offer clients therapy sessions more than once a week when necessary; use psychoeducation to normalize the grief process, helping clients who may think they are "losing their minds" because they are overwhelmed with grief; and encourage group therapy since the hard work of grieving always seems lighter when it is shared.

• *The caregiver is also subject to bereavement overload.*

To remain effective, we must learn to deal with the accumulated grief. Competent work with the terminally ill requires the clinician to come to terms with his or her own mortality and with death in general. Because the work is so demanding emotionally, spiritually, and psychologically, it is essential for the caregiver to have ongoing supervision. Staff support groups that are offered in a politically safe atmosphere also prevent the negative effects of massive bereavement. Memorial services provide much-needed ritual for provider and client alike.

• *The provider working with PWAs must ultimately be capable of talking about death in a direct manner.*

When I first began working with people with HIV/AIDS, I was fearful and anxious as I grappled with constant change and complete loss of control. I was dragged kicking and screaming, by supervisors and colleagues, through the myriad emotions that the work elicits. This labor of love has changed my life.

It is a very unique and powerful experience to be invited into a person's life when he or she is HIV-positive or has AIDS. The relationship makes both client and provider very vulnerable, as a real connection is encouraged despite the ever-present knowledge that death is near. This connection that we feel with our clients, and they with us, is not explainable solely in psychological terms but instead feels spiritual to me. The provider and client are on equal footing, both human, both mortal.

Working with people with AIDS has allowed me to become comfortable "enough" with death to talk about it in a direct way.
This may be what clients most appreciate about our presence in their lives. The ramifications of being involved with clients on this level are really quite enormous, and the work has afforded me the opportunity to grow right alongside them. Together we have faced our anger, fears, doubts, and insecurities about how to handle the real stuff of life. Through loss and grief, I feel we have experienced genuine healing.

REFERENCES

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