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Keywords

HIV, grief, bereavement, mental health

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Melissa Zeligman and Andrew William Wood

For people living with HIV/AIDS, grief and bereavement typically refer to the loss of life felt in the HIV community. However, changes in HIV treatments allow care providers to view HIV grief in a way that considers physical, social, and emotional loss, as well as a loss of the life they had previously pictured for themselves. Kübler-Ross's (1969) model of bereavement is presented as a way to conceptualize clients living with HIV who are dealing with grief and bereavement. In addition, popular bereavement counseling approaches relevant to clients with HIV are discussed, and a case illustration is provided.

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Thirty-five million people are currently living with HIV and AIDS worldwide, with an estimated 1.15 million of these individuals residing in the United States (Centers for Disease Control and Prevention [CDC], 2013). It is estimated that 24% of those living with HIV are adults over the age of 50 years (CDC, 2008). From the time HIV and AIDS were first recognized in 1981, the disease has claimed more than 636,000 lives in the United States alone (CDC, 2013). With mortality rates being so prominent, clinical mental health interventions have prioritized addressing grief associated with loss of life and coming to terms with imminent death (Britton, 2000; Maguire, McNally, Britton, Werth, & Borges, 2008). However, since its discovery, the treatment of HIV/AIDS has advanced significantly.

The introduction of highly active antiretroviral therapy (HAART) has allowed people living with HIV/AIDS (PLWHA) who previously prepared

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for end-of-life concerns, including anxiety over facing death (Hintze, Templer, Cappelletty, & Frederick, 1993), to often view their illness as more manageable and chronic (Maguire et al., 2008). The changing face of the disease demands that mental health practitioners take on new approaches in working with PLWHA and potentially conceptualize HIV grief in a way that includes loss of former self in addition to loss of life. Despite medical advances changing the disease from terminal to chronic, PLWHA are not sheltered from a myriad of mental health concerns (e.g., AIDS-related bereavement, chronic sorrow) following such a diagnosis (Roos, 2013; Sikkema et al., 2006).

AIDS-related bereavement is traditionally presented in a way that examines the emotional impact of losing members of support networks to HIV/AIDS (Ickovics, Druley, Morrill, Grigorenko, & Rodin, 1998; Sikkema et al., 2006). In addition to bereavement associated with loss of life, the evolution of HIV may more accurately include bereavement over the loss of a former self (e.g., former abilities, former perception of the world) following an HIV diagnosis along with the reality of now living with a chronic illness (Roos, 2013; Weingarten, 2013). The sense of bereavement over the loss of self that follows a chronic illness experience—called *chronic sorrow*—has most notably been used to reference the experiences of those caring for children with disabilities (e.g., Gordon, 2009; Olhansky, 1962) and fails to include those living with HIV. Furthermore, grief counseling as a whole, as well as popular bereavement theories (e.g., Kübler-Ross's 1969, model), has regularly neglected to consider the mental health needs of PLWHA (Peters, 2013).

The need to address bereavement issues in PLWHA is perhaps more essential given the physical and behavioral consequences associated with this type of grief. For example, bereavement may increase the likelihood of risky sexual behaviors because of issues of stigma and a lack of adequate social support (Villa & Demmer, 2005). In addition, feelings of worthlessness and isolation that emerge from HIV-related grief can lead to not prioritizing safe sexual practices or failing to consider additional health consequences (Villa & Demmer, 2005). Bereavement concerns can further influence one's ability to be adherent to a medication regimen, because it is tempting to avoid taking medication in order to avoid living with HIV (Brion, Menke, & Kimball, 2013). Finally, PLWHA who are unable to effectively deal with their grief are more likely to show greater CD4 cell loss (i.e., the cell responsible for protecting the body from infection) over time, leading to increased immune suppression and a decrease in overall health (Goforth, Lowery, Cutson, Kenedi, & Cohen, 2009).

To this extent, the purpose of this article is to illustrate how the process of grief and bereavement has changed for PLWHA as the disease itself has progressed, as well as how Kübler-Ross's (1969) model of bereavement can be adapted to conceptualize grief with this population. Specifically, we provide

(a) details on the presence of loss and bereavement in the lives of PLWHA, (b) an overview of Kübler-Ross's model of bereavement and how it can be adapted for PLWHA, (c) complicating factors to HIV grief, and (d) clinical implications for working with adults living with HIV on grief issues. A case illustration is provided to tie these points together.

HIV AND BEREAVEMENT

Bereavement researchers (e.g., Ickovics et al., 1998) have focused almost exclusively on the loss of a spouse or child. Later, incorporating the loss felt in social networks, such as the loss of life experienced in the HIV community, came into focus. Today, HIV bereavement is most often conceptualized through the repetitive loss of life experienced by those in the HIV community (Sikkema, Kochman, DiFranceisco, Kelly, & Hoffmann, 2003). This conceptualization of grief continues to be fitting given that nearly 80% of those living with HIV have experienced multiple losses of loved ones to the disease (Sikkema et al., 2003). Viewing HIV bereavement from a loss-of-life standpoint continues to be relevant; however, medical advances suggest that bereavement also includes grief associated with HIV diagnosis and a perceived loss that comes from such a diagnosis (e.g., loss of former self). In interviews with homeless men living with HIV, Meris (2008) found that experiences of grief encompassed more than mourning the loss of life seen in the HIV community and included mourning the loss of a former physical, emotional, and mental self.

A loss of self that results from a diagnosis of chronic illness is often referred to as chronic sorrow, or living life with continued loss (Lichtenstein, Laska, & Clair, 2002). Conceptualizing loss and grief as chronic sorrow allows bereavement to include the physical, social, and emotional losses that often follow an HIV diagnosis. Chronic sorrow further includes loss in the areas of physical functioning, former relationships, and previously held identities (Ahlström, 2007). In addition, individuals with chronic illness often grieve the loss of the life they had pictured for themselves and the changes in self-image that accompany such a loss (Ahlström, 2007). PLWHA reported grieving the loss of their support networks as a result of both the mortality brought on by HIV and the stigma attached to having the virus (Lichtenstein et al., 2002). With so many elements of loss and grief associated with PLWHA, professional counselors can begin to conceptualize these individuals through a model of grief and bereavement, including the stage model of Kübler-Ross (1969). Multiple bereavement theories have been developed as a way to conceptualize the grieving process, but perhaps none has become as widely known and appreciated as the Kübler-Ross model. In addition, Kübler-Ross's model continues to be the model most closely affiliated with those who are personally facing mortality, such as those living with HIV.

KÜBLER-ROSS'S THEORY OF GRIEF

From the beginnings of research and thought on grief, bereavement, and loss, the literature has shifted from abstractions of grief (Freud, 1917/1957) to formulated stages (Bowlby & Parkes, 1970) and tasks (Worden, 2009). However, the stage theory developed by Kübler-Ross (1969) stands out as the most popular conceptualization of grief, bereavement, and loss for both mental health practitioners (Ober, Granello, & Wheaton, 2011) and laypeople alike.

Sometimes known as the five stages of grief, the Kübler-Ross (1969) model is an often discussed and applied theory of people's experiences of grief. What is unique about Kübler-Ross's conceptualization of grief is that previous theories of grief related to the experiences of grieving others (e.g., Freud, 1917/1957). Kübler-Ross's model can be applied to those who are grieving the loss of a loved one as well as to individuals' own grief in response to their impending death or differing expectations of their life (Boer et al., 2014). The five stages of grief in Kübler-Ross's model are (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. These stages are adapted and illustrated in the following sections through examples of PLWHA to highlight how clients living with HIV can be conceptualized through a grief and bereavement framework.

Denial

For some, a state of denial comes before an HIV diagnosis and exists in a client's hesitancy to be tested (Brion et al., 2013). In contrast to the notion that denial is the first stage of a defined loss (Kübler-Ross, 1969), PLWHA may exhibit denial by reporting that they suspected that they had HIV for many years before deciding to get tested (Brion et al., 2013). Once they are diagnosed, denial can serve as a strong barrier to obtaining the medical and emotional treatment PLWHA need in dealing with HIV. Jenness et al. (2012) cited denial as the primary response for why a sample of those living with HIV delayed their entrance into medical care. Participants chose to avoid their diagnosis and, therefore, perceived medical care to be unnecessary (Jenness et al., 2012). Likewise, denial may manifest through PLWHA continuing in their previous lifestyles, including behaviors that are particularly unhealthy (e.g., increased alcohol or drug use) for those with a suppressed immune system (Brion et al., 2013). Thus, counselors may be aided by the traditional view of denial (e.g., choosing to continue previous lifestyles) and an adapted view of denial (e.g., suspecting one has HIV but refusing screening) to develop a fuller picture of how individuals cope with their illness.

Anger

Identifying the presence of anger within individuals with chronic illness proves difficult as a result of conflicted feelings within the population on

expressing this emotion. Ambivalence over emotional expression can be seen in those experiencing chronic illness or pain and encompasses a tentativeness to express both overly positive (e.g., affection) or overly negative (e.g., aggression) emotions (Carson et al., 2007). Furthermore, PLWHA experiencing ambivalence over expressing anger may feel regretful after choosing to show emotional expression (Carson et al., 2007). When anger is easily expressed by those struggling with chronic illness, it is not concentrated to self-anger and may present itself as anger with a higher power (Exline, Park, Smyth, & Carey, 2011). Although religion can be a source of great strength and coping for those with a chronic illness, it can also serve as a source of pain and contribute to feelings of sin and guilt following a diagnosis (Exline et al., 2011). In addition, anger may be directed at an inanimate presence, such as medication and the demands medication makes both physically and in terms of time (Brion et al., 2013). PLWHA may further express anger over the need to surrender to their medication regimens to maintain health, leading medication to feel like a controlling presence in their lives (Brion et al., 2013). As with the traditional view of anger in the Kübler-Ross (1969) model, there is an outburst of emotion toward the loss. However, in this case, the outburst of emotion may be confusing to both PLWHA and those who care for them, because the anger stage comes at the cost of PLWHA's own personal loss and can also be directed at themselves. Thus, the traditional view of the anger stage must be broadened to understand the unique expression of anger during this stage.

Bargaining

As previously stated, religious coping can be both a positive and a negative coping reaction for people living with a chronic illness. In the bargaining stage, the use of religion and spirituality often come back into play as PLWHA begin to bargain with God for an improvement in their condition (Rodriguez, Glover-Graf, & Blanco, 2013). In this stage, individuals begin to negotiate with their higher power in a way that parallels a business contract (e.g., promising payment in the form of life changes if they can be healed). Aside from full-on bargaining, individuals also choose to use prayer to communicate with God and ask for healing from the chronic illness (Rodriguez et al., 2013). Thus, the traditional view of the bargaining stage (Kübler-Ross, 1969) does not fully capture the unique experience of an HIV diagnosis. Bargaining is focused on the individual who is experiencing loss. Furthermore, with advances in medical treatment, the bargaining done during this stage may appear to PLWHA as working, which could provide a false sense of hope and more severe grief if individuals get worse over time. Similarly, if the bargaining does not work, individuals can reexperience denial or anger, thus showing a weakness in the Kübler-Ross (1969) model.

Depression

During the depression stage, individuals may mourn the loss of their potential selves (Bruce & Schultz, 2001). After the initial denial of the illness has worn off, PLWHA may experience depressive feelings as they recognize that their reality is now different from the one they had hoped for (Brion et al., 2013). In addition, feelings of hopelessness, often stemming from the belief that death may be near, can leave individuals paralyzed by feelings of depression (Brion et al., 2013). These beliefs may be further heightened because of stigmatized beliefs, which can contribute to the fear that death is imminent. Feelings of depression are some of the more common concerns voiced by PLWHA and can lead to other concerns, such as those related to medication adherence (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). When PLWHA are feeling debilitated by their experiences of depression, they are less likely to prioritize proper adherence, which, in turn, can lead to decreased overall health. A newer conceptualization of the depression stage is aided by the addition of the concept of chronic sorrow (Roos, 2013). The depression felt by PLWHA can be an ongoing process. Continued losses can place PLWHA at any point in the stages of grief (Kübler-Ross, 1969), but the realization that an HIV diagnosis will mean multiple future losses can make the depression stage more severe than a normal loss.

Acceptance

Although many individuals have experienced the previous stages in order (Kübler-Ross, 1969), not everyone has the opportunity to experience acceptance related to grief. The acceptance stage is unique to Kübler-Ross's (1969) model, because previous models of grief describe a letting-go process (Bowlby & Parkes, 1970; Worden, 2009). PLWHA can begin to integrate their own experiences and hopes into a new identity of someone surviving with HIV. That is not to say that individuals are happy or without grief during the acceptance stage, but that the reality of the situation is beginning to take shape. Individuals may withdraw from family or friends during the acceptance stage as they begin to adjust to a new conceptualization of their life.

As stated by numerous critics (e.g., Maciejewski, Zhang, Block, & Prigerson, 2007), there are problems with the Kübler-Ross (1969) stage theory. The criticisms of the model are valid: Individuals might not experience every stage, individuals may pass through stages out of order, or the stages may not fully encapsulate the feelings of loss (Maciejewski et al., 2007). However, because the stage theory (Kübler-Ross, 1969) is arguably the most widely known conceptualization of grief and loss (Ober et al., 2011), it is a useful tool to adapt in providing counseling services, teaching students, or providing education to PLWHA. Furthermore, its use with this unique type of loss has not been studied thoroughly, and its usefulness has yet to be validated or invalidated. Throughout these stages of grief, PLWHA must also overcome challenges unique to their community: the experience of disenfranchised grief and developmental considerations.

COMPLICATING FACTORS TO HIV GRIEF

Disenfranchised Grief

The forced silence of mourning experienced by PLWHA mirrors *disenfranchised grief*, or a grieving or loss that is not socially acknowledged (Doka, 1989; Robson & Walter, 2012). Disenfranchised grief extends to include grieving experiences that are recognized but then met with dismissal, along with losses that are not able to be openly mourned (e.g., loss of a same-sex romantic partner in a nonaffirming social circle; Doka, 1989; Robson & Walter, 2012). Likewise, grief can be seen as disenfranchised when referring to highly stigmatized groups (Livingston, 2010), such as those whose grieving is tied to their HIV status. The lack of societal acknowledgment for HIV-related grief inevitably leads PLWHA to remain isolated during their grieving. A lack of support during the grieving process can be harmful for PLWHA; those with adequate community support have an easier time transitioning through their mourning (Livingston, 2010; Piper, Ogrodniczuk, Joyce, & Weideman, 2009).

Individuals living with HIV have admitted to experiencing disenfranchised grief in their own lives and in their interactions with professional counselors. In interviewing gay men living with HIV, Meris (2008) found that grief concerns were a recurring theme among the participants. Amid these grief concerns was the narrative that care providers (e.g., social workers, mental health counselors) seemed more willing to acknowledge issues of substance use than the bereavement issues for which the client had sought care (Meris, 2008). Perceiving grief to be socially insignificant to care providers further exacerbates feelings of shame, stigma, and isolation during the grieving process (Meris, 2008). Adding to the complexities of healing from disenfranchised grief are the profound consequences to the life of the griever. Those who are unable to publicly mourn their losses can experience impaired emotional functioning, as well as increased feelings of anger and depression (St. Clair, 2013). In addition to the added complexities of disenfranchised grief, the expanding life expectancies of those living with HIV bring a slew of developmental challenges.

Developmental Considerations

As previously mentioned, the introduction of HAART has brought about a decrease in mortality postdiagnosis in areas where medication is accessible (Sikkema et al., 2006), thus bringing unique developmental considerations when working with adult clients living with HIV. This shift from terminal to oftentimes chronic illness has allowed many adolescents with HIV to consider preparing for independent living, because these clients are more likely to live into adulthood (Battles & Wiener, 2002). Likewise, adult clients living with HIV/AIDS are regularly living into older adulthood, bringing a host of additional challenges, such as long-term survivors who have experienced prolonged and repeated loss. PLWHA who survived the first era of AIDS (1983–1995)

make up a unique cohort of adults who have witnessed a profound loss of social networks (Leaver, Perreault, & Demetrakopoulos, 2008). The loss of partners, family members, friends, and neighbors has left long-term survivors with a complete loss of community and, therefore, a great sense of grief. Furthermore, this more traditional portrayal of bereavement has been found to be directly related to the physical health of those living with HIV, including faster progression to AIDS and greater frequency of HIV symptomatology (Bower, Kemeny, Taylor, & Fahey, 2003; Sikkema et al., 2000).

In addition, adults who have been living with HIV for an extended time may have been taking medication in the beginning of the development of antiretroviral drugs. During this time, prescribed treatments produced an even greater burden on those taking the medication, often including debilitating and life-altering side effects (Slomka, Lim, Gripshover, & Daly, 2013). These experiences only further exacerbate the pain adults with HIV have had to endure over their lifetimes. In response to living longer with HIV, however, long-term survivors have managed to find meaningful ways to cope with their illness. For example, long-term survivors often cite social networks (e.g., spouses, children, grandchildren) for providing a purpose for continuing to live (Sally, 1994; Slomka et al., 2013). In addition, long-term survivors often have learned to navigate the complicated needs of long-term illness, such as remembering to take medications and fostering effective communication with health care providers (Slomka et al., 2013). Keeping the process and challenges of HIV bereavement in mind, in the following section, we use Kübler-Ross's (1969) theory of grief to demonstrate how bereavement can manifest in a client with HIV.

CASE APPLICATION: THE CASE OF MIRIAM

Miriam (pseudonym) is a 45-year-old, African American woman who has chosen to speak with a mental health counselor following an HIV diagnosis. Miriam is a self-identified Christian and professes that her faith is one of the most important areas of her life. Miriam was diagnosed with HIV 1 year ago but is just now seeking counseling after her medical doctor recommended that she do so. Miriam's doctor recommended that she seek counseling after recognizing that Miriam was noncompliant with the medication regimen she had been prescribed. Miriam is also experiencing concerns in her social network; she has attempted to completely isolate herself from family and friends in an effort not to disclose her HIV status. With limited social support at this time, Miriam admits to feeling isolated and lonely. Furthermore, she admits to being sad that she can no longer socialize with her friends as freely as she once did, and to no longer feeling that she can be open and honest with her church community. In addition to the aforementioned concerns, Miriam's case also exemplifies a series of challenges seen in bereaving clients. Miriam shares that

she has chosen not to take her HIV medication because it is “not that big a deal,” and, therefore, she is choosing to rely on God’s ability to heal her. Miriam appears agitated that her doctor was so insistent on her taking medication, particularly because she shared with him that she did not think medication was necessary until she felt sicker.

Through downplaying and minimizing her health problems, Miriam is showcasing a level of denial of her illness and may not be fully accepting her current health condition. Choosing not to take medication allows Miriam to avoid daily reminders that she is sick and that her reality has changed significantly. In addition, Miriam’s choice to rely on God may have resulted from a bargaining conversation, or through prayerful conversations in which she requested healing. Miriam also hints at some feelings of anger, mostly geared toward her medical doctor and his medication suggestions. These feelings of anger appear to be originating from her lack of acceptance of her declining health and, therefore, the incongruence between her doctor’s opinions and her own perception of her health.

Considering Miriam’s choice not to take her medication, it would also be beneficial to check in on symptoms of depression, given that she may be experiencing feelings of hopelessness. Furthermore, Miriam admits to keeping to herself as a way to hide her HIV diagnosis, which suggests concerns in her current level of social support. Miriam admits to feelings of sadness because of a loss of social support and appears to be grieving her former social freedoms. The perceived stigma she is feeling, as evidenced by her decision not to disclose her diagnosis, may also contribute to feelings of depression. At this point, it does not seem that Miriam has accepted her HIV diagnosis, and it seems that she is actively working to maintain a level of unawareness surrounding her HIV status. It is worth noting that Miriam may not ever achieve the acceptance stage in her grieving process, and even if she did reach this stage, reaching acceptance is not synonymous with reaching happiness or fulfillment. The following section includes implications for mental health providers working with PLWHA, including implications relevant to Miriam’s case.

IMPLICATIONS FOR COUNSELORS

As shown in the case application, counselors can often conceptualize clients living with HIV through a grief counseling perspective. In doing so, counselors can use grief counseling approaches, such as reconstructing meaning and catering to support needs, in their work with PLWHA.

Reconstructing Meaning

The process of grieving can be conceptualized as meaning making, in which clients reconstruct meaning in their lives to adapt to their new realities (Neimeyer, 1999). Rooted in constructivism, this technique gives bereaving clients an opportunity

to make meaning of their illness and create a new narrative based on their current reality. Furthermore, clients in mourning are able to assimilate losses into their life stories and produce new conceptualizations of themselves, their priorities, and their worlds (Alves, Mendes, Gonçalves, & Neimeyer, 2012). Thus, constructivist theories (e.g., narrative therapy) may assist counselors working with clients who are grieving an HIV diagnosis (Zeligman & Barden, 2014). In addition to aiding in the grieving process following a diagnosis, constructivist approaches allow PLWHA to combat issues of stigma by encouraging clients to review socially constructed messages and externalize their diagnosis from themselves (Zeligman & Barden, 2014). Mourning clients often ask themselves why an illness or accident has happened to them, leading them to inherently search for meaning of the event and naturally engage in this process (Servaty-Seib, 2004). If meaning making is not initiated by the client, however, counselors play an important role in initiating this process, while being mindful that constructing new meaning is a process and not an outcome (Servaty-Seib, 2004). From this approach, counselors are integral in providing a safe place for clients to voice their stories and reintegrate their experiences of loss into their new narrative.

In the case of Miriam, the client may need to reconstruct what it means to have HIV. In her current narrative, having HIV appears to be something shameful that requires a level of secrecy. This narrative may have been influenced by stigmatized messages she has incorporated into her personal narrative and may benefit from constructivist techniques that externalize these messages and beliefs. This diagnosis may also bring changes in how Miriam conceptualizes her relationship with God. For example, Miriam may begin to view HIV medications as a way that God has been able to provide for her. In turn, Miriam's new narrative may include a strengthened spiritual relationship.

Catering to Support Needs

In addition to the aforementioned bereavement counseling approaches, grieving clients like Miriam benefit from being reconnected to social and community resources. This type of support may be particularly meaningful considering the disenfranchised elements of mourning an HIV diagnosis, as well as the isolation that often accompanies feelings of stigma and shame. With the concern of disenfranchised grief in mind, counselors have an added responsibility to validate a client's HIV grief experience. In addition, group support may provide added validation through the experience of universality (i.e., the sense that one is not alone because others share similar concerns; Yalom, 2005). Furthermore, HIV-related bereavement groups, aimed at enhancing social support and providing space for grieving, may benefit a client's overall quality of life as well as overall physical health (Sikkema, Hansen, Meade, Kochman, & Lee, 2005). In Miriam's case, the use of group intervention could provide the first piece of social support she is craving and assist in the feelings of depression she has shown. In addition, meeting with others with HIV may have an effect on how

Miriam conceptualizes living with HIV and play a part in her meaning-making process. For example, Miriam may see that others who take medication do so as a way to maintain their current level of health, and not as a response to dire physical needs, and therefore change the way she views medication and its meaning in her life.

CONCLUSION

Although PLWHA continue to benefit from mental health care, their clinical needs have shifted dramatically with the introduction of HAART and, therefore, the ability to live fuller, longer lives. With these medical advances in mind, counselors and care providers are now able to work with PLWHA on quality-of-life and adjustment issues, rather than solely on end-of-life concerns and existential struggles. Alternatively, counselors can now conceptualize clients with HIV through a bereavement lens and recognize the potential grief and loss associated with receiving an HIV diagnosis. Numerous grief theories have emerged over the years as a way to illustrate the process of grieving following loss, but none are so widely known as the grief theory of Kübler-Ross (1969). Through this conceptualization, which we have broadened in some respects, grief is experienced in five stages: (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. This unique way to conceptualize clients with HIV allows mental health clinicians to reconsider previous clinical approaches used with this population and now consider the use of bereavement counseling in practice with PLWHA.

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