

HIV/AIDS and Grief: Implications for Practice

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HIV/AIDS touches all of humanity. Yet historically, churches and social workers have been relatively unsuccessful in meeting the needs of people living with HIV/AIDS and individuals grieving AIDS-related deaths. In contrast, spirituality, social support, and finding meaning have been found to be successful aspects of healthy coping and healing. To increase efficacy social workers need to have specific knowledge and skills. Using an empathetic, client-centered approach in conjunction with narrative theory has been found to facilitate the successful infusion of spirituality, social support resources, and the client's search for meaning into the therapeutic process. The purpose of this article is to explore the grief experience of people living with HIV/AIDS, individuals grieving the loss of a loved one to AIDS, the response of the church and social workers, and discuss implications for social work practice.

MORE THAN 1.2 MILLION AMERICANS LIVE WITH THE CHRONIC LOSSES associated with having HIV (Centers for Disease Control and Prevention, 2012). From the moment of the diagnosis, people with HIV experience a multitude of changes, which affects all aspects of a person's life. In addition, an estimated 619,400 Americans have died from AIDS, leaving bereaved loved ones behind. Grieving is painful under any circumstance. As a result of the associated stigma, prejudice, and discrimination, grieving a death from AIDS often comes with specialized complications.

Historically, the response of the religious communities to HIV/AIDS has been compared to the treatment of leprosy at the time of Christ—judgment, prejudice, discrimination, with resulting separation and isolation (Dilger, 2008). In fact, it might even be said that in the United States, HIV/AIDS is the leprosy of the 20th and 21st century. While that trend is changing (van Wyngaard, 2006), much remains to be done to meet the needs of individuals diagnosed with HIV/AIDS and their surviving loved ones.

Similarly, grief counseling has historically failed to meet the needs of people living with HIV/AIDS (PLWA) (Jordon & Neimeyer, 2003; Peters, 2008a; Schut, Stroebe, Van Den Bout, & Terheggen, 2004). In contrast,

spirituality, social support, and finding meaning have been found to be key aspects of healthy coping and healing (Liu, Johnson, Ostrow, Silvestre, Visscher, & Jacobson, 2006; Neimeyer, Prigerson, & Davies, 2002; Tsevat, et al., 2009).

Clearly, to successfully address the needs of individuals and bereaved loved ones, social workers will be more successful if they have a specialized skill set with knowledge in both theory and implementation. Skills and knowledge needed include the ability to use empathetic, client-centered theory (Clark, 2010; Pinderhughes, 1979; Rogers, 1961) in conjunction with narrative therapy (White, 1995). Although social workers normally use empathetic, client-centered approaches, determining which additional theories to practice can often present challenges. Reams of literature exist that explore the use of empathy and client-centeredness from numerous theoretical perspectives, in countless settings, and with various populations. Few, if any, articles exist, however, that examine the use of an empathetic, client-centered, narrative approach with people living with HIV/AIDS or individuals grieving the loss of loved ones to AIDS.

While not negating the importance of countless alternative theories such as cognitive behavioral therapy for addressing potentially faulty beliefs (Beck, 1995; Leahy, 1997; Leahy, 2003), or solution focus brief therapy for examining daily coping (De Jong & Berg, 2002), narrative theory is a well-documented evidence-based style of listening, processing, and reframing that has proven to be particularly helpful with grief issues (Bosticco & Thompson, 2005; Gilbert, 2002; Keeling & Bermudez, 2006; Neimeyer, 1999; Pearce, 2011; White, 1995).

Using empathetic, client-centered, narrative approaches to infuse spirituality, social support resources, and the client's search for meaning into the therapeutic process (Neimeyer & Currier, 2009; Neimeyer, et al., 2002) facilitates clients' ability to embrace their experience and holistically weave them into the tapestry of their lives. The purpose of this article is to explore the grief experience of people living with HIV/AIDS and individuals grieving the loss of a loved one to AIDS, the response of the church and social workers, and discuss implications for practice.

HIV and Loss

*The most terrifying illnesses are those perceived not just as lethal
but as dehumanizing (Sontag, 1989, p. 38).*

Finding out that one is infected with HIV begins a process of chronic sorrow, adaptation, and living with imbricated layers of loss. Consequently, with no cure in sight, ongoing medical needs, and societal stigmas, the person now living with HIV faces a life that is permanently altered. Despite the fact that HIV no longer carries an immediate death sentence, the term itself

often raises an overwhelming fear that one will die. Common emotional responses include numbness, denial, pain, frustration, anger, depression, anxiety, fear, helplessness, hopelessness, sadness, loneliness, powerlessness, regret, remorse, never ending uncertainty, and suicidal thoughts (Anderson & Rowe, 2006; Mphande-Finn & Sommers-Flanagan, 2007; Plattner & Meiring, 2006; Rokach, 2000; Theuninck, Lake, & Gibson, 2010; Walker, 1991). A participant in a qualitative study on HIV-positive women (Enrique, et al., 2010) described her emotional and mental response when she found out she had HIV,

When they tell you that you have HIV, this is an experience one can never forget...When you hear this diagnosis, you feel you don't want to live, the first thing you think is "I'm going to die," I'm going to suffer a lot and die (pp. 935-936).

In another study, a woman shared her emotional pain, saying,

Even denial does not help ... when one has to face the disease and the moods that it comes with. It is hard to be cheerful when one's condition causes serious problems (Mphande-Finn & Sommers-Flanagan, 2007, p. 6).

Complicating the natural process of living with loss are the added elements of self-blame, shame, humiliation, social stigma, secrecy, and additional life losses. Furthermore, there is the ongoing vulnerability to physical relapses and a never-ending need for medical interventions (Dahlbeck & Lease, 2010; Rokach, 2000; Theuninck et al., 2010).

Self-blame and Shame

Due in part to society's perception of how HIV is transmitted, HIV can carry with it an element of choice and a feeling of personal blame (Plattner & Meiring, 2006). As a result, individuals diagnosed with HIV/AIDS express internal self-blame and shame and often want to hide the fact that they have HIV. A participant in a study on stigma expressed her shame, disclosing,

I'm just feeling ashamed to tell my mother and my sister that my husband and I are having the disease, so I decided that I would not tell them about what has happened to me (Mwinituo & Mill, 2006, p.375).

Another individual from a study of AIDS-bereaved women living with HIV (Damar & du Plessis, 2010) conveyed her sense of shame, stating,

When I realized that I was positive, I thought it was the end of the world...Well I just wanted to die. I wanted to kill myself. Life seems pointless when you have this kind

of infection. Like people say, it's a curse. Very shameful. I was terrified that people might think I was not better than a prostitute, although I got the disease from my husband. That's all I could think about when I found out about my status (p. 428).

Social Stigma, Disclosure, and Secrecy

What started in the 1980s as a mysterious illness with unknown origin quickly became associated with a defined set of deviant social and sexual acts (homosexuality, illegal intravenous drug use, and prostitution). Thus society's permission to acknowledge the multiple layers of losses experienced by the people living with HIV/AIDS became intertwined with societal fears, stigmas of self-righteousness, and internalized personal blame (Foster & Gaskins, 2009). Today, fueled by prejudicial attitudes and misinformation about risks of transmission, social stigmas associated with HIV/AIDS continue to be a major barrier in receiving and providing adequate care (Mwinituo & Mill, 2006). Personal impacts are far-reaching, ranging from fear, bitterness, hostility, depression, isolation, loneliness, increased shame, stress, worry, and poor self-esteem to various levels of secrecy, lack of social support, and an inability to mourn (Antle, Wells, Goldie, DeMatteo & King, 2001; Boon, Ruiters, James, van den Borne, Williams, & Reddy, 2010; Dowshen, Binns, & Garofalo, 2009; Faithfull, 1997).

Regardless of whether a person discloses or elects to remain silent, each decision carries stress. Disclosure, for example, carries the risk of rejection. In addition, fear and the desire to protect oneself or loved ones from experiencing stigma creates a major struggle with the decision to disclose (Dowshen et al., 2009; Enriquez et al., 2010; Faithfull, 1997; Foster & Gaskins, 2009). From the moment of diagnosis, people living with HIV face the ramifications of stigma regarding their decision to disclose or not. In a study of stigma's impact on health seeking behaviors (Carr & Gramling, 2004), a woman shared her doctor's advice,

The first words out of his mouth after he told me it's the worst were, 'Keep your mouth shut. Find you a good doctor and keep your mouth shut' (p. 32).

A participant of a study on women living with HIV whose husbands had died from AIDS (Damar & de Plessie, 2010) shared her fears,

I thought he's dead, so who do I talk to? What's gonna happen to my daughter? My thoughts were focused on my seropositivity. Even if my husband died a year later, my thoughts would still be focused on the fact that I'm HIV-positive. I don't think that the death of a husband has

such a great impact on a woman, especially if she already has children. My concern was that I now lived with HIV, so what should I do to live longer? What's important to me is how to feed my daughter, how to keep my status secret in order to protect her (p. 45).

Furthermore, the desire to protect family members from stigma, knowing that disclosure can result in being thought of as promiscuous, sexually deviant, or a drug abuser, keeps many people living with HIV silent (Carr & Gramling, 2004). Secrecy, however, regardless of cause, comes with a price. One woman shared her experience, saying,

Keeping it secret is more stressful than telling. The stress will kill you. You try to keep it all balled up inside and not tell anybody, where if you tell somebody, than you have somebody to talk to, and sometimes that's all you need is somebody to talk to (Carr & Gramling, 2004, p. 36).

Another stated,

I avoided everyone. I didn't want to go see my parents. You know I didn't want to be with old friends. I cut myself off from a social life. I isolated myself so I wouldn't have to tell (Carr & Gramling, 2004, p. 36).

Foster and Gaskins (2009) found that the majority of people living with HIV/AIDS do not disclose to friends, co-workers, church communities, or their pastors. The comment of a participant illustrates the feeling of most when he said, "The church is the worst place you can be for gossipers" (p. 1309). Another stated the "average person is going to tell it if you tell them, so I keep it to myself" (p. 1309). One participant shared that he learned to hide the fact that he had the disease by holding his head up and not responding when others talked about HIV/AIDS. Consequently, secrecy regarding HIV/AIDS results in hidden grief, family problems, transference of emotions, and attachment disruptions between family members and friends (Walker, 1991).

An additional factor that contributes to social stigma, a lack of disclosure, and thus a lack of appropriate medical care and support is the growing push to criminalize HIV exposure and transmission (Jurgens et al., 2009). Since 2004, at least 15 African countries have passed legislation making the transmission of HIV a crime (Pearshouse, 2008). Additionally, Asia, Latin America, and the Caribbean have also created HIV-specific laws allowing criminal charges to be pressed for HIV exposure and transmission. North America and Europe are not far behind. Currently, thirty-six states and territories have laws criminalizing HIV exposure and/or nondisclosure (The Center for HIV Law & Policy, 2011a), with at least eighty prosecutions in the last two years (The Center for HIV Law & Policy, 2011b).

Despite attempts by governments to force disclosure by people infected with HIV, the decisions to do so is generally guided by who is considered most trustworthy and supportive. As a result, the majority of individuals living with HIV reserve disclosure for close family members. A study of 24 individuals living with HIV/AIDS (Foster & Gaskins, 2009) found that participants mostly disclosed to their mothers and sisters. One shared,

My mother was the first person that I told. I wouldn't tell my father because of the type of person he is. I wouldn't tell my brothers. I did tell my sister because she is more understanding (p. 1309).

As feared, not all reactions are positive. One woman, who had been infected by her husband, shared her experience with family members not wanting to get together,

I asked (sister-in-law), "You talked to them about Christmas, didn't you?" She said, "Yeah, they don't want to eat your food" (Carr & Gramling, 2004, p. 33).

Additional Life Losses and Loneliness

Countless losses are associated with HIV/AIDS. For example, individuals become morally suspect and are frequently blamed for their circumstances (Anderson & Rowe, 2006; Plattner & Meiring, 2006). Additionally, they are often denied insurance, experience difficulty securing housing, employment, and medical care (Carr & Gramling, 2004), and are not allowed to enter the U.S. military. Additionally, individuals living with HIV often experience unnecessary travel restrictions and are denied entrances into foreign countries (Titus & Moodley, 2009). Furthermore, they face the daily risk of rejection, potential hostility, violence from hate groups, and the fear that disclosure will result in the loss of friends, family, and loved ones (Foster & Gaskins, 2009; Heckman, 2003). Further losses are incurred, including personal freedom, when the HIV-related criminal charges are pressed (Jurgens et al., 2009).

Living with HIV is further complicated for individuals who witness multiple AIDS-related deaths. Researchers (Sikkema, Kalichman, Hoffmann, Koob, Kelly, & Heckman, 2000) estimated that approximately 91% of HIV positive individuals have experienced the loss of a friend, family member, or partner to AIDS. Participants of a study on AIDS-related bereavement among gay men (Wright & Coyle, 1996) shared that because of the complicated dynamics of everyone that is grieving, (friends, family, and loved ones), social support often became challenging to receive. One shared,

After [he died] Toni couldn't cope. Her grief started to come into play which meant that she couldn't support me.

Lawrence was deeply in grief, so that's two, if you like, of our immediate family [of choice] not available. Steve, you've got to remember, he'd died so he wasn't available and then there was me. It was like my entire family was actually falling to pieces at the same time. So actually I've felt very alone (para. 25).

Vulnerability to Relapse

With advances in medical care, particularly in the availability of the highly active antiretroviral therapy (HAART), an HIV diagnosis has increasingly become a diagnosis of a chronic, long-term illness rather than impending immediate death (Sabin, 2002). Consequently, life becomes a time of continual challenges. Cycles of good health, followed by a decline in viral counts, hospital stays, then improved health, which creates ongoing discouragement and fear, followed by relief with each survival (Theuninck et al., 2010). In addition, watching the death of fellow patients, family members, friends, or partners, and confronting one's personal mortality results in an increased stress-response. Each physical symptom, health crisis, and new death compromises the immune system and the threat of HIV developing into AIDS looms (Kemeny, Weiner, Duran, Taylor, Visscher & Fahey, 1995; Kiecolt-Glaser, 1999; Leserman et al., 1999).

The final move from an HIV diagnosis to AIDS is devastating, resulting in renewed, heightened levels of grief for both recipient and loved ones. A participant in a study that examined the interrelationship between grief and attachment (Peters, 2008b) shares his story, saying his partner

didn't want to tell me that he had the virus right away... [After] six months...together...he finally came and told me that he was positive... Some more time passed and we were just living our life. And one day he came home...and said 'I got tested and...I officially have AIDS.' And was devastated by it.... That was the point where we almost broke up. He was discouraged, he didn't want to do anything...I remember him saying, 'I'm going to die and I'm just stuck.' It was very disheartening. I reminded him then what I said before... 'No matter what happens I will take care of you. I will always be with you.'

AIDS and Grief

Be kind, for everyone you meet is fighting a great battle
(Anonymous, O'Toole, 2010)

Following an AIDS death, individuals left experience grief anew as they attempt to adjust to life without their loved ones. Bereaved people often portray the loss as unfair and difficult to accept (Boon et al., 2010). Despite the pre-death preparation time, grief is described as shocking (Peters, 2010). Grieving individuals often say, "I did everything I could to be ready and I am still not ready" or "I knew he was going to die. I thought I was ready." They express feeling "foggy," unable to make decisions, excessively vulnerable, and fearful. Common grief reactions include wanting to deny the death, while at the same time knowing that the loss is real. As the ability or need to deny decreases and acceptance of the death increases, emotional, physical, spiritual, and social pain also increases. Experiencing physical ailments, often similar in nature to the deceased are common for bereaved individuals (Sheldon, 1998; Worden, 2009).

A study of the interrelationship between grief and attachment (Peters, 2008a) found that one of the most painful aspects of grief for the bereaved is the accumulation of seemingly never-ending changes in daily routine, personal lifestyle, close friends, and even living circumstances. In fact, it is common for bereaved individuals to change living arrangements shortly after their loved one's death. Beyond the moment-by-moment changes, emotional grief experiences often include relief conflicting with guilt, as well as anger, depression, or a combination of the two. Bereaved persons also express experiencing the desire to emotionally unload, transfer feelings, or act out as a way of dumping pain. As a result, the bereaved convey feeling the need to do ongoing relationship repair. For years following the death of a partner, it can be common for grieving people to relationship jump and develop a fearful attachment style in which they wish for a relationship, but shy away from having one (Worden, 2009). A participant in the Peters study (2008b) shared his experience with relationships after his partner died, saying,

Dating itself, like gee, I think I'll go out and be romantic tonight and have a date and get all dressed up, it didn't really have a lot of appeal to me [for years]. In fact, I know that first date, I was sort of relieved when the date was over. It was—thank goodness we never saw each other again or even talked. That was a relief....I don't have a significant other now. I recently went out on a date with a young guy.... If it works, it works, and if it doesn't, it doesn't.... As far as it being R, I don't think I'm going to use R as a benchmark as to what this relationship will be.

Cognitively, bereaved individuals often experience disorientation, confusion, and poor concentration (Love, 2007; Peters, 2010, Worden, 2009). Physically, it is common to experience body aches and pains, increased tension, appetite changes, and sleep disorders (Boon et al., 2010; Rando, 1984).

Additional experiences include processing pre-and post-death regrets for things said, not said, done or not done (Peters, 2010). The bereaved often question everything about their lives, examine their own mortality, and often consider the option of suicide. Commonly, grieving individuals express with sadness the loss of hope that their loved one would survive and attempt daily to come to terms with life without the deceased (Cadell & Marshall, 2007; Worden, 2009). One grieving person shared,

Well, you know, I hope I adequately described the feelings of devastation that come after [R's death]. Yeah, there's a certain solace that I have the memory, but it was a very—feelings of such a vacancy, part of my soul had been ripped from me. That's—I guess—I don't think I ever put it that way up to this point. I recall realizing at that point that, yeah, part of my soul had been taken away from me and I felt less, much less than I had before. Two people grow together. When they're not, it's quite a loss (Peters, 2008b).

Grieving individuals often express the expectation that they should “feel better” and be able to cope quicker by “moving on,” “letting go,” and “resolving their pain” (Peters, 2010). In contrast to the endless list of shoulds, internally they often feel crazy, out of control, and powerless. Commonly, grief manifests as an obsession or preoccupation with the deceased and an attempt to make sense of the loss (Love, 2007; Worden, 2009). The bereaved seek to remember their loved one forever. However, if they find that time does heal, they then grieve again for not grieving. When all other grief induced emotions are spent, they often describe their grief in terms of deep, overwhelming sadness and a feeling that something is just not quite right with their world. One grieving person summarized it for many when he said, “He'll never be forgotten by me. The things that I went through with him will never be forgotten (Richards, Acree, & Folkman 1999), p. 116).

Grief is further complicated by the stigma and secrecy associated with HIV/AIDS. Societal opinions and a lack of disclosure leave the bereaved with few, if any, outlets for their grief. Demmer's study on AIDS-related bereavement (2007a; 2007b) found that the majority felt it best to not share the cause of their loved one's death. Thus, they resign themselves to being silent, hidden grievers (Dane & Miller, 1992) and consequently receiving less social support. As one bereaved individual noted,

Sometimes it [an AIDS bereavement] can be more difficult to talk about...you know, because if someone died of cancer, it's more socially acceptable than it is to die from an AIDS-related illness (Wright & Coyle, 1996; para. 15).

Another shared,

It would have been nice for them to have accepted that it was a big loss. They couldn't understand why I was cut up so much by it (Wright & Coyle, 1996; para. 19).

Beyond the common grief response and the complication of stigma and secrecy is the added burden of experiencing multiple losses. One grieving person stated,

It's very difficult to separate the deaths out, because each time you go to a funeral, you are reminded of previous funerals (Wright & Coyle, 1996, para. 56).

Bereaved persons who acted as the primary caregiver for the deceased describe additional grief factors in terms of lost roles and personal identity (Cadell & Marshall, 2007). They express feeling unsure how to fill their time and what to do next. One participant said it well when he shared,

I don't feel complete. If I were a ship, I would be rudderless. Yes, I guess that is what I have in my mind, I am adrift (pp. 542-543).

Another described his grief as the

worst thing I ever felt in my life. I've had friends die—dozens of friends, but I had never felt anything like what I felt when [my partner] died. I realized why old married couples, when one of the couple dies, shortly thereafter the other one dies, and I know why. I wouldn't have minded dying myself. The feeling of just not wanting to be without my partner was so overwhelming. The loss was so profound. I can't describe the profound loss, feeling of utter devastation that occurs when a partner goes. No amount of tears can dissolve that. After the funeral, one of our friends asked, "What are you going to do now?" The only thing I could tell him was I think I will go down and have a cup of coffee. You know, that's the way my life looked. The only thing I knew was, I think I will take another breath (Peters, 2008b).

Like people living with HIV, religion and spirituality are an essential part of the grieving person's life and healing (Peters, 2010). Religion, viewed as the relationship with a church, carries with it much of the stigma

experienced by the people living with HIV/AIDS. On the other hand spirituality, viewed as a direct relationship with a higher power, is often a place of refuge and strength. One grieving person expressed the importance of his spirituality, saying,

I've learned a lot about myself and what weight I'm able to carry. And delving way down deep inside myself about—not only mental issues, physical issues, but spiritual. That really made its presence known. I mean, it's probably what's carried me through (Richards et al., 1999, para. 27).

Response of the Church

Churches have strengths, they have credibility, and they are grounded in communities. This offers them the opportunity to make a real difference in combating HIV/AIDS. (World Council of Churches, 2001, p. 3)

Official positions of religious hierarchies have placed moral values on issues of sexuality, gender, and the transmission of HIV/AIDS. Believed by some to be the results of negative behavior (Enriquez, et al., 2010) and a punishment from God, HIV/AIDS and bereaved loved ones have often been the recipients of intolerance from religious communities (Jacobson, Luckhaupt, Delaney, & Tsevat, 2006; Jenkins, 1995). Fear-based beliefs promoted by some religious organizations have a far-reaching impact for people living with HIV/AIDS and their loved ones. As early as 1987 (Johnson), it became apparent that churches profoundly influenced societal blame, intolerance, prejudices, and acts of discrimination. As a result, lines of communication between HIV/AIDS-impacted populations and the church communities have often been effectively severed. One bereaved man shared his experience, saying that when his dying partner,

wanted to have communion...he called his [church] and said, I'm home and sick and I'd like to have communion. And I know the [minister] asked him what's wrong. And he said, 'Well, I have AIDS.' The [minister] hung up on him (Peters, 2008b).

Unfortunately, churches are often identified as less-than supportive, with homophobia being a major barrier in prevention education and support for the infected (Foster & Gaskins, 2009; Jenkins, 1995; Joyce, 2010). One individual who had been very active in her church is quoted as saying,

I had to address the issue of how the church was handling it because fear and ignorance were rampant at that point. It was the only way it was going to keep the wrong rumors from flying, because it was getting back to me that someone

said I had AIDS and that my baby was dying. I was like, please, if you're going to tell it at least tell it right; if you're going to talk about me, let's get it right. I told them what the situation was, that they had nothing to worry about being around me or my children. It did get nasty about the nursery, and I ended up coming out of the nursery. There's a lot of times I've left church thinking "I thought these were Christian friends" (Carr, & Gramling, 2004, p. 35).

She eventually left her church community and began attending a different one. Another shared his experience,

Sometimes I believe in the Bible and sometimes I don't... I used to go to church but due to the stigma and discrimination from the church members, I decided to stay home and pray (Demmer, 2007a, p. 868).

Churches can easily be portrayed as self-righteous, uncaring—strong contributors to the negative stigmas of HIV/AIDS, prejudice, and discrimination. However, not all ministers have proposed the rejection of individuals with HIV/AIDS. A man who had witnessed his AIDS-infected partner be rejected by one church, shared a religious experience he had with a new church,

R was in tears [after being hung up on by the minister]. So I called a member of a [local church] and one of the [ministers] came out and gave him communion...and volunteered to come out as many times as R wanted to have communion. So she turned out to be a weekly visitor bringing communion and spending time with him (Peters, 2008b).

In addition to the individual clergy who work from a place of compassion, for a select group of churches, change is also occurring. van Wyngaard (2006) describes the change when he says,

As we formulate a Theology of HIV/AIDS, we are learning to speak freely about this disease. We may no longer speak about *them* and *us*. It is God's children, our brothers and sisters, who are dying of HIV/AIDS. 'If one member suffers, all suffer together' (I Corinthians 12:26). It is time to speak the truth. It is time to act only out of love. It is time to overcome fatigue and denial (p. 72).

The changes van Wyngaard proposes were further acted on in March 2010, at the first ever high level Religious and Spiritual Leaders Summit on HIV where Dr. Gunnar Stalsett, Bishop Emeritus of the Church of Norway and Moderator of the European Council of Religious Leaders is quoted as saying,

We are here to address important human and spiritual aspects of the epidemic. And we will be doing so with a sense of humility for the harm that people have suffered in the name of religion, but also with the confidence that faith matters and that faith can make us proud (Ecumenical Advocacy, Alliance, 2011, para. 6).

HIV/AIDS, Grief, Religion, and Spirituality

There is no fear in love. But perfect love drives out fear, because fear has to do with punishment. (1 John 4: 18, NIV)

While some PLWA and bereaved individuals viewed their situations as a test or punishment from God (Plattner & Meiring, 2006), most relied heavily on religion and/or spirituality as a system of support. In fact, regardless of the church's response, the majority of PLWA and bereaved loved ones do not forsake spiritual beliefs (Dalmida, Holstad, Diiorio, & Laderman, 2009; Foster & Gaskins, 2009; Tuck & Thinganjana, 2007). Researchers (Cotton, Tsevat, et al., 2006; Ironson, Stuetzle, & Fletcher, 2006; Kremer, Ironson, & Kaplan, 2009) found that both religiosity and spirituality increase in times of serious illness, with prayer being a significant coping strategy (Casarez & Miles, 2008; Kaplan, Marks & Mertens, 1997). In a study on the role of spirituality and religion for people living with HIV (Ridge, Williams, Anderson, & Elford, 2008), one participant shared the sentiments of several, saying,

God has not cast you out because of your condition. God loves everybody.... The lepers were just at almost the same situation as ours.... Jesus (put) out a hand and took them on (p. 418).

Another commented,

I listen to a lot of church music that comes on TV or on the radio. A lot of gospel. My mother, when she was alive, would always put that on everyday. And it gives me comfort. I usually hum along with the songs. I like to hear the music, and it is very relaxing and gives me a peaceful feeling. So, it has made me feel a lot better, just something to lift my day a bit (Siegel & Schrimshaw, 2002, para. 15).

One person shared the importance of prayer for him, saying,

I feel very good because I feel very good to talk with God. I talk to God and I feel good. I feel supported. Like there is someone who is always there for me. I talk to Him and I

ask Him for things. I talk to Him at night, in the morning, and I go to church. Knowing that He is there for me, and that I can talk to Him personally has been very good for me (Siegel & Schrimshaw, 2002, para. 41)

Spirituality has shown to be positively correlated with improved mental health, psychological well-being (Flannelly & Inouye, 2001; Tsevat et al., 2009), and physical health (Frame, Uphold, Shelhan & Reid, 2005), as well as decreased depressive symptoms (Braxton, Lang, Sales, Wingood, DiClemente, 2007), increased hope, and is a determining factor in life satisfaction (Cotton, Puchalski et al., 2006). People living with HIV/AIDS and bereaved loved ones perceived spiritual beliefs as beneficial to their health, healing, and coping. They view spirituality as providing them with personal strength, a purpose, and a sense of control over the hopelessness of the disease. One woman living with HIV shared,

I think a person needs to believe in God. I really believe that if you don't have some kind of higher power in your life, then your really going to feel overwhelmed and almost like hopelessness. But having a higher power in your life, you know what you can't do, but you can get help from your higher power. Doing the best you can do, and having the faith that if you do everything you need to, that He will help you (Siegel & Schrimshaw, 2002, para. 23).

Social support, a proven asset for coping (Casarez & Miles, 2008; Tuck & Thinganjana, 2007), is an integral part of spirituality (Siegel & Schrimshaw, 2002). People living with HIV/AIDS and the bereaved often find a sense of belonging and a desired connectedness through their religious affiliation and spiritual beliefs (Vance & Woodley, 2008). Relationship with friends, family, and God take on a new depth and significance. A grieving person shared his feelings about having HIV and the importance of fellowship with others,

It makes (life) more real. And so you think about some of the things in my life that are really important. It's not money. It's not things that everybody frets about. And it's really love. That's the bottom line. It's about friends and family (p. 51).

Another individual grieving the loss of a loved one to AIDS shared,

I think what needs to be glorified is the fact that we are all spiritual beings having our own experience. The focus needs to be on who we truly are. We are beings in connection with one another. We are here to love and support one another. And if we don't know how, then our purpose is to learn how (Richards, et al., 1999, para. 29).

One commented,

It caused me to learn to rely upon God. It caused me to realize that when you have faith, what needs to be done will be done. And that my needs are always met (Richards et al., 1999, para.43).

One woman summarized the importance of spirituality well when she said, "What faith teaches you is to stay positive and fight on" (Ridge et al., 2008 p. 423).

Suggestions for Practice: An Empathetic Client-Centered Narrative Approach

There is no agony like bearing an untold story inside you.
(Zora Neale Hurston, 1996 p. 189)

Social workers have often been accused of failing to address the needs of clients living with a loss such as HIV/AIDs and individuals grieving a death. In a study of 16 participants who had lost partners (Peters, 2008a), six sought various forms of counseling. One participant's comment summed up the feelings of the group, "It really didn't meet my grief needs, but it was helpful for other things."

Knowing what to do and how to select a theory that will provide best practices for working with individuals living with HIV/AIDS or suffering a AIDS-related loss can be a challenge for many social workers. With the push for evidence-based practice (Gambrill, 1999; Thyer & Pignotti, 2011) practitioners can have a tendency to tip the scales too far and look for a theory with a guaranteed intervention formula to follow. Additionally, the ongoing debate between quantitative and qualitative research also fuels the confusion over theory selection. Some researchers go as far as to discount qualitative research for establishing efficacy, stating that it lacks the rigour of quantitative studies (Bryman, 1984; Mertens, 2010; Stroebe, Stroebe, & Schut, 2003). Unfortunately, social workers can get caught up in the debates, making theory selection for the wrong reasons.

In reality, theory selection is made for a number of reasons. For example, the worldview of the social worker is a driving force (Baldwin, 2000; Koltko-Rivera, 2004), as well as the policies and mission held by places of employment. Financial issues and time constrains also determine theory selection.

Five primary aspects of theory selection need to be carefully considered, however, when working with clients living with HIV/AIDs and individuals grieving an AIDS related death. For instance, social workers need to remember that each therapeutic approach has aspects that are useful (Corey, 2013). Social workers also need to have a respect for various ways of knowing, including both evidence-based practices and anecdotal.

Third, social workers need to have a respect for the client as the expert. It is also critical to recognize that each style of research has its place in guiding practice (Mertens, 2010). Most importantly, social workers need to keep in the forefront of their mind the concept that issue drives theory and theory drives intervention. Thus, with issue driving theory and theory driving intervention, it follows that understanding the dynamics surrounding living with HIV/AIDS and the specialized aspects of grief for surviving loved ones are essential aspects in the selection of theory and the resulting interventions.

Research (Rothschild, 2000; Scaer, 2001; Worden, 2009) has well documented that holding in life experiences can have negative consequences. In contrast, the expression of life events facilitates healthy coping skills and healing (Enriquez, et al., 2010; Kloss & Lisman, 2002; Strobe, Stroebe, Schut, Zech, & vanden bout, 2002). Furthermore, having social support systems (Benkel, Wijk, & Molander, 2009; Reich, Lounsbury, Zaid-Muhammad, & Rapkin, 2010; Stowers & Kohli, 2012), and a sense of spirituality (Ironson, et al., 2006; Kremer, et al., 2009; Peterson, 2011) have proven to be important aspects of life satisfaction. Similarly, finding meaning out of pain (Jacobson, et al., 2006; Neimeyer & Currier, 2009; Neimeyer et al., 2002; Plattner & Meiring, 2006; Tuck & Thinganjana, 2007) can validate the losses, and consequently facilitating an increase in coping. Due to the unique aspects experienced by individuals living with HIV/AIDS, such as self-blame, shame, social stigma, secrecy, loneliness, health concerns, potential religious and spiritual issues, facing death and losing loved ones, combined with their individual grief experiences, research has found that infusing social support resources, spirituality, and the client's search for meaning into the therapeutic relationship is vital.

The basic tenets of social work are important to any theoretical selection. These include ecological system theory (Compton, Galaway, & Cournoyer, 2005; Hepworth, Rooney, Dewberry Rooney, Strom-Gottfried, & Larsen, 2010; Sheafor & Horejsi, 2012), strengths perspective (Saleebey, 2009), developmental and communication theories (Zastrow & Kirst-Ashman, 2010), cultural competency (Sue, Arredondo & McDavis, 1992; Sue & Sue, 2008), coping theories (Cannon, 1932; Lazarus & Folkman, 1984), and the various problem-solving models. However, empathy (Goleman, 1995, 2008) and client-centered regard for the client (Rogers, 1951; 1961) stand out as paramount. Goleman, (1995) contends that success in any field of practice is dependent upon the emotional intelligence and empathy that is brought to the relationships. Furthermore, the concepts held forth in a client-centered approach, such as a belief in the uniqueness of the client, respect for the client, and the ability to meet the client where they are, are considered to be critical in each step of the therapeutic relationship. Therefore, combining empathy and client-centeredness, provides the clinician with a specific skill set for addressing the unique aspects of

individuals living with HIV/AIDS and grieving the loss of loved ones.

Coined in 1909 by the German philosopher Edward Titchener, empathy describes a person's "ability to perceive the subjective experiences of another person" (Goleman, 1995, p. 98) or be aware of and "take the role of the other" (Rogers, 1961, p. 348). Discussion regarding the importance of empathy to the therapeutic relationship begins for most social workers in their first social work class and continues throughout their training (Clark, 2010; Pinderhughes, 1979) and beyond. In reality, the debate on whether empathy can be taught in adulthood is an ongoing discussion in social work circles. While debate flows, one area of agreement stands out; a lack of empathy equals a lack of a therapeutic relationship. Goleman (2008) defines three types of empathy; cognitive, emotional, and compassionate. Elements that have been found to influence empathy are one's personal attitudes, attunement to the client's position, an understanding of our shared humanity, the context of the client's experience, relational processes (Gibbons, 2011), and a willingness to engage with the client (Gerdes, Lietz, & Segal, 2011).

Client-centeredness, defined as a non-directive approach to therapy (Rogers, 1961) is considered (Clark, 2010; Goleman, 1995; 2008) to be intricately intertwined with empathy. Aspects of client-centered therapy includes a trust in the client's ability to heal, honoring of individual uniqueness, and respect for life experiences and choices. The clinician's responsibilities are to be authentic, have an accurate empathic understanding, and have unconditional positive regard through acceptance, caring, and nonjudgmental interactions. Key to the success of a client-centered approach is an ongoing respect for the client's right to self-determination and a belief in the client's ability to make the changes they desire. As a theory that has evolved over the last 70 years, techniques have increased from reflective listening skills and validation of the client's process, to the use of expressive art (Rogers, 1993, 2011).

People living with HIV/AIDS and who potentially face or live with the loss of loved ones often experience overwhelming emotional ramifications of their grief. Grief, defined as every human emotion accentuated 1000 times (Peters, 2010), is not a thought process to be controlled, molded, or fixed (Neimeyer, 1999; Peters, 2008a; Worden, 2009). Rather, healing requires the embracing of the story (McAdams, 1993). Grieving, or the process of experiencing one's internal feelings of grief, becomes for many people living with HIV/AIDS or suffering the loss of a loved one to AIDS, an expression and reframing of their life story (Worden, 2009). Thus keeping in mind that issue drives theory and theory drives intervention, narrative theory, defined as the use of client's stories to address life experiences (Epston & White, 1992; Neimeyer, 2009), becomes the best-practice evidence-based fit.

A primary concept of narrative therapy is that the person is not the problem; the problem is the problem (Epston, 2009; Epston & White,

1992; White, 1995). Additional concepts that guide narrative work are that people are essentially storytellers, and identities are shaped by how they tell their stories (McAdams, 1993). In addition, narrative theory proposes that decisions are made for good reasons and are influenced by history, culture, character, and past and present events. Narrative therapy further contends that the client's story holds the basic unit of experience and determines how a person thinks, acts, makes sense of new experiences and the world. Social workers using a narrative approach are interested in forming a collaborative alliance with the client and modeling supportive relationship skills (Corey, 2013). A primary goal is to assist and bear witness to the client's process of weaving their story into the tapestry of their life (Sharf, 2012). The role of the clinician is to assist the client in describing their story, modes of living and the possibilities associated with them by exploring life shaping moments, key turning points, and important relationships.

Narrative interventions include asking open-ended questions, exploring times when the presenting issue is not present, using a thick descriptive voice to share the story (Epston & White, 1992), linking the client's story to the past, present, and the future, acting as a witness to the story, facilitating client-to-client sharing, reframing the story from a negative perspective to strength-based, and exploring the meaning in the events (McAdams, 1993; Neimeyer, 2009; Sharf, 2012).

Narrative approaches also promote the use of homework assignments involving expressive arts, such as story and letter writing (Graybeal, Sexton, & Pennebaker, 2002), altered book making (Cobb & Negash, 2010), poetry, collaging, and drawing (Carlson, 1997), combined with in-session verbal processing (Keeling & Bermudez, 2006; Neimeyer, 1999; White, 1995) to facilitate healing. While the verbal processing is important, it is the combination of the expressive arts, with the verbal telling of the client's story that determines success. David Epston, (Epston & White, 1992; White, 1995) one of main contributors in the development of narrative theory, contends that the use of expressive arts increases the effectiveness of talk therapy fourfold. Neimeyer (1999), in his article, "Narrative Strategies in Grief Therapy," suggests that the integration of homework into each session can assist in building an empathic bridge between the client and practitioner.

Due to the nature of narrative theory, it provides no set of rules, formulas, or specific steps to follow (Corey, 2013). Rather it emphasizes the importance of being where the client is. Therefore, when intertwining narrative with an empathetic, client-centered approach clinical practitioner's working with individuals living with HIV/AIDS and the bereaved are concerned with creating a safe environment, the development of trust, being willing to let go of pre-existing agendas, giving attention to where the client is emotionally (Rogers, 1961), providing kindness and compassion, (Buechler, 2004), creating a nurturing alliance (Mackey, 1996), normalizing feelings (Houck, 2007), and actively listening to the client's story and thus needs (Mason, 2009).

Furthermore, an empathetic, client-centered, narrative approach facilitates the clinician being able to enter the world of the client with an open heart and mind that accepts the client's choices, and outcomes. Consequently, the social worker has a framework to work successfully cross-culturally (Enriquez, et al., 2010; Epston & White, 1992; Thomas, 2008; Undie, Ziraba, Madise, Kebaso, & Kimani-Murage, 2009), globally (Winskell & Enger, 2009), and with all ages, as well as being able to address the various aspects specific to living with HIV/AIDS and the associated grief.

One individual said it well, stating,

The only way to help others is to encourage and support them to find out their own ways [of grieving], rather than trying to come up with a very prescriptive way of dealing with grief and loss (Wright & Coyle, 1996, para. 49).

An example of an empathetic, client-centered, narrative approach is the use of AIDS Memorial quilt panels to tell the story of the deceased and the bereaved (Kausch & Amer, 2007). Doing so validates grieving individuals' losses, thus facilitating increased coping. It further provides for a spiritual outlet (Deluca, 2007), as well as a connection to community support, and gives a sense of meaning to their loss. One anecdotal story told by Thorley (1993) describes the importance of taking a position of attunement,

There was this little boy, and she'd [the quilt volunteer had] taken down one of the panels with a pair of jeans on it. And this little boy became fascinated with them and, you know, kept coming back. "Were they his favorite pair of jeans?" "Yes." And a little bit later came back, "He must've loved those jeans." And just this little cycle of this boy connecting with the jeans... I mean, if his knowledge of AIDS comes through connecting with that pair of jeans, then, you know, it's a learning thing.

Another example is the use of an empathetic, client-centered, narrative therapy group, which provides a safe environment for sharing and processing one's story (Garte-Wolf, 2011). Narrative theory is often used with families to create an atmosphere of sharing that facilitates healing (Epston & White, 1992). Regardless of the narrative approach taken, whether individual, family, group, or community, narrative gives voice through both verbal actions, tactile and visual representation of the life experiences of people living with HIV/AIDS and associated grief responses.

Ackerman, (2001), brings it all together when she states,

The stories of people living with HIV/AIDS are individual tales with meta-narrative of the pandemic. Hearing and engaging with these stories in communities of faith [and within the social work profession] has the potential to draw members into relationship. We all have stories to tell. As our stories intersect, they change. We become part of one another's stories. In this process, we are all changed. Hearing and telling stories begins a process of openness, vulnerability and mutual engagement that challenges stigma, ostracization, and the loneliness of suffering, and hopefully leads to acts of engagement, affirmation, and care (p. 27).

Conclusion

The value of compassion cannot be over-emphasized. Anyone can criticize. It takes a true believer to be compassionate. No greater burden can be borne by an individual than to know no one cares or understands
(Arthur H. Stainback, 2006 p. 36)

Living with the diagnosis of HIV/AIDS and grieving the loss of a loved one to AIDS are complicated processes that require churches and social workers to move outside themselves to a place of compassion, caring, and kindness. Churches that listen to the stories of PLWA and the bereaved provide opportunities for spiritual expression and increased coping. In addition, social workers who use an empathetic, client-centered, narrative approach provide a foundation for hearing the client's story without judgment, prejudices, or discrimination and provides a place of refuge where individuals can find a renewed purpose in living (Mphande-Finn & Sommers-Flanagan, 2007) as they discover meaning (Plattner & Meiring, 2006) in times of great sorrow and pain. Daniel Goleman (2008) says it well,

The act of compassion begins with full attention, just as rapport does. You have to really see the person. If you see the person, then naturally, empathy arises. If you tune into the other person, you feel with them. If empathy arises, and if that person is in dire need, then empathic concern can come. You want to help them, and then that begins a compassionate act. So I'd say that compassion begins with attention (para. 1).

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