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AIDS AND BEREAVEMENT IN SOUTH AFRICA

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ABSTRACT

AIDS is the leading cause of death in South Africa and attention needs to be focused on the needs of countless individuals who grieve AIDS-related deaths. Social workers must be prepared to assist those who grieve AIDS-related losses, especially children, women, and the elderly. AIDS-related bereavement must be understood in terms of the complex social, political, and economic factors inherent in South African society. Strategies are suggested for addressing AIDS-related bereavement in the local context.

INTRODUCTION

South Africa has been particularly hard hit by HIV/AIDS. It has the largest number of people living with HIV/AIDS in the world and an extraordinarily high proportion of its citizens have died of AIDS due to a lack of access to antiretroviral (ARV) treatment. The purpose of this article is to discuss the impact of AIDS deaths on survivors, with special attention to the local context. The author draws on empirical studies on AIDS-related bereavement as well as insights gained from his professional and personal experience with AIDS-related loss in both South Africa and the United States (US).

BACKGROUND

To appreciate the extent of bereavement associated with AIDS in the South African context, we need to examine the nature of the HIV/AIDS pandemic in South Africa.

HIV/AIDS IN SOUTH AFRICA

The AIDS pandemic in South Africa is considered “unique” (Fassin, 2003). Sub-Saharan Africa makes up 70% of the world’s HIV cases and South Africa accounts for over 50% of new reported HIV cases in this region (Winter, Jacobs, Delate & O’Malley, 1998). The first AIDS cases in South Africa were reported in 1982, and there were 353 reported AIDS cases by 1990 (Mitton, 2000). In 2003 it was estimated that there were 4.69 million South Africans living with HIV or AIDS, more than in any other country in the world (Rehle & Shisana, 2003). Unlike the US, where male-to-male sex and needle sharing are the most common means of HIV transmission, most infections in South Africa are through heterosexual sex (Abdool-Karim, 2000). Vertical transmission, or transmission of the virus from mother to child perinatally or during breastfeeding, is also a serious problem in South Africa (Ades et al., 2000). Surveys in KwaZulu-Natal, which has the highest incidence of HIV/AIDS in South Africa, indicate that more than one third of women attending antenatal clinics are HIV-positive (Gilbert and Walker, 2002a; SA Department of Health, 2001).

A number of factors have contributed to the extent and severity of the HIV/AIDS pandemic in South Africa (ABT Associates Inc. South Africa, 2000). They include the following:

- the high prevalence of other sexually transmitted diseases;

- high levels of poverty;
- disruptions of families and communities due to apartheid and the migrant labour system;
- high mobility, which has allowed for the rapid spread of the virus to new communities;
- resistance to using condoms;
- the low status of women in society and within relationships;
- social norms that endorse multiple sexual partners, especially among men;
- norms that do not encourage discussion of sexuality issues and HIV/AIDS.

AIDS-related mortality

The AIDS pandemic has been described as a “tidal wave of death approaching South Africa” (Ashforth, 2002:124). To get a sense of the gravity of the AIDS crisis in South Africa, let us compare the AIDS mortality rate in South Africa with that of the United States. In 2001 there were approximately 360 000 deaths from AIDS in South Africa, up from 200 000 in 1999 (UNAIDS, 2002; UNAIDS, 2000). In the same year the cumulative number of AIDS deaths in the United States since 1981 was 467 910 (CDC, 2003). The cumulative number of AIDS deaths in South Africa is expected to be 2.56 million by 2005 (Rehle & Shisana, 2003).

A report released by the South African Medical Research Council in July 2001 indicated that AIDS had become the leading cause of death in South Africa, and it was estimated that 40% of all adult deaths were now due to AIDS (Dorrington *et al.*, 2001). South Africa is reported to have entered the “death phase” of the pandemic; meaning that the number of people dying of AIDS has begun to outstrip the number of new infections, (Associated Press, 5 August, 2003).

If we continue on our current course with limited public access to antiretroviral (ARV) treatment, the annual number of deaths due to AIDS is projected to peak with 487 320 AIDS deaths in the year 2008 (Rehle & Shisana, 2003). The authors provide additional disturbing projections (2003:4):

- Life expectancy at birth will hit a low of 45.6 years (this is 22 years less than it would be without AIDS) between 2005 and 2110;
- There will be over 2.5 million AIDS orphans ten years from now.

Official response

It is important to consider the political context in order to understand the reasons for the high AIDS mortality rate in South Africa. There has been much criticism of the government’s handling of the AIDS crisis over the years and commentators, health care professionals and individuals affected by HIV/AIDS have expressed dissatisfaction and frustration over the lethargic response of the current government (Van Niekerk, 2001; Walker, Reid & Cornell, 2004). Nattrass (2004:41) states that “The history of AIDS policy in South Africa is a sorry tale of missed opportunities, inadequate analysis, bureaucratic failure and political mismanagement”.

The apartheid government failed to respond appropriately to the growing number of HIV cases (Phillips, 2003). During the post-apartheid era President Mbeki’s querying of the connection between HIV and AIDS created a great deal of controversy. Nattrass (2004:51) states that “Mbeki’s questioning of established scientific knowledge and best-practice medical interventions succeeded in driving a wedge between the scientific community and the government”.

During the past decade there have been a number of indicators of a lack of political will to address the issue of HIV/AIDS in South Africa including: (a) a delay in allowing infected mothers to be given prophylaxis treatment to prevent transmission to their infants; (b) misappropriation of state funds for dubious HIV-prevention campaigns; (c) failure to spend all the funds that were allocated in the AIDS budget; and (d) denying public access to lifesaving drugs (ARV treatment) (Mitton, 2000; Delius & Walker, 2002; Henderson, 2000; Schneider & Fassin, 2002; Van Niekerk, 2001). More recently, the President has provoked reaction again by questioning the magnitude of mortality associated with AIDS in South Africa (Philips, 2003). The slow actions of the government have been described by one commentator as “death by dithering” (*Economist*, 2003:67).

In November 2003 the government finally endorsed a National Treatment Plan for HIV/AIDS. The Cabinet plan was committed to treating 53,000 infected people by 31 March 2004. In the current budget more funds have been allocated for HIV/AIDS - R12,3 billion over the next three years and R166 million has been allocated to the national health department for the ARV treatment plan (*Mail & Guardian*, 2004a).

At the time of writing this article progress in implementing this plan has been slow and uneven across the provinces (*Mail & Guardian*, 2004b). Natrass (2004:86) warned that it is unacceptable to continue to explain the lack of access to ARV treatment by citing “implementation challenges” or “legacies of the past”. But at least there is hope now for extended survival for those living with HIV/AIDS. Social workers will be faced with the difficult task of helping survivors come to terms with the fact that their loved ones did not live long enough to benefit from ARV treatments.

NORMAL AND COMPLICATED BEREAVEMENT

Before discussing bereavement due to AIDS deaths it is important to clarify the terms *bereavement* and *grief*, which are often used interchangeably. *Bereavement* is the long-term adjustment or accommodation to the loss of a loved one. *Grief* refers to the emotional component of the bereavement process and includes specific emotions and behaviours in response to the loss such as depression, loneliness, yearning and searching for the deceased (Goodkin *et al.*, 1996). Grief work is the process and work of adjusting to irrevocably lost objects, relationships and dreams. It is a universal and normal response to loss and it affects all aspects of an individual's life - physical, emotional, cognitive, behavioural and spiritual (Worden, 1991). The most important thing to remember is that grief is a highly individualised experience and that it is influenced by a variety of factors including its context and concurrent stressors (Mallinson, 1999).

Because of the unique aspects of a loss due to AIDS, survivors are at increased risk of complicated bereavement (Dane & Miller, 1992; Nord, 1997; Sherr, 1995). Research has shown that individuals who grieve an AIDS death confront a host of issues that may complicate the grieving process; these issues include the nature of the disease, the HIV status of the bereaved, multiple losses and inadequate support due to the social stigma associated with AIDS (Nord, 1997; Mallinson, 1999; Houseman & Pheifer, 1998; Catalan, 1995; Sherr, 1995; Maasen, 1998). These will be discussed in more detail. Ample evidence exists from the US that AIDS survivors are likely to experience more losses, greater stigma, less social support and greater reluctance to disclose the cause of death than those grieving other types of deaths such as cancer (Kelly, Raphael & Statham, 1996).

The following are signs of complicated bereavement (Demmer, 2002a):

- Difficulty resolving loss from the past;

- Not being able to let go (keeping the deceased's room intact long after the death, idealising the deceased, holding on to anger or guilt);
- Feeling chronic intense pain years after the death;
- Not being able to return to normal day-to-day functioning years after the death;
- Engaging in self-destructive behaviours that mask grief (e.g. impulsiveness, not taking care of oneself, suicidal thoughts, persistent psychosomatic complaints, including feeling the same physical symptoms the deceased had when ill);
- Psychiatric disorders, including depression, anxiety, eating disorders and drug addiction.

FACTORS INFLUENCING BEREAVEMENT DUE TO AIDS

Since the mid-1980s a body of research has evolved in the United States that has examined the bereavement experiences of those who have lost loved ones to AIDS. This research has focused mainly on gay men, since they have been most affected by the AIDS epidemic in the US. In South Africa there has been scant research on the bereavement experiences and concerns of survivors of AIDS-related deaths. In the light of this gap in knowledge, the best we can do in the interim is to review some of the main things that have been learned from studies of AIDS-related bereavement in the US context and apply them to the local context. Of course, the lessons we draw from the West must be viewed with caution due to the distinct differences in AIDS contexts between the US and South Africa.

Characteristics of AIDS-related illness and death

Since 1996 the introduction of antiretroviral therapy (ARV) treatment has altered the course of HIV/AIDS and helped transform HIV/AIDS from a quick fatal disease to a more chronic disease (Deeks, Smith, Holodniy & Kahn, 1997; Porche, 1999; Karon *et al.*, 2001). Before the introduction of ARV treatment, patients with AIDS in the US were destined to experience progressive physical and mental deterioration. This is still the case for most South Africans with HIV/AIDS. The emotional toll on family members and other loved ones is enormous. They must cope with shock, sadness, frustration, helplessness and sadness as they witness the decline of their loved one. The following characteristics of HIV/AIDS present challenges to family members and loved ones: the unpredictable nature of the disease, disfigurement associated with the disease, neurological problems, the young age of those who are sick, and the likelihood of death (without antiretroviral treatment) (Walker *et al.*, 1996; Sherr, 1995).

Family members and significant others may experience what has been termed anticipatory grief, a term that was introduced 60 years ago by Lindeman (1944). It describes the emotions and behaviours that individuals experience in response to awareness of the pending death of a loved one. The needs of individuals who are grieving in advance the death of a loved one to AIDS are likely to go unrecognised (Walker *et al.*, 1996). Social workers need to help individuals in the local context deal with the anticipatory grief process. This will require some degree of expertise in grief counselling on the part of the social worker.

Social Stigma

Since the first cases were reported, AIDS has been known as a highly stigmatised disease. In the United States today AIDS is not as stigmatised as it was during the 1980s, but that does not mean that people are no longer prejudiced against those with HIV/AIDS and their loved ones. In fact, a recent study of adults in the United States who had experienced the death of a sibling from AIDS

showed that the stigma associated with AIDS persists and continues to complicate the grieving process for survivors (Robinson 2001).

Individuals in South Africa who lose a loved one to AIDS are not likely to receive the same amount of support and sympathy that they would receive if their loved one had died of more socially acceptable causes (e.g. cancer, car accident, heart disease). Survivors may be forced to keep the nature of the death secret and to hide their own grief. As a result, AIDS survivors have been called “hidden grievers” (Dane and Miller, 1992). Because of fears of being ostracised by others, survivors may be hesitant to mourn openly in public and to seek support from others (Walker et al., 1996; Mallinson, 1999). The death of Gugu Dlamini at the end of 1998 by a mob who accused her of degrading her community by revealing her HIV status has prompted concerns that those affected by AIDS will withdraw further from society (Lancet, 1999). AIDS survivors may be forced to remain silent about their loss and to grieve in isolation. Social workers are faced with the huge challenge of reaching out to survivors who are fearful and suspicious of not only their neighbours but of professionals as well.

In addition to the secretiveness of HIV/AIDS, the relationship between the deceased and survivor may not be socially sanctioned (e.g. gay relationships). AIDS survivors are regarded as disenfranchised grievers. This term was coined by Doka (1989) and is used to describe the grief that individuals experience when they are not allowed to publicly mourn and do not receive adequate social support for their grief. There is no doubt that, because of the stigma attached to AIDS, survivors in South Africa will not be accorded the same respect and support as survivors of other deaths. The stigmatisation of AIDS not only increases the pain and suffering of survivors, but contributes to the social and economic vulnerability of those living in AIDS-affected households (Strode and Grant 2001). The stigmatisation continues even through death, according to some religious belief systems. In Kenya an AIDS death is viewed as ‘permanent’ in a way that other deaths are not. According to Nzioka (2000:6), “Those who die of HIV/AIDS are equated to those who hang themselves... Death from HIV/AIDS is of particular concern because it does not just threaten to annihilate and tarnish the individual’s identity, but also to do the same for family, clan and community”. Nzioka (2000) also states that families bereaved through AIDS have difficulty obtaining support (public sympathy and financial assistance) when planning funerals, and attendance at funerals is low.

Multiple losses

AIDS is a disease of loss. Family members experience various losses throughout the course of the patient’s illness, including the loss of the person they once knew as s/he declines (Demmer 2002a). Other losses include hopes and dreams for the future, the feeling of being in control and the predictability of life events, physical intimacy, social, financial and emotional support (Walker *et al.*, 1996). Survivors in South Africa, like those in the gay community in the US, are subjected to ongoing loss, meaning that they are forced to witness the deaths of a number of people within their social network. The subject of multiple loss has been widely covered in the literature on gay survivors and the term ‘bereavement overload’ has been used to describe the compounding impact of surviving multiple AIDS-related deaths, usually in a short time frame (Bigelow and Hollinger, 1996; Nord, 1997). The constant onslaught of AIDS deaths does not allow the survivor enough time to grieve a loss before another death occurs and this complicates the grieving process. Each time a death occurs it reminds the survivor of a previous loss, especially when previous losses are unresolved (Nord, 1997; Walker *et al.*, 1996). As a result, survivors become emotionally “overwhelmed, physically exhausted, or spiritually demoralized” (Mallinson, 1999: 167). Survivors of multiple AIDS-related losses may protect themselves by deadening the pain or going

into denial (psychic numbing) (Nord, 1997). There may be changes in personality and the following emotions may dominate: pessimism, rage, disillusionment, despair and powerlessness. In addition, survivors may experience guilt that they survived while their loved did not, and they may question whether they did enough for their loved one (Dane & Miller, 1992; Nord, 1997).

Resource-poor setting

AIDS primarily affects the poorest, most disadvantaged groups in South Africa (Mitton, 2000). An editorial in *The Washington Post* described AIDS in South Africa as “a medical holocaust” in large part due to “inadequate health care, poor education and social stigma” (*Washington Post*, 2000:A 28). AIDS survivors in the South African context are faced with considerable daily hardships that make them extremely vulnerable. In addition to being subjected to social stigma, disenfranchised grief, multiple losses and bereavement overload, AIDS survivors in the local context must deal with poverty, malnutrition, poor housing and a host of other quality of life problems. More often than not these demands must take priority over the need to seek help with the grieving process. Even if they have the time or energy, survivors are likely to have difficulty locating bereavement support services. The scarcity of support services in the local context stands in marked contrast to the US, where a number of AIDS service organisations (ASOs) and other related AIDS-dedicated institutions across the country have provided an array of services (including bereavement support) to people with HIV/AIDS and their loved ones since the beginning of the pandemic. For instance, between 1981 and 1998 one and hundred and sixty six ASOs were created in New York alone (Chambre, 1999).

Poverty

AIDS survivors in South Africa live in one of the most unequal societies in the world (Johnson and Budlender, 2002; UNISA, 2000). Economic power is still heavily concentrated in the hands of whites, who represent about 10% of the total population (Schneider & Fassin, 2002; Gilbert & Walker, 2002b). There is widespread poverty - mainly among black citizens. Approximately two-thirds of black households live in poverty compared to 6.7% of white households (Gilbert & Walker, 2002b). Even though South Africa is classified as a middle-income country by the World Bank, about 40% of the workforce is unemployed (Gilbert & Walker, 2002b). The majority of the poor have inadequate provision of water, sanitation and electricity, and more than one third of children under 5 years of age are undernourished (*South African Health Review*, 1999; Gilbert & Walker, 2002b). According to Poku (2001:203), these social and economic problems: “create a particular vulnerability to the devastating consequences of the epidemic”.

Education

The apartheid legacy has resulted in significant racial imbalances in education for the poor that lasts to this day (Gilbert & Walker, 2002b). Unlike the US, where most schools are equipped with psychologists, social workers, nurses and guidance counsellors who can help children affected by HIV/AIDS, schools in South Africa offer limited support services, but this kind of support is non-existent in most schools in rural areas. Thus, children who have lost parents or siblings to AIDS are not likely to obtain much support within the school setting. Even if support services were provided by schools, they would probably not be accessed by those children who are orphaned by AIDS, because many have to drop out of school to take care of their siblings. A vicious cycle exists; studies show that youths who are less educated and less skilled are more vulnerable to HIV infection (Shisana & Simbayi, 2002; Evian, 2003). A recent national survey of life skills teachers in South Africa showed that, while most secondary school teachers were knowledgeable about HIV/AIDS, they were only “moderately comfortable” teaching AIDS-related topics (Peltzer &

Promptussananon, 2003). Another concern was that there was insufficient support in terms of resources and materials, from students' parents and religious groups (Peltzer and Promptussananon 2003). The country's higher educational institutions have also been sluggish in responding to the HIV/AIDS pandemic - a significant change in attitudes only began from late 1999 (Martin and Alexander 2002). Through a comprehensive analysis of these institutions' policy documents and practical, programmatic responses (e.g. condom distribution, educational programmes, counselling, campus health care), Martin and Alexander (2002:343) conclude that at this time "No single university provides a model approach to HIV/AIDS that others should follow".

Health care

There are huge disparities between health care facilities in the private sector (which are excellent) versus the public sector. Walker, Reid and Cornell (2004: 73) comment that "health services are most available to the people who need them least. Those who need health care the most have inadequate access to it".

The health care system in South Africa is clearly overwhelmed and poorly equipped to handle the AIDS crisis (Walker, Reid and Cornell 2004). A study of a hospital in Durban showed that almost half the beds in the adult medical wards were being occupied by HIV-infected patients and there were far fewer beds available to non-HIV patients (Colvin *et al.* 2001). A similar study was conducted on the paediatric medical wards at Chris Hani Baragwanath Hospital in Guateng, where the proportion of HIV-infected children admitted rose from 2.9% in 1992 to 20% in 1997 (Zwi, Pettifor and Soderlund 1999). A study of terminal care for hospitalised HIV-infected children in Cape Town showed that 55% of patients experienced pain and distress in their last 48 hours (Henley 2002).

Some public hospitals have had to turn patients away and physicians have been forced to make difficult decisions about limiting treatment and deciding who to save (Henderson 2000; Walker, Reid and Cornell 2004). The desperation is summed up by a local AIDS researcher (Henderson 2000: 20): "We can't afford to spend money on people who are going to die".

AIDS survivors may need help expressing their feelings about their experiences with the health care system. Survivors may feel anger and bitterness over the way the deceased was treated (or not treated). Some may feel guilty that they did not do enough to obtain appropriate medical care for their loved one.

Rehle and Shisana (2003: 7) predict a bleak future for the health care system in South Africa and they state that "it is expected that that the number of people seeking care is likely to increase substantially, 'crowding out' those who suffer from non-AIDS related illnesses. As more AIDS patients need care, staff are likely to experience 'burnout', low morale and increased absenteeism. The health care workers, as part of the community, might also become infected and develop HIV/AIDS-related illness, which will render them unable to provide health care to those who fall victim to the disease. This may result in a non-functional health care system".

Social welfare

In the US people with HIV/AIDS can qualify for a variety of services and benefits, including medical care and ARV drugs, monthly financial support (social security), food stamps and case management services from local community-based organisations that can include help with housing, psychological support and even recreational services (Demmer 2003). On the other hand, welfare support for people with AIDS and their families in South Africa is limited.

The South African social welfare system is unable to adequately meet the basic needs of those suffering from AIDS and their families. Many individuals (including children) who are trying to cope with their loss must summon the energy and determination to embark on the often frustrating and draining process of applying for minimal government benefits. It can take an extremely long time (sometimes up to several years) to process welfare applications and the lack of appropriate documentation (birth and death certificates, identity documents) prevents many people from applying for and receiving welfare support (Walker, Reid and Cornell 2004). This can be a life or death situation for some bereaved families who have no food or shelter.

More than five million children regularly go hungry and, at most, only 12% of the poor children in South Africa receive child-support grants (less than R200 a month) (Walker, Reid and Cornell 2004). Many AIDS orphans must head households and take care of their siblings without help, because if they are under 21 years of age they cannot qualify for grants as the 'primary care-giver' (Walker, Reid and Cornell 2004).

Social workers can become overwhelmed by the plight of individuals and families affected by AIDS and they may experience frustration themselves at not being able to do more for them. A number of voluntary organisations serving people with AIDS and their families have emerged in recent years, but they are largely under-funded and understaffed. A social worker in an AIDS-care unit of a hospital in Durban reported that she was the only social worker for several hundred HIV/AIDS patients, in addition to serving other patients in the hospital (personal communication, 17 January 2004).

ARV TREATMENT AND BEREAVEMENT

For those who have lost loved ones to AIDS in South Africa this is a bittersweet moment in the AIDS epidemic. As ARV treatments are beginning to be rolled out, survivors may feel anger and a sense of unfairness that their loved ones did not live long enough to benefit from the new treatments. We need to consider the impact of ARV treatment on bereavement.

Survivor guilt

HIV-infected individuals who are lucky enough to access ARV treatment and experience improved health will look around and find that many in their social network (family members, friends and other loved ones) are no longer around due to AIDS. In the United States AIDS has wiped out a generation of gay men and survivors are likely to experience loneliness and depression as they face the future alone (Rofes 1998). Bereaved South Africans may experience survivor guilt because many of their loved ones died before they could benefit from the new treatments. They may question why they survived while their friends did not. Social workers should be alert to the possibility that some individuals (those on ARV treatments) may not see a future worth living for as they contemplate the many losses in their life (Demmer 2001).

Treatment failure

It is important that social workers in South Africa realise that ARV treatment will not be effective for everyone who receives it. Research in the United States has shown that, despite widespread access to ARV treatment, some HIV/AIDS patients still die (Demmer 2002a). The reasons for this include:

- Patients may experience initial benefits but then the treatment is no longer effective;

- Patients may fail to respond to ARV treatment because of severely compromised immune systems or drug resistance;
- Treatment may be discontinued because of intolerable side effects;
- Patients may experience great difficulty following complex medication regimens that require extraordinarily high levels of compliance (inadequate adherence will diminish the effectiveness of treatment);
- As patients survive longer, their risk of developing various types of cancers as well as organ deterioration increases, which could lead to death.

Social workers must acknowledge and support the needs of those who are unable to benefit from ARV treatment. Survivors may feel sadness, anger and resentment that ARV treatment failed their loved one.

Anticipatory grief

ARV treatment results in extended survival for many other patients, but a challenge for family members and loved ones is that they will have to cope with a longer period of uncertainty and anticipatory grief (process of anticipating the loss of the patient with AIDS) (Demmer 2001). The unpredictable nature of the disease as well as its longer duration may result in physical and emotional exhaustion among caregivers (Walker *et al.* 1996).

IMPLICATIONS OF AIDS-RELATED BEREAVEMENT

There is substantial evidence that survivors are at risk of prolonged grief and psychiatric problems as they mourn an AIDS death (Houseman and Pheifer 1998; Catalan 1995; Dane and Miller 1992). A study by Summers *et al.* (1995) showed that survivors with unresolved grief were more likely to suffer from major depression and panic disorder. Kemeny *et al.* (1995) conducted a longitudinal study to investigate the immunological impact of bereavement in HIV-infected gay men after the death of their partner to AIDS. Unlike HIV-negative gay men, those who were infected showed immune changes after the death of their partner, putting them at risk of more rapid disease progression.

Another study indicated that some survivors (gay men who were sampled) are more likely to engage in high-risk sexual behaviour as a reaction to the death of a loved one (Mayne *et al.* 1998). The implications of these findings for the local context are deeply disturbing, especially considering the greater obstacles that survivors in South Africa confront on a daily basis. Research is urgently needed in the local context to assess the impact of AIDS-related bereavement on survivors, in terms of physical and psychological health, as well as sexual risk behaviours.

Children

AIDS has left many children without parents in South Africa. There were approximately 666 000 AIDS orphans under the age of 15 years in South Africa at the end of 2001 (UNAIDS 2002). This is compared to 420 000 at the end of 1999 (UNAIDS 2000). As stated earlier in this article, it is projected that there will be more than 2.5 million AIDS orphans by 2010 (Rehle and Shisana 2003).

In addition to the trauma of losing their parent/s to a highly stigmatised and devastating disease, they risk abandonment by extended family members, abuse and neglect, and are vulnerable to a host of physical and emotional problems. Research has shown that AIDS-affected households have

less money to spend on food, clothing and education, and children in poor, female-headed households may have their schooling interrupted (Booyesen *et al.* 2002). Children require assistance with their daily survival needs as well as emotional support. However, welfare organisations are struggling to cope with the needs of children affected by AIDS, and mental health services are not readily available in poor communities (Walker, Reid and Cornell 2004).

Loening-Voysey (2002) and Landman (2002) indicate that AIDS orphans are particularly vulnerable for the following reasons:

- They have witnessed the deterioration, suffering and death of their parent/s;
- They experience multiple losses - not only do they lose both parents, but their siblings may die as well;
- They may be HIV-infected themselves and be in very poor health;
- They are denied their childhood by having to take on caretaker responsibilities and/or becoming the breadwinner in the household;
- They may not be able to attend school, because they have to take care of their siblings, thus reducing their chances of ever getting a job in the future;
- They are deprived of parental love and guidance and have no role models;
- They are more likely to become victims of crime, violence and sexual abuse;
- They may be taken advantage of in foster care placements (their grants may be used to support the whole family or they may be used as cheap labour);
- They may be ostracised by the community, because their parents died of AIDS and they may be driven out of their home.

There is little empirical research on the experiences of children orphaned by AIDS in South Africa. Research is urgently needed on the impact of AIDS on children's physical and psychological well-being, and suitable programmes and policies must be both developed and evaluated (Walker, Reid and Cornell 2004; Loening-Voysey 2002). A study of caretakers (adult women) of orphaned HIV-infected children in Uganda found that caretaker worries centred on the health of the child, poverty (not having enough money to buy food, medicines, or paying school fees), and fearing the early death of the child (Brouwer *et al.* 2000).

Women

Black women in South Africa are particularly vulnerable members of society. Their status and role in society puts them at greater risk of violence as well as of HIV infection (Campbell 2003). They are more likely to be illiterate, have few marketable skills, and to be dependent on men (Van Niekerk 2001). Women affected by AIDS are more likely to get inadequate treatment, have primary responsibility of caring for sick and dying family members, and have the shortest survival rate (Gilbert and Walker 2002b). Women in rural locations are more likely to die than those in urban areas and they are subjected to greater economic hardship and lack of access to primary care (Booyesen *et al.* 2002).

The elderly

The physical, economic and psychological toll of AIDS on the bereaved elderly in South Africa is immense, but there are few interventions to support them. AIDS in Africa has also been called the

'grandmother's disease' because older women are expected to care for their grandchildren as they watch their own children die (Moller 1997). They are expected to take in children orphaned by AIDS and to feed, house, clothe and educate them, as well as care for them if they are HIV-infected and later bury them (Williams and Tumwekwase 2001). They are deprived of any support in their old age that their deceased children would have provided. Williams and Tumwekwase (2001:231) report on the personal as well as community grief that is experienced by elderly residents of a rural Ugandan village and states that "To lose one's children not only means that one will not be honoured by a fitting funeral, but that there will be no-one left alive to record one's contribution to one's clan, or one's very existence".

Little research has been done on the health care needs of elderly caregivers of AIDS orphans, even in the US. Joslin and Harrison (2002) indicate that older adults who raise HIV-orphaned and -affected children are likely to be 'hidden patients', meaning that their own health needs are neglected because of their care-giving responsibilities. In their US study of 20 caregivers (mostly grandmothers) of HIV-orphaned and -affected children Joslin and Harrison (2002) found that more than half rated their own health as 'fair' or 'poor', and 70% reported that they did not have enough time to attend to their own health.

Gay men

While most research on AIDS-related bereavement in the US has been conducted among gay men, little is known about the experiences of gay men who have lost loved ones in the South African context. No data are available in South Africa that delineates the breakdown of AIDS by mode of transmission or population group, so it is unknown what proportion of gay men are infected and how many AIDS deaths have occurred within the gay community. Gay men in South Africa are subject to the same stressors as gay men in developed countries, but probably to a greater degree. South African gay survivors must cope with the death of loved ones in an environment where both homosexuality and AIDS are highly stigmatised. Unlike the US, where a host of service organisations are available nation-wide to serve the needs of gay clientele, there are far fewer resources in South Africa that are structured to meet the specific needs of gay AIDS survivors. Gay men appear to be an invisible group of grievers in South Africa.

HIV/AIDS service providers

Social workers who work with people with AIDS and their survivors must deal with issues surrounding ongoing loss (Demmer 1999a). It is crucial that social workers in this setting confront their own fears about death (Killeen 1993; Saloner 2002), otherwise they may be insensitive to the needs of bereaved survivors due to their own discomfort in the presence of death and dying (Dane and Miller 1992; Demmer 1999b).

Van Rooyen and Sewpaul (1993) wisely advocate that social work educational institutions in South Africa should place more emphasis on preparing students to meet the challenges of AIDS, and that curricula should include the issue of grief, death and dying. It is essential that education continue at the workplace, through in-service training and supervision, and support groups need to be developed to assist social workers in dealing with the stresses of AIDS work (Dane and Miller 1992; Demmer 1999b). When social workers are untrained and unsupported, their ability to provide effective services to those affected by AIDS is diminished (Demmer 2002b).

INTERVENTIONS FOR BEREAVEMENT

Most of the people in South Africa affected by HIV/AIDS are disadvantaged in terms of socio-economic status, race and gender (Van Rooyen and Bernstein 1992; Fassin 2003; Gilbert and

Walker 2002a). Those who are infected are primarily black and poor. Thus the target population most in need of support with AIDS-related bereavement is black women in impoverished circumstances. These women must struggle with multiple stressors on a daily basis, including extreme poverty, lack of support services and social stigma as they care for sick relatives and grieve losses (Mitton 2000; Van Niekerk 2001). In addressing the needs of AIDS survivors, social workers are encouraged to develop “holistic, multifaceted interventions at all levels from individuals and families, to bureaucracies, communities, and national policies and programmes” (Gray and Mazibuko 2002:191). Granted, this is a tall order indeed.

Research

There is no doubt about the important role that social workers can play in the current context of HIV/AIDS in South Africa (Saloner 2002). But social workers in South Africa have been criticised in the past for being slow in responding to the challenge of HIV/AIDS; a major reason for this may be because they have not felt prepared, in terms of knowledge and skills, to address the complex issues involved in working with individuals affected by HIV/AIDS (Van Rooyen and Bernstein 1992). There has not been much evidence in South African professional literature of defining and positioning the social worker’s role in confronting the HIV/AIDS pandemic. A review of the social work journal *Social Work/Maatskaplike Werk* over the past ten years yielded only a handful of articles on HIV/AIDS; this is disappointing considering the sheer enormity of the AIDS crisis in South Africa. In defence of the social work profession, however, a similar judgement can be made about the psychology profession. There have been few articles on HIV/AIDS in the *South African Journal of Psychology* since the publication of a special issue on this topic in 1995.

With regard to AIDS-related bereavement, there is scant mention of this important issue in the handful of articles on HIV/AIDS in South African social work and psychology journals. Saloner (2002) briefly mentioned AIDS-related bereavement in her article on the role of social workers in addressing HIV/AIDS in South Africa. The same was true for Lindegger and Wood (1995), who looked at the role of psychologists in addressing HIV/AIDS in South Africa. Strydom (2002) conducted a qualitative study of the feelings and perceptions of AIDS patients attending a clinic at the Potchefstroom Hospital in South Africa; what is interesting is that participants hardly mentioned any thoughts about death or coping with the deaths of others from AIDS, which is surprising considering the high probability of death associated with AIDS as well as the numerous losses that people face as a result of the AIDS pandemic. It appears that the interviews, which were semi-structured, most likely did not incorporate questions that spoke directly to the issue of loss and bereavement. Again, this omission seems odd considering the enormous death toll from AIDS in South Africa.

Professional preparation

Saloner (2002: 155) takes the position that, because there are fewer than 10 000 registered social workers in South Africa working in a context of several million infected people, the primary role of social workers in the AIDS pandemic should be disseminating “skills, knowledge and attitudes (SKAs)” to various “professional bodies” broadly defined as “medical professionals, active youth groups, women’s projects, the business sector and allied health professionals”. Saloner acknowledges that social workers need to have sufficient training in dealing with HIV/AIDS issues. I believe that before advocating a role of “AIDS trainer” for social workers, it would seem wise first to conduct an assessment of the nature and extent of AIDS-related social work education in South Africa. The last known survey of this type was conducted in 1992 (Van Rooyen and Bernstein 1992). It would also be prudent to conduct an assessment of the perceived capability of

practising social workers who work with people affected by HIV/AIDS. Such a survey could examine their perception of what would be appropriate preparation for this work, their perceptions of their own competence in assisting clients affected by HIV/AIDS, and it could explore their training needs as well as suggestions for enhancing the role of the social work profession in dealing with the HIV/AIDS pandemic in South Africa.

A substantial number of South Africans are mourning the loss of loved ones to AIDS and social workers can help them work through the grief process as well as address issues that typically make AIDS-related bereavement more difficult. It is normal not to know where to begin and to feel frustrated and confused by the variety of bereavement models and theories of grief present in the literature. Social workers who are overwhelmed by the grief of their clients and those who feel ill-equipped to address AIDS-related bereavement may avoid this issue altogether in their practice. This would indeed be unfortunate, because when the needs of the bereaved are ignored, their risk of complicated grief increases. Strategies can in fact be developed to help AIDS survivors cope with the complex nature of their bereavement (Sikkema et al. 1995; Walker et al. 1996).

Bereavement assessment

A first step for social workers is to recognise the social context of AIDS, acknowledging the diverse grief experiences, beliefs and rituals of various cultural groups (Mallinson 1999; Bernstein and Van Rooyen 1994). Strategies or interventions should be implemented that meet the unique bereavement needs of individuals from various backgrounds. A thorough assessment of the bereaved individual should be conducted before decisions about therapeutic intervention are made. Information must be gathered about the following: circumstances of the death, relationship with the deceased, history of loss, coping style, physical problems, existence of support systems, spiritual and religious beliefs, and cultural background (Demmer 2002a).

Individual counselling

In their casework role social workers can help family members and significant others cope with issues that typically make AIDS-related grief difficult. Social workers should know that there is no single grief theory or approach for working with those grieving an AIDS death (Mallinson 1999). In fact, current grief theories have been criticised as being inadequate for addressing the extent and complex nature of AIDS-related bereavement (Schwartzberg 1992).

The following are guidelines for counselling individuals grieving an AIDS death (Worden 1991; Cook and Dworkin 1992):

- Assess the bereaved individual;
- Help the bereaved accept the reality of the loss;
- Help the bereaved identify and express their feelings;
- Assist the bereaved in living without the deceased;
- Help the bereaved establish a new relationship with the deceased;
- Provide opportunities for the bereaved to grieve and to obtain ongoing support;
- Give the bereaved permission to grieve their own way;
- Identify effective and ineffective coping behaviours;
- Identify pathological grief responses and make professional referrals.

The following are useful activities and techniques (Worden 1991; Cook and Dworkin 1992; Niemeyer 1998):

- Open-ended questions/probing to explore the impact of the loss and to develop deeper insight into the thoughts and feelings of the bereaved;
- Use of symbols such as photos of the deceased to help the provider get a better sense of the deceased and to help the bereaved talk to the deceased rather than about him or her;
- Have the bereaved write a letter or poem to the deceased or keep a journal;
- Have the bereaved, especially children, draw pictures to help reflect their feelings and thoughts;
- Role play situations to help the bereaved express their feelings and build their social skills;
- Have the bereaved make a memory book of the deceased that can include photographs, letters, drawing, memorabilia, etc.;
- Record the life story of a loved one;
- Recommend books that can provide information, guidance and comfort;
- Use of psychological techniques such as reframing, cognitive restructuring and directed imagery.

Support groups

Besides individual counselling, support groups can be useful tools for helping the bereaved (Barroso 1997). Sikkema *et al.* (1995) describe the development of a group intervention for people experiencing AIDS-related bereavement in the US. This intervention combined cognitive behavioural and support group approaches, and contained six components: developing social support and group cohesion, identifying and expressing emotions, identifying coping challenges specific to AIDS loss, recognising current coping strategies, setting goals and implementing adaptive coping strategies to reduce distress. Common concerns and issues for participants of the group included feelings of helplessness and guilt, anger and resentment, mental replay of the partner's death, the difficulties of grieving when being HIV-infected and the impact of multiple losses on developing new social relationships. Overall the group intervention resulted in improvements in participants' adjustment to AIDS-related loss.

Goodkin *et al.* (1999) demonstrated the positive effects of a bereavement support group intervention for gay men in the US. Their bereavement support group consisted of 10 sessions and combined cognitive-behavioural strategies, social support and stress management training. Using several standardised measures, they found that the intervention reduced overall distress and accelerated grief reduction in the bereaved participants. Goodkin *et al.* (1999) recommend the use of bereavement support groups for anyone who has experienced the loss of a loved one to AIDS, and not just individuals with psychopathology or at high risk of subsequent maladjustment.

Monahan (1994) provides useful tips for establishing and facilitating AIDS bereavement support groups. They include the following:

- Announce the establishment of the group through a sponsoring organisation;
- Select a group leader who is knowledgeable about AIDS and the grief process;

- The group can be open-ended, a drop-in style group, or closed and time limited (open only to members and meeting once a week for 90 minutes over 6-10 weeks);
- Make the group available to anyone who is interested, but make them register in advance so that you can predict group size and composition, and ask participants to complete a brief screening/information form;
- Strive for a heterogeneous group (i.e. anyone who is grieving an AIDS-related death);
- Encourage individuals to join who experienced the death 2-14 months ago;
- Educate members about the ground rules for the group (e.g. confidentiality, everyone has a right to be heard);
- Establish some sort of structure for the sessions (e.g. each session could have a specific topic, but be open to changing the topic if the group wants to talk about something else);
- Arrange for the group to meet in a 'hope-filled, supportive environment' that does not provide painful reminders of the deceased;
- Provide handouts and brochures that members can take home with them.

Weiner (1998) reported on a unique type of support group - a telephone support group for HIV-infected mothers whose children had died of AIDS in the US. The group consisted of 5 mothers who lived far apart from each other. Sessions were conducted at pre-arranged times and the group was conducted over the telephone for a total of 12 sessions. Weiner (1998: 284) concluded that this modality was "a practical, cost-effective, and therapeutically sound means of reaching people who may not geographically or emotionally be ready to attend face-to-face groups".

Memory box projects

A bereavement intervention that has become very popular and well-known in Africa is the memory box, which is also relatively inexpensive. Both dying parents and their children work together on collecting a variety of things and placing them in metal or wooden box. Anything can be put in these boxes including photographs, birth certificates, a letter from the parent, audiocassettes capturing stories and voices, drawings and mementoes. Children can also decorate the boxes. Another option is to make a memory book and fill it with documents, letters, drawings, poems, family trees, etc. Memory boxes or books should not be thought of as symbols of dying, but rather they can provide a sense of personal history and identity. They can also be used in support groups and members can share their boxes or books with other members (Blom and Bremridge 2003).

Developmental approach

Gray and Mazibuko (2002:199) indicate that changes in the past decade in South Africa require social workers to shift their orientation from primarily casework and they recommend "greater use of diverse social work methods, such as advocacy, community development, empowerment, consultation, networking, action research and policy analysis"

We need to go beyond merely identifying suitable and willing members in the community to take on the responsibility of caring for children affected by HIV/AIDS in South Africa (Sewpaul 2001; Loening-Voysey 2002). Many social workers in non-profit organisations (NPOs) are concerned about the state's expectations of services they must provide to those affected by HIV/AIDS, particularly since NPOs are so severely under-funded. Loening-Voysey (2002) states that there is a

lack of collaboration between the state and NPOs, and inefficiency on the part of the state is a particular obstacle to the delivery of services to people affected by HIV/AIDS. There is no way of getting around the fact that NPOs in South Africa, which bear the primary responsibility for the delivery of services to those affected by HIV/AIDS, need more funding to adequately address the impact of the HIV/AIDS pandemic (Foster 2002). Loening-Voysey (2002) makes the following recommendations:

- There needs to be more networking and ‘cross-fertilisation’ among NPOs and sharing of resources and lessons learnt;
- State departments need to become more efficient and speed up services (e.g. state support grants to those with no income);
- NPOs need to strengthen their ability to engage in policy analysis;
- A non-government ‘watchdog’ could be created to monitor state department reports, policies and services;
- There needs to be a better working relationship and communication between the non-profit sector and the state departments.

Rehle and Shisana (2003:7) state that the large number of AIDS orphans in South Africa “warrant intensified interventions to provide care for these children within homes, through a combination of programmes that aim to keep children in child-headed households and foster care homes. The children should be kept in schools to equip them to be productive members of society as they get older. The country will need to ensure food security and nutrition for them, and also provide health care for them, particularly as some may already be living with HIV/AIDS”.

In a qualitative study of AIDS-affected children in Lesotho and Malawi, Young and Ansell (2003) found that up to half of the children had been sent over long distances to live with kin. The authors recommend that AIDS policies consider the difficulties experienced by young AIDS migrants and policy interventions need to support and empower children in the migration process.

CONCLUSION

Death is a normal part of life and so is grief. However, grief stemming from an AIDS death is likely to be exacerbated because of a number of factors such as greater social stigmatisation, less social support, a greater reluctance to disclose the cause of death, multiple losses and the HIV status of the bereaved (Dane and Miller 1992). Because of the context of AIDS in South Africa, it is likely that survivors may experience these factors with even greater intensity than survivors from more developed countries. AIDS survivors in the local context have to confront additional stressors that are not common in developed countries, such as a grossly inadequate health and social services, minimal governmental assistance, and extreme hardships in daily living such as lack of food, water, housing and widespread employment (Mitton 2000).

The future role of social work in addressing the AIDS pandemic in South Africa is daunting, yet promising. In recent years social workers and NGOs have taken the initiative and developed innovative community-based programmes, particularly for children infected with and affected by HIV/AIDS (Sewpaul 2001).

A challenge facing social workers is finding the ‘time, energy and skills’ to help the AIDS bereaved (Wiener 1998). There is no doubt that a variety of grassroots projects exist that provide bereavement counselling for AIDS survivors, but accounts of them have not yet found their way into the academic literature. Universities and researchers can play a role in collaborating with local

social workers, volunteers and activists in documenting these projects. One example of an innovative community project is the Rob Smetherham Bereavement Service for Children, which is attached to the uMngeni AIDS Centre in Durban (Jewitt 2001). The project provides psychosocial support for bereaved children, particularly those whose parents have died or are dying of AIDS. Activities include providing support and counselling to bereaved children as well as those involved in the care of these children, group play therapy for the children, and community work that involves raising awareness of the needs of bereaved children and their families, and training community members to meet the emotional needs of children affected by AIDS.

Research on AIDS-related bereavement in the South African context is in its infancy, to say the least. One solution is to create opportunities for collaboration between social work researchers and practitioners in the local context with those in more developed countries. Researchers in countries such as the US can share their expertise on AIDS-related bereavement with their South African counterparts. This has already been done in the arena of HIV prevention in the prison system, where researchers from the South African Medical Research Council and the Department of Correctional Services forged links with researchers from Emory University in Atlanta, Georgia (Reddy, Taylor and Sifunda 2002). Collaboration and research capacity building between researchers from developed countries and less developed countries have the potential of advancing knowledge about AIDS-related bereavement in South Africa, provided that there is mutual recognition and respect for the talent of all partners. It is of the utmost importance that collaborative efforts recognise the unique characteristics of the local context as well as the skills and talent that are available in this context.

Kasiram and Partab (2002:43) express the opinion that “death in South Africa is embraced with warmth, care and compassion”. This may be a somewhat simplistic and overly optimistic view, especially when one considers the context of AIDS. Nevertheless, social workers can strive to make this a reality for all those who are suffering the loss of loved ones to AIDS in South Africa.

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