

Chapter 17

Loss, Grief, and Bereavement

Overview

Grief and loss are expressed in a multiplicity of words and languages by different peoples. A wealth of diverse ritual serves to guide people in societies through the grief process. It is important to note that even within the same country in Africa, different tribes may have different practices.

In sub-Saharan Africa, the high incidence of AIDS-related death means that many families experience multiple losses and ongoing loss becomes a way of life. In this part of the world, which already experiences high rates of other losses, such as unemployment, poverty, and malnutrition, bereavement through AIDS worsens people's circumstances and removes from communities those who might otherwise have helped to feed their families.

This chapter considers the nature and process of grief, the specific aspects of loss and grief around an AIDS-related death, and the type of support families may find helpful after an AIDS-related death. For issues related to children, see Chapter 30: Loss, Grief, and Bereavement in Children.

Palliative care is a holistic approach to medicine that does not end with the death of a patient. Caring for the bereaved is a responsibility and a privilege. In AIDS-related deaths, the bereaved face significant issues that can complicate their grief process. Interventions that incorporate a holistic approach to grief and loss can facilitate the bereavement process, possibly improving the bereaved person's ability to function, reducing some of the pain experienced, and providing an opportunity for transformation.

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At a Glance

The Language of Grief

Anticipatory Grief

Factors Affecting the Grief Process

Stages, Phases, and Tasks – Ways of Addressing Grief

Supporting the Bereaved

References

Suggested Resources

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Table of Contents

Overview	249
The Language of Grief	251
Anticipatory Grief	251
Factors Affecting The Grief Process	253
Stages, Phases, and Tasks – Ways of Addressing Grief	256
Supporting the Bereaved.....	258
References	260
Suggested Resources.....	260

The Language of Grief

Grief is the normal, dynamic process that occurs in response to any type of loss. It encompasses physical, emotional, cognitive, spiritual, and social responses to the loss. It is highly individualised, depending on the person's perception of the loss, and influenced by its context and concurrent stressors.

Mourning is often used interchangeably with grief, but mourning more specifically refers to the public expression of grief. This public expression (perhaps crying or wailing) does not necessarily relate to the significance of the loss; it is usually related to cultural and religious values and encourages social support for the mourner.

Bereavement is the state of having suffered a loss and incorporates the period of adjustment in which the bereaved learns to live with the loss.

Complicated mourning arises from an interrupted or obstructed grief process, and can result in potentially harmful outcomes, from somatic discomfort to chronic emotional distress, and even the possibility of death. Many of the risk factors that can lead to complicated mourning apply to AIDS-related deaths.

Anticipatory Grief

Grief begins as soon as a loved one develops symptoms perceived as life-threatening, rather than beginning only at the person's death. This has been called anticipatory grief. Although both the person with AIDS and his or her carers experience anticipatory grief, it does not replace the necessity of grieving after the death. Studies of anticipatory grief have been inconsistent in determining whether grieving before the death shortens the bereavement process afterward or eases the pain of grief.

Anticipatory grief includes changing assumptions; adapting to role changes; balancing the need to stay separate from, yet involved with, the patient; and experiencing feelings of sadness, depression, and anxiety. Anxieties at this time typically revolve around the future care of children, especially if the person with AIDS is a single parent. The practical issues of life take precedence — how to feed the family, get the person to the toilet, and prevent the neighbours from finding out about the illness.

If the illness is prolonged, the period of anticipatory grief may become problematic. Those caring for the person with AIDS may emotionally withdraw too soon and experience ambivalence about the length of the illness and caregiving responsibilities. This can lead to feelings of guilt during the illness and bereavement. Another complicating factor is that because the caregivers often are also HIV-positive, they may be confronting their own health challenges and mortality in addition to the threat or the prospect of losing a loved one.

Effects of Stigma on Anticipatory Grief

People can only complete their unfinished business — whether practical, emotional, or spiritual — if they are aware of the life-threatening nature of their own or their loved one's illness. But in some cultures it is taboo to talk about death and dying, and this belief must be respected. Whilst some people in urban areas may need the opportunity to return to their rural family home to die, others may believe that talking about death will hasten its arrival.

In South Africa, and likely in other sub-Saharan countries, the stigma associated with HIV/AIDS is such that relatives may be unaware that their loved one is infected with HIV. For example, a grieving Xhosa mother, who had cared for her daughter, reported that the daughter had not informed her about her illness, and she learnt it was AIDS only when she visited the daughter in hospital and read the chart (Nieuwmeyer, 2003). Even if uninformed, others will have suspicions about the nature of the illness because they notice certain physical changes in the ill person's body.

Facilitating the Anticipatory Grief Process

The palliative care team should be aware of the process and common themes that emerge during anticipatory grief because their outcomes may have an effect on caregiving and the emotional status of the person with AIDS. Team members can assist individuals in handling their anticipatory grief in ways that enable them to take care of themselves and their loved one (Rando, 1986), including:

- Helping to address practical issues, such as food, accommodation, and care for their children
- Identifying and legitimising feelings of sadness, anger, guilt, and anxiety
- Encouraging expression of feelings in privacy
- Enabling them to complete unfinished business
- Encouraging them to live fully and enjoy life whenever and wherever they can

Life Review and Memory Work

As people face their death, they want to know they will be remembered and that their life has had meaning. Engaging patients and caregivers in life review and memory work are effective interventions in coping with anticipatory grief. This can include using religious rituals, meditation, photography and/or videos, and journeys (one last trip to a favourite place) as therapeutic tools. Tradition in Uganda and elsewhere requires that the close family gather around the bedside of the dying person. Instructions are given for burial and the rituals to be followed. Any important 'last words' will be said.

In South Africa and elsewhere, community health workers assist parents — usually mothers — to create memory boxes that contain important legal documents and significant items about their lives and family history for their children to have after the parent's death (Morgan, 2001). Documents will include the children's birth certificates, family photographs, drawings, simple wills, family trees, and other items for children to open up and appreciate later. The box which houses them can be of cardboard, wood, or metal, according to availability, and can be decorated on the outside.

Factors Affecting The Grief Process

Several factors affect the length and intensity of the grief process and the bereaved's movement through it. Many of the factors experienced by those dealing with AIDS-related deaths are significant risks and often complicate the grief process, leading to potentially dangerous health outcomes.

Nature of the Relationship Between The Bereaved and the Deceased

Generally the greater the bond between the deceased and the bereaved, the greater the grief experienced. The type of bond (parent, child, partner, sibling) does not necessarily indicate the intensity of grief; every relationship is unique. However, the death of a child is usually considered a high risk for the bereaved parent(s). An ambivalent or co-dependent relationship with the deceased can also complicate the grief process, as the bereaved may face intensified emotional responses (Worden, 1991).

Children

Children who have been cared for by a single-parent mother and whose relatives are not available, unable, or unwilling to help them may become a child-headed household, with or without accommodation. These children need support and assistance from state and welfare organisations. Many areas in sub-Saharan Africa do not receive enough practical assistance from non-government and faith-based organisations. In the past, the extended family would have done their best to care for orphans within the family. But with the high level of unemployment and poverty, fear of HIV/AIDS, and fewer adults alive to care for children, many extended families have reached their limit.

Symptoms and Side Effects

People in communities notice when others lose weight. If toilets are separate from dwellings — as in informal settlements (shacks) — it becomes obvious if someone is frequently using them. Diarrhoea is known to be a symptom of AIDS. Rashes and pustules are noticed, and AIDS dementia with mental disorientation cannot be hidden away. Family and neighbours may be fearful of these signs of infection and withdraw from the ill or bereaved person.

Stigma

Because of the widespread stigma associated with HIV/AIDS, the surviving partner may find him/herself without adequate support for resolving feelings and experiences around the death of the loved one. The fear and lack of support for the AIDS bereaved can lead to what is called 'disenfranchised' grief because it is not socially accepted or supported. AIDS stigma can lead to a breakdown of 'Ubuntu' — the mutual caring for others within the community, the sense that 'I am because you are, and because you are, I am' (Tutu, 1999) — and result in unavailable essential support.

After the death, the bereaved person may mourn alone, feeling unable to talk about the partner, child, or parent who died. The infected survivor's grief process may be complicated by fears for her/his own health and continued need for secrecy, so there is no opportunity to share at the very time when open talking and support are most needed. The partner who was not married to her deceased boyfriend may be harshly excluded from the funeral and even accused of killing him by her boyfriend's parents. In many parts of sub-Saharan Africa, the partner who first falls sick and later dies is usually blamed for infecting the other partner. In South Africa, Xhosa-speaking men often believe it is women who spread HIV, though the reverse is more often the case. In some cultures women are traditionally viewed as 'polluted' or 'contaminated', and this has made it easier for men to blame women for spreading HIV.

Lack of Disclosure

The need for openness or secrecy about HIV/AIDS varies throughout sub-Saharan Africa. For example, there is a greater level of public acceptance in Uganda, whilst there is a high level of secrecy, stigma, and non-disclosure in South Africa. Patients sometimes choose not to inform family that they are HIV-positive. There can be dangers in pressuring a woman to disclose to her sexual partner because physical violence and even death can follow. A mother may fear losing her children's esteem if she tells them she is infected with HIV. Health professionals should encourage a patient to inform the sexual partner at diagnosis but have to respect the person's decision. When the patient requires much more care, health professionals will seek permission from the patient to inform the caregiver.

Cultural and Religious Beliefs and Practices

The palliative care team should be familiar with the different cultures and belief systems within the areas they serve. In sub-Saharan Africa these professionals and lay workers will often be members of the same communities, so will have this understanding. Overall it is important for community health workers to be culturally sensitive and respectfully acknowledge the client's expertise and knowledge of his/her own body, circumstances, and culture. By asking clients to enlighten them, health workers can help empower clients and give them a sense of control in a situation where they face increasing loss of control.

In Xhosa, Zulu, and other communities, it is customary that members of a church visit the bereaved person or family every evening until the funeral to pray with them. In Zimbabwe, Kenya, and Malawi, people stay with the bereaved for at least three days. Islamic communities will also pray with and support their members in a structured way over a 40-day period. It is important to note that people in faith-based

organisations may hold judgmental attitudes towards an obviously infected person or a bereaved family member. They may think that the person with HIV has defied religious or traditional teachings by engaging in pre- or extra-marital sex or sex work. Judgmental attitudes from those who should support the person can actually intensify grief reactions.

The funeral is an important event. The tradition in many cultures is that everyone's hair is cut, but this practice is now changing. Many families pay into traditional burial societies and will receive a pay-out for funeral costs. Others are prepared to run into huge, even crippling, debt to be satisfied that the person who has died and the ancestors will be pleased.

With the increase in AIDS-related deaths, not all family members are insisting on traditional burial at the place of birth. In some societies in Zimbabwe, it is now accepted that families do not have to feed the mourners present, another practical adaptation to the enormous increase in deaths. In Malawi, everyone is buried in a cemetery in a rural area, and graves may be visited only by permission of the local chief and committee. Graveyards and cemeteries are associated with witchcraft in many people's minds. In rural Kenya, widows may visit the grave in the early morning for extended periods of time. Although there is more support and openness about HIV/AIDS in Kenya, it seems that many people still do not tell others what caused the death.

The palliative care team must be mindful of traditional rights of succession in assisting the dying person. For example, in some societies when a mother has died and young adult children are living in the dwelling, a family member on the mother's side may arrive and claim the home as his property. This may or may not be a problem, depending on the individual circumstances.

Personality Traits and Coping Style

The personality traits and coping style of the bereaved will also impact on the bereavement period. There is no 'right' or 'wrong' way to grieve (as long as it is not harmful to the bereaved or another); the key is to find what works for that particular person. Some people will never shed a tear publicly, while others will cry every day for months. Talking about the loss and expressing feelings related to the death can be very healthy for some people, yet threatening for others. For example, someone who deals with grief by accomplishing tasks may not find it helpful to be part of a bereavement support group that encourages expressions of feelings.

Bereavement Overload

The excessive number of AIDS-related deaths in some communities can cause what is often called 'bereavement overload', which can lead to unhealthy physical, emotional, and spiritual responses. Besides the deaths of many loved ones and friends, the bereaved may also experience other losses, including loss of their community, meaning and purpose, privacy, or their role in society. Coping with bereavement overload and multiple losses increases the risk of a complicated grief process.

Other Stressors

The grief process can also be complicated by other stressors, including mental health or substance abuse issues, and problems with physical health. If the bereaved survivor is also living with HIV, he or she may experience normal physical grief reactions that can mirror AIDS symptoms. For example, weight loss is a typical physical grief response, yet can also be a symptom of AIDS-related wasting. The inability to concentrate, a common cognitive response, can also look like a symptom of dementia. It is important in these circumstances to refer the bereaved for appropriate medical evaluation.

Substance abuse issues can complicate the grief process in several ways. Survivors may experience guilt related to participating in activities that increase the risk of HIV transmission. Using drugs and/or alcohol as coping mechanisms during bereavement often leads to complicated grief because these methods of coping mask the actual grief responses and can limit the opportunities for the bereaved to deal fully with their grief issues.

Stages, Phases, and Tasks – Ways of Addressing Grief

Recent models of bereavement describe grief as a dynamic process in which certain themes can be distinguished and personal growth and transformation can emerge as possible outcomes. Accommodation is perhaps a more appropriate goal of the grieving process rather than the traditional focus on resolution, recovery, or completion. Accommodation implies an active process of adapting to fit specific circumstances, rather than a linear process with a final endpoint (Rando, 1993).

Traditional bereavement models usually describe grief that results from a single loss, but the experience of bereavement overload because of multiple losses from AIDS challenges these frameworks. Although the ‘models’ that have emerged from western cultures may not be suited to African situations, the authors of this chapter — who represent five countries in sub-Saharan Africa — nevertheless feel these models can help in more fully understanding the grief process.

We use William Worden’s ‘tasks of mourning’ below to illustrate the grief process (Worden, 1991). Worden intentionally uses the phrase ‘tasks of mourning’ to emphasize that dealing with grief takes effort; hence ‘grief work’. Worden acknowledges that the tasks do not have to follow a specific order and that people can work on more than one task at a time.

Task 1: Accept the Reality of the Loss

The first task of mourning is to acknowledge and accept the reality that the person is dead and will not return.

This can take time, as the bereaved often experience a period of numbness, shock, and disbelief even if the death was expected. The bereaved may experience a period of searching or yearning for their loved one. Some people report that they expect to see their loved one when they arrive at home, calling out before remembering that the person is gone. Others find themselves continuing their old routine, such as setting the table for two. The bereaved may even refer to the deceased loved one in the present tense or use the present and past tense together in the same conversation.

Traditional rituals such as funerals or memorial services can help people accomplish this task. This public good-bye helps people confront the finality of the death. Often the first visit to the cemetery reinforces the finality of the loss as well.

The primary aim of grief support at this task is to help people accept the reality of the loss in their own time and at their own pace. It may take days or weeks for the reality to be accepted, even longer for it to be fully absorbed.

Task 2: Experience the Pain of Grief

The second task of mourning is to express the pain of grief in a healthy way.

The pain of grief includes physical, emotional, behavioural, cognitive, spiritual, and social responses to the loss. This task is crucial because if the bereaved cannot, or does not, acknowledge the pain of grief in some way, these responses could manifest themselves in unhealthy ways. Coping with the pain of grief is unique for each individual.

As noted, survivors who are themselves HIV-positive may experience normal **physical responses** to loss as well as symptoms of AIDS if their own infection is advanced. Medical evaluation is needed to distinguish these.

People experience a wide range of **emotional responses** in connection with grief. The initial shock and numbness usually subside after a few weeks or months and thoughts and feelings that were present all along begin to surface. While some people need to express their feelings and talk about the loss repeatedly, others do not experience grief emotionally and therefore do not need to process their feelings. Some may even experience dissonance if painful feelings are experienced but are unable to be expressed: 'I may appear normal on the outside but on the inside, I'm screaming'.

Sleep disturbances and appetite changes are the most common behavioural responses.

Behavioural responses may vary due to cultural and gender factors, but most cultures permit crying as an acceptable response to death. The bereaved should be wary of the risk of increased use of alcohol, tobacco, and tranquilizers.

The **cognitive responses** to loss may be the primary way some people experience grief. Initially many bereaved report a fear of 'going crazy', education and normalisation of the grief process may help assuage this fear.

Spiritual responses to loss are also highly individual. Even those who have a strong spiritual or religious belief system may not be comforted by their beliefs. One of the crucial aspects of the spiritual response to loss is the ability to make meaning from the experience.

The **social response** to loss is often overlooked. But in AIDS-related deaths, people may be coping with social isolation due to stigmatisation.

Task 3: Adjust to the Loss

The third task of mourning is to develop the skills and fill the roles needed to move forward without the physical presence of the deceased.

This can usually begin only after several months of dealing with the loss. It may include adjusting to living alone, being a single parent, getting a job, learning to manage finances, or taking on household tasks. For those dealing with HIV themselves, it can also mean needing to find other caregivers.

Part of adjusting to the loss is facing all the significant 'firsts' that occur in the first year of bereavement. Coping with the first holiday, birthday, or anniversary without the loved one can trigger a temporary upsurge of grief, including a return of physical symptoms, various emotional responses, changes in social behaviour, and spiritual distress. These temporary reactions must be distinguished from complicated grief, and should not be misdiagnosed as pathological responses.

Task 4: Reinvesting Energy From the Deceased Into New Life

The fourth and final task of mourning entails transferring the emotional energy invested in the relationship with the deceased into new, healthy approaches to life.

Working through this task does not mean the deceased is 'forgotten' or that the bereaved has 'obtained closure', but that the bereaved can establish a new connection with the deceased that can transform their new life.

Reinvesting the emotional energy into new life may include gestures such as considering the deceased's perspective in a difficult situation or wearing a locket with a picture of the deceased. Others may reinvest this energy outward in sociopolitical activity such as becoming active in an AIDS organisation or creating a memorial for the deceased.

Some bereavement experts encourage a continued relationship with the deceased by mentioning the person who has died in conversations with the bereaved. This inclusive attitude may be helpful in the healing of the grieving person and seems to provide relief. Maasdorp and Martin (2004), Zimbabwean writers, note that maintaining a continuing bond with the deceased is a natural way of coping with grief in cultures which believe in the ongoing presence and intercessions of ancestors in their daily lives.

In general the signs that bereaved people are learning to accommodate their grief include:

- A return to good health (or their health status before the death of their loved one)
- Acknowledgment of the reality of the loss
- Redefined identity
- Emergence of new skills or roles
- Establishment of or reconnection with a social support system
- Ability to cope effectively with temporary upsurges of grief
- Comfort with the quest to find meaning
- Personal growth/transformation

It is important to understand that those who grieve the death of a loved one never truly 'get over' the loss. Even after people accomplish the tasks of mourning, the pain of the loss is still present though hopefully less intense and more manageable.

Supporting the Bereaved

Members of the palliative care team can reach out and support the AIDS bereaved in a variety of ways.

Reaching out to the bereaved: Acknowledge the loss, share memories of the deceased, give permission to grieve, and do not take sides in family disputes.

Assessing the bereaved person/family's physical/situational needs: Acknowledge and assist when possible with practical difficulties, such as assisting with developing income generation skills or registering children's births if they are unregistered.

Networking with other resources and organisations: Palliative care workers should be networked with community and faith-based organisations that can assist bereaved individuals, families, or child-headed households.

Visiting the bereaved/family: The bereaved appreciate gestures and expressions of condolence and sympathy, including telephone calls, cards, and visits.

Providing details about the deceased's illness and treatment, as appropriate: Many bereaved people find it helpful to meet with the physician or members of the health care team after a loved one's death to review the course of treatment. The bereaved need reassurance that they did everything possible and did not 'cause' their loved one's death.

Taking cues from the bereaved about their wishes to remain in contact (or not): Some people may not wish to remain in contact with the palliative care team because it reminds them of their loved one's illness and death.

Educating the bereaved about 'normal' responses to grief: By learning what typical physical, emotional, spiritual, cognitive, and social responses they can expect, the bereaved can have less stress and anxiety in facing the pain of grief. This includes reassuring them that it is normal to experience upsurges in grief related to significant days or events, such as birthdays, anniversaries, and holidays, or simply at random.

Encouraging good self-care: Remind the bereaved that grief affects them on every level. Encourage appropriate physical exercise, proper diet, and rest. Explore their spiritual responses and efforts to find meaning, and understand that it is important for them to find their own answers or learn to live with the unanswered questions. Suggest that they explore their own creative side by keeping journals or using art or music to work through their grief.

Encouraging the use of ritual: Rituals can be useful to symbolize transition, continuity, and healing. In dealing with bereavement, they may include writing letters to the deceased and then burning them, or taking off a ring and perhaps melting it into another piece of jewelry. Rituals of continuity may symbolize the transformed relationship or new connection with the deceased, and include visiting the grave, or mentioning the deceased's name during prayer.

Helping the bereaved recognize opportunities for personal growth: People who are able to find meaning in the death have a sense of connectedness with life, and are flexible in coping with change are likely to be positively transformed by their grief. The health care team can support this process by recognising that positive transformation develops as people move through the grief process. Useful questions to help the bereaved work on this transformation include: What do you want to bring from your old life into your new life? What do you need to leave behind? What do you need to add? (Sanders, 1989).

Keeping the professional's grief separate from the bereaved client's: Palliative care workers should confront their own issues of grief and loss so they can be fully present to their bereaved clients. It may be appropriate to cry with the bereaved, though it is inappropriate for clients to feel they need to comfort the palliative care worker. It is important for professionals to practise good self-care and identify their own healthy, appropriate coping mechanisms. Health care professionals also must address other challenges of their own, including substance abuse, mental health, and the side effects of stigmatisation, homophobia, racism, and advocate for accessible community resources and services (Mallinson, 1999).

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