Grief, Loss and Bereavement

The challenge of AIDS grief is to understand what is "normal" in such an "abnormal" situation

The death of a person living with HIV/AIDS represents the end of a life which profoundly affected many circles of people: family members, loved ones, neighbours, acquaintances, and volunteer and paid caregivers who accompanied them through their fight with AIDS.

Just as AIDS has challenged us to rethink much about providing Palliative Care, so too has the disease impacted our understanding of grief. This section reviews issues pertinent to AIDS grief, along with interventions for working with multiple loss and supporting community initiatives related to grief.

AIDS GRIEF

"We expect our grief to be something special. In fact, our grief is as old as our self-image, so familiar in fact that we often do not recognize it when it affects us."[2]

Stephen Levine

While there seems to be a natural constellation of responses to death, additional factors associated with AIDS increase the complexity of grieving (see Table 1). There is tremendous impact from social isolation, stigma, disenfranchisement, lack of spiritual support, fear of contagion, multiple loss, homophobia, illness related complications and survivor guilt.

Other grief experiences accompanying the loss of a person with HIV/AIDS include:

- inner chaos, i.e. future is a "void"
- outer chaos, i.e. accident-prone, absent-minded
- intense intellectual efforts to regain control, and to make sense of the experience
- sensed presence of the loved one
- desire to help others living with AIDS

In any general study of bereavement, these symptoms might signal "pathology". However, this type of reaction can also be seen as *normal response to catastrophic events* rather than maladaptive reaction to a normal stressor.[1] *AIDS grief must be perceived as "normal grief" in an "abnormal time".*

WORKING WITH AIDS BEREAVED INDIVIDUALS

Several approaches can help bereaved individuals:

- support groups
- listening one-on-one
- buddy systems
- professional therapeutic support

Symptoms of grief associated with AIDS include a greater than usual amount of rage, fear, shame, unresolved grief, guilt, helplessness, loss of intimacy, physical symptoms, self-destructiveness, insecurity, numbness, and pessimism

Ultimately, bereavement support should take the mourner beyond reactions to the loss. Many caregivers assist the bereaved with beginning stages of grief, encouraging people to express reactions to the death. Caregivers do not always continue with the important latter processes involving reorientation to the deceased, self and external world.[3]

Modest goals of bereavement care include:

- supporting the griever through initial pain of loss
- working gently to mobilize coping strategies so they feel they can carry on
- providing useful information on grief, rather than rigid frameworks
- reviewing the lost relationship to help integrate past and present

The goal is to grieve well, not to grieve right

- reinforcing outcomes of increased self-awareness, self-esteem, stronger coping mechanisms
- renewed awareness of strengths
- growing sense of identity, deeper engagement in social network of friends and intimates

INTERVENTIONS

There are general guidelines for supporting individuals who have lost loved ones to AIDS. These apply in more condensed form to people suffering from anticipatory grief, including people infected with HIV and their friends/families who are dealing with a series of losses preceding death. For a comprehensive guide to bereavement counselling, an excellent resource is *Treatment of Complicated Mourning* [5] by T. Rando, from which the following interventions are summarized:

"In times of grief, you are often running on your reserve tank of oil, and you don't know that your main tank has run out until your reserve tank is empty too."
- one voice -

- **establish a relationship** through your presence and active listening, as you assess and plan appropriate interventions
- **reach out** to the bereaved, offering to help them in some concrete manner, especially during the early aftermath of death when they are dazed and in shock. Say "Let me accompany you to the casket" rather than "Call me if you need anything"
- it is a critical time to give people permission to grieve. They may begin to cry and check for your tolerance and support
- maintain a **"family systems" perspective** in dealing with the griever
- ensure the griever receives **appropriate medical evaluation** and treatment if physical symptoms warrant

Rando's *Treatment of Complicated Mourning* [5] has a detailed, structured interview schedule and inventory for assessing grief and mourning.

WHEN GRIEF GOES WRONG

There may be times when additional resources can help with problematic grief reactions. The following may indicate complications with mourning and require expert consultation:

- chronic or exaggerated grief responses with extreme reactions over prolonged period of time
- self-destructive impulses and behaviour
- delayed grief reaction and absent mourning with "flight" cure, i.e. radical changes in lifestyle, avoidance of activities, places and people associated with the deceased
- long-term clinical depression or false euphoria

USE OF MEDICATION

Grieving people often consult family physicians about medication to help abolish suffering. There has been much discussion about use of medication to manage acute, normal grief. Medication ought to be used sparingly to provide relief from anxiety or insomnia, rather than relief from depressive symptoms (see *Symptom Management*-Anxiety, Insomnia and Depression). Worden[6] advised against giving antidepressant medication to people undergoing acute grief reactions, noting that antidepressants take time to work. They rarely relieve normal grief symptoms, and by not facilitating verbal expression of grief, a delayed or abnormal grief response may occur.

TABLE 1: GRIEF ISSUES IN AIDS BEREAVEMENT

	Partner/spouse	*Family of origin*
DISENFRANCHISED GRIEF[4]	• relationship not recognized: ex-spouse/common-law/affair • loss not supported: partner was IDU so "is to blame" • inadequate bereavement leave • lack of meaningful funeral • practical problems: will, belongings • lack of spiritual support	• relationship to person with AIDS not acknowledged, thus delaying grief • shame or anger about family member's "lifestyle" • grief needs of children • complexity of sibling relationships not acknowledged
HOMOPHOBIA AND HETEROSEXISM	• lack of institutional sanctions for relationship • problem with will, belongings, home, financial future • lack of meaningful funeral and religious/spiritual support • internalized homophobia: doubts about self-worth	• may blame partner for disease • may be dealing with shock of having gay child • may be in conflict with partner and friends • shame about life-choices of gay family member
STIGMA OF AIDS, SECRECY AND ISOLATION	• may be isolated from own family/friends • reluctance to disclose details of death, prolonging grief • insufficient/no bereavement leave • discrimination in workplace and home/neighbourhood	• issues of disclosure and confidentially • may be geographically distant • traditional sources of support unavailable • lack of meaningful funeral/memorial
SURVIVOR GUILT	• "why not me?" • difficulty feeling joy in being alive • guilt if suspected source of transmission	• "children don't die before their parents" • guilt if source of transmission (mother/child) • other family may wonder "why not me?"
ILLNESS RELATED COMPLICATIONS	• fear of contagion • anger about quality of care if poor • exhaustion due to roller coaster of illness and caregiving • spectrum of losses along the way: sight, physical appearance, ability, dementia	• fear of contagion • low level of physical and emotional reserve if caregiving • young deaths: forces confrontation with own mortality • may be dealing with Hemophilia • there may be several in same family with HIV
MULTIPLE LOSS	• many friends may also have died, depleting sources of support • uncertainty about future: AIDS is not over loss of community • may be called on to care for others	• may be coping with additional illness of several family members • mourning the death of a family in bits and pieces

Friends	*HIV +*	*Caregivers*
• lack of recognition of relationship • lack of closure; funeral	• own needs put aside	• trained not to "attach" as professional resulting in denial of grief • lack of closure; rituals/funerals
• invalidated and unrecognized in role of "chosen family"	• dealing with societal blame	• may negatively affect caregiving role, resulting in guilt, anger • may be pulled into conflict between family/partner
• may be isolated from family/ friends • reluctance to disclose details of death, prolonging grief • no bereavement leave • lack of meaningful funeral/ memorial	• issues of disclosure about own status	• may face harassment about caring for people with HIV/AIDS
• "why not me?" • difficulty feeling joy in being alive	• "why not me?" • difficulty feeling joy in being alive	• may lead to overwork/burn-out to compensate for internal distress about own health
• fear of contagion • anger about quality of care if poor • exhaustion due to roller coaster of illness and caregiving role • spectrum of losses along the way: sight, physical ability	• sexual repression • fear about progression of own infection	• fear of contagion • low level of physical and emotional reserve from complex care • young deaths force confrontation with own mortality • may be working with hemophilia or other complicated illnesses as well
• many friends may have died, depleting sources of support • "grief on the run" • uncertainty about future • may be called on to care for others	• stress of multiple loss can impact immune system • may worry about who will be there for him/her	• lack of structured support for integrating ongoing losses, delaying grief • may be affected by inadequately addressed losses prior to AIDS death • helplessness/lack of joy in work

SPECIAL CONSIDERATIONS

CHILDREN:

- children's understanding of death depends on their stage of development:
  - generally, pre-school children (3-5) view death as a temporary departure
  - in early school years (5-9), death is an entity which surprises or takes people away. Children begin to understand death as a permanent separation
  - by 10, children usually understand that they themselves must die at some point[7]
- children feel the pain of death but are often unable to verbalize their feelings. Parents may need support in being gentle but truthful when telling children about an impending death
- some children lose both parents to AIDS. This group often benefits from professional help to work through grief, and a safe place to talk about what happened
- part of bereavement support involves disclosing issues about the nature of AIDS death, i.e. stigma, shame, anger, fear of contagion, peer rejection. If facilitators are AIDS-sensitive, bereavement groups for children are an excellent referral

HIV STATUS:

- when mourners themselves are HIV+:
  - intense grief work for lost friends is often "put on hold" as they struggle with their own health status. Watching a friend die of AIDS can intensify fears about their own impending death
  - physical symptoms associated with grieving often mimic HIV related illnesses, i.e. shortness of breath, headaches, fatigue
  - educational material about grief provides a cognitive framework allowing individuals to normalize grief responses
  - encourage people to develop a comprehensive health maintenance plan which integrates ongoing grief work
- when mourners are HIV negative:
  - there can be a sense of joyous relief about their sero-status which may be unacceptable to express within their social circles
  - grief may be complicated by survivor guilt and a sense of exclusion
  - fears of an uncertain future must be explored, i.e. "what will my world be like when AIDS is over?"
  - encourage people to develop a comprehensive health maintenance plan which integrates ongoing grief work

"At this point in the AIDS crisis, communities of HIV affected people are suffering from bereavement overload. We are in a constant state of mourning, even though we may not be in a state of acute grief."[8]

L. McKusick

LOSS OF A CHILD:

- whether a child is six or twenty-six, his/her death is very difficult for everyone involved. Most affected are the parents whose grief reactions are often more intense and longer lasting
- disclosure issues may prevent a parent from receiving appropriate support from friends and community. Caregivers involved with the child become important links following his/her death

- when an adult child dies in a large city, and the family lives in a small community and choose not to disclose his/her sero-status, local resources will not be able to support the parents appropriately
- for more information on dealing with the needs of parents and siblings facing the loss of child, see *Psycho-Social Support*

FAMILY MEMBERS:

Grief can rip families apart. This may be compounded by multiple HIV infections and anticipatory grief within the family, or caregiving responsibilities following the death of one family member. Individuals grieve in their own way and time. Family members may find themselves in their own grief spiral, unable to provide adequate attention and support to one another. Recognizing this as normal can help families:

- facilitate open dialogue about changes occurring in the family as a result of the death
- the stigma of AIDS can remove traditional sources of family support, increasing the caregiver's responsibility to maintain consistent external support. Family network systems can help parents, siblings and extended family members communicate openly with peers
- contact the Bereaved Families Association or grief support services in your area for information about groups

INTERVENTIONS IN MULTIPLE LOSS

People experience bereavement overload when they have no time to express fully one loss before other losses occur, or further losses are anticipated. Multiple loss requires additional help in developing enhanced coping skills.

"It's going to be really strange when they announce a cure. On the one hand it will be great, but on the other, people will finally be able to stop and will have to come to terms with the incredible amount of death that has occurred. I think that will be very scary."[9]

Working with multiple loss:

- the first step is for individuals to admit all losses so they can begin to move through the process of grief
- focus on one central loss and work it through so the bereaved can have the experience of completing one grief process.[5] Develop the mourners' trust, deal with their feelings of not knowing where to begin, and help them focus on one loss
- people may be dealing with a diminished capacity to feel because they have psychically insulated themselves from the world. Rando [5] suggests additional techniques for helping the mourner confront denial and numbing reaction, and experience emotional expression/catharsis
- expect to hear stories repeatedly, about the way things were and who the loved ones were
- secondary losses must be thoroughly explored because they often go unrecognized in multiple loss, i.e. social support, sexual freedom, ability to have children, hope for the future
- the concept of the assumptive world is powerful in HIV/AIDS, as people are continually forced to reassess assumptions of the way the world "should have been". Purposes in living and reasons for suffering must continually be re-examined as losses mount

PLANNING AND PROVIDING BEREAVEMENT FOLLOW-UP

Good bereavement care includes consistent, on-going outreach through the first year of bereavement. It provides information and support to the bereaved and permits monitoring to identify people needing helpful intervention. A plan for bereavement care must consider three primary components:

- **community**: demographic information, awareness and attitudes, existing services, current needs
- **program**: mandate, staffing, financial resources
- **client**: assessment, referral procedures, available support, information requirements, grief related considerations

For more information, refer to *Bereavement care: a plan for grief support*, Victoria Hospice Society, 1993.[10]

RESPONDING TO COMMUNITY NEEDS

Along with individuals and families suffering from AIDS loss, entire communities are moving through stages of communal grief. The role of communities in supporting bereaved individuals is essential. The goal of attending to the health of communities and their members is equally worthwhile. We must expand our intervention to the community level, using goals similar to those for bereaved individuals:

- acknowledge what has been lost: death notices in community papers, public AIDS memorials
- mourn what has been lost: candlelight vigils, regular AIDS memorial services offered in churches and synagogues
- popularize the topic of grief through educational forums
- promote awareness that volatile reactions of some community members or agencies is potentially rooted in unrecognized grief
- mobilize coping strategies so people feel they can carry on in the midst of the crisis. Provide community leaders and key members with information, train peers to provide informal individual and group support. Encourage public acceptance of active mourning, not simply tolerance
- actively endorse and participate in the creation of rituals and memorials to remember, celebrate and learn from those who have died, so their gifts, stories, and contributions will never be lost

> *"Heal the community by healing the individuals and in this way, resurrect the sense of community fundamental to the mental health of the individual."*[11]
>
> Herman Kaal

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