Chapter 30

Loss, Grief, and Bereavement in Children

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At a Glance

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Overview

AIDS has made children even more vulnerable and exposed them to multiple losses, often from a very early age. In many cases the adults who would have supported and cared for them at a time of loss are either dead or ill. The child's guardian may be an elderly relative or a teenage sibling, without the emotional resources, time, or energy themselves to deal with their own grief and to help a child, or children, grieve.

Losses are not only related to the death of a parent or family member, but include loss of education; loss of a home; loss of childhood when children have to care for their siblings; loss of self-esteem through stigmatisation; and loss of dreams for their future. An ill child also goes through a period of anticipatory grief at the prospect of losing his or her own life. The child's grief is often disenfranchised, and adults are ill-equipped to identify the child's emotions and help the child to deal with loss and grief. All these factors put the child at risk for complicated grief, which requires professional interventions.

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Unique Aspects of Children's Grief

AIDS-related deaths are often hidden or kept secret because of the stigma and lack of social support for the infected or affected. For this reason, children's grief, like adults' grief, often is 'disenfranchised'. It is frequently compounded by the fact that they may be considered too young to understand what has happened. A child's age, intellectual and emotional developmental stages, as well as circumstances of the loss, will affect her or his experience of grief. It has been noted that children often initially experience shock and disbelief, then experience physiologic responses similar to adults: fatigue, changes in sleep patterns, appetite changes, headaches, and/or tightness in the throat. They also tend to experience a wide variety of emotions and cognitive responses.

One unique aspect of children's grief is regressive behaviour — such as wanting to nurse, sleep with a parent, use baby talk, or suck their thumb even though they may not have exhibited such behaviour for a while. This has been attributed to a desire to return to an earlier time when the child felt protected and secure. Children also may approach grief 'in bits and pieces' — crying or calling out for the loved one, then returning to play moments later. This coping mechanism works well for the child but can be difficult for the family to understand. A child also may act in ways that attempt to get attention. Even if a child is unable to comprehend the loss, he or she can respond to the changes in the family's emotional status.

Developmentally, children must come to understand that death is final, irreversible, inevitable, unpredictable, and universal. Children dealing with AIDS-related deaths may be coping with the deaths of other family members or have HIV themselves. They are at risk for complicated grief because of the disenfranchised nature of their grief experience. As for adults, complicated grief can include somatic discomfort and emotional distress.

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Grief at Different Developmental Stages

Grief is experienced and expressed differently according to a child's developmental stage, requiring age-appropriate support from adults (see Table 30.1). It is helpful to understand the child's concepts of death at different developmental stages. In summary:

The baby and very young children have no concept of death, but may instinctively experience the loss of a loving and consistent caregiver or parent.

Ages 3-5: Children may have some concept of death but often think that death is a reversible and temporary occurrence. 'Magical thinking' may mean they feel responsible for the death due to bad behaviour or thoughts. This may lead to excessive guilt and shame.

Ages 5-7: Children at this age may have an incomplete, partial understanding that death is irreversible. They may still feel responsible for the death, with concomitant guilt and shame.

Ages 8-9 and upwards: Children at this point see death as universal and inevitable, and can understand that all living things die. Older children experience grief in a manner similar to adults.

In children, the experience of grief following loss may be associated with a number of factors including:

The child's age and/or developmental stage.

Hindered normal development from frequent illnesses, poor nutrition, and lack of developmental stimulation if the child is also infected with HIV. These children may in fact grieve in a manner usually associated with younger children.

The closeness of the relationship with the person the child has lost. The closer the relationship, the deeper will be the experience of loss and grief.

The socio-economic situation in which the child lives. If children are provided with a safe home, food, and basic comforts, the loss may be easier to endure.

Inadequate preparation for the loss. Children who are old enough to understand need to be told the truth about the situation that will lead to loss. Simple explanations that are age-related, and ongoing support, help them to prepare for the time of loss or death.

The child's own health status. Children coping with the loss of their own health and life will have few emotional resources to deal with other losses.

Insecurity about the future. Loss is magnified when there is no certainty about the future. Children need to feel secure and know that they will have a home and support from a suitable, caring adult.

The presence of hope in their lives despite the loss. The hope can include knowing they will be cared for, continue with their education, or stay in the same neighbourhood with their friends.

Table 30.1 Age-Appropriate Responses to Loss

Age-Related Response	What Can Help
Babies 0 to 3 Years Old	
• Inability to talk about grief, expressing it physically • Crying, regressive behaviour • Delayed progress in speech, walking • Fearfulness, clinginess • Problems eating, sleeping, or with toilet habits • Development of comfort habits, such as thumb sucking	• Patience – can take a year or longer before progress is made in independence and confidence • LOTS of cuddles, love, attention, and patience • Familiar routines • Prayer in family's spiritual tradition
Preschoolers 3 to 5 Years Old	
• More difficult to calm • Naughty behaviour, due to emotional stress and hurt • Physical expressions of grief • Outbursts • Refusal to be comforted • Fluctuation between happy and sad within minutes • Repetition of questions • More understanding than is verbalised • Regressive behaviour • Feelings that God is very real • A developed sense of right and wrong	• Patience — recovery can take up to two years • Hugs, attention, cuddles • Making them feel important by, for example, helping in the home • Encouraging them to talk about event through stories, puppets, art • Helping them understand it is not their fault. They can't wish something into being. • Memory work (all ages) • Maintainence of routines • Prayer in family's spiritual tradition
Children Aged 6 to 12 Years Old	
• Ability to think logically, talking and remembering • Ability to understand what causes death • Tendency to recover faster than younger children • Grief similar to adults and older children • Loss of concentration and poor school work • Aggression • Aches and pains • Nightmares, anxiety attacks • Feelings of helplessness and vulnerability to further loss	• Non-judgmental listening • Encouraging expression of feelings through means such as art • Allowing the name of deceased to be mentioned • Supporting a loving relationship with the caregiver • Structure and stability • Allowing the child to be a child, to have fun without guilt • Providing opportunities to help others, regain sense of control, value, and belonging • Prayer in family's spiritual tradition
Adolescents	
• Feelings of weakness and helplessness • Understanding that death is irreversible and final • Ambivalence about their bodies • Life crisis of transition to adulthood • Denial of feelings, seeing the need for consolation as immature • Anger and rebellion • Lack of trust, feelings of being let down • RISKS: Running away, seeking out undesirable peers, promiscuity, substance abuse, eating disorders, suicidality, depression, morbid thoughts	• Peer support • Recreation • Have a trusted adult to talk to • Respite, such as walks or camp with carer • Creating interest in the future • All interventions for children 6 to 12 years old • Prayer in family's spiritual tradition

Sources: Papadatou, 1991; Ramsden, 2002.

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Expressions of Grief

Children Express Their Grief in a Variety of Ways

Initial shock and disbelief, and spending a great deal of time searching for the person they have lost. Even very young babies appear to know when a loving and caring person has gone.

Separation anxiety and 'clinginess' caused by fear of losing another significant adult. The child may insist on sharing a bed with the adult to ensure that this person does not also disappear.

Regressive behaviour, such as bed-wetting, baby talk, and thumb sucking. This may be an attempt to return to an earlier, safer, happier time of their lives.

Short bursts of anger and temper tantrums, excessive crying, attention-seeking, and destructive behaviour, followed by times of quiet play and normal behaviour.

Depression, which is often under-diagnosed, especially in resource-limited settings where children may have little access to professional evaluation and treatment.

Physical signs such as loss of appetite, insomnia, weight-loss, palpitations, headaches, sore neck, and other areas of the body showing signs of stress, heartburn, and increased susceptibility to infections.

Addressing Grief and Bereavement in Children

Encouraging Adult Caregivers to Help Children Grieve

Most children respond well to the presence of a consistent and caring adult; open lines of communication; respect for and opportunities to express their feelings; and a safe and comforting environment. Unfortunately, these are often lacking. Most adults do not know how to communicate with a grieving child and many children are unable to communicate their feelings in words. However, health care workers can model appropriate behavior toward children and encourage other caregivers in children's lives to help them grieve (see Table 30.2).

Using Memory Work

Memory work is becoming increasingly used in Africa (see Chapter 29: Psychosocial and Spiritual Care). The use of memory books and memory boxes may help children maintain their sense of identity, of where they come from and belong. It also assists the parents to prepare for their own death, whilst having the comfort of knowing that they have left something precious for their children. This special legacy left to the child is especially comforting to a parent who has little in the way of financial resources to leave the child.

Helping Children Communicate Their Grief

Communication needs to be appropriate to the child's age and development. Children may communicate their emotions through art, story-telling, and play rather than in plain speech. Some of the useful ways adults can help children communicate their feelings of loss and grief are to:

- Listen to them so they can share their understanding of the loss or death.
- Encourage them to use symbolic language to explain their feelings and concerns.
- Encourage them to express and examine their feelings. Music, dance, and art may be effective with all age groups and in all cultures in expressing emotions.
- Help them to deal with guilt and feelings that they are responsible for the loss.
- Encourage them to express their feelings, examine the truth behind the feelings, and put them into perspective to assist them to gain control over these feelings.
- Build their self-esteem through encouragement and compliments.
- Assist them to develop new skills.
- Provide ongoing support to help them cope with the loss.
- Reassure them that they are not different or unusual because of their loss. In Africa, so many children have experienced loss that the fact that they are not alone and different helps them cope with death and loss. Many of their peers have experienced similar emotions and can be very empathetic.

Family Conferences

Planning for the child's future should ideally begin before the parent dies. A meeting of all the relevant family members and, in some cases, good friends and leaders of the family's church or other faith-based organisation, is called to discuss the future care of the child with the child's best interests as the focus (see Chapter 14: Communicating with Patients and Their Families). During these conferences plans can be made to keep the child in contact with family members. The importance of a will is often not understood, and children may be left without any of their parent's possessions, which are taken by adult family members once the parent dies.

Table 30.2 How to Help a Child Grieve

Do	Don't
• Give assurance of love and support. • Use opportunities to teach about death (e.g., a dead bird). • Encourage children to participate in family sorrow (e.g., let them attend the funeral). • Notify the child's school, day care about death/illness. • Refer to spiritual leaders, supportive people, other professionals. • Consider support groups for children, where available.	• Avoid the subject at home, school, or church. • Discourage emotional response. • Tell children something they will need to unlearn (e.g., Mom is gone on a long holiday). • Alter the child's role (e.g., little boy becomes man of the house). • Speak beyond the child's level of comprehension.

Adapted from Papadatou, 1991.

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Supporting Children Orphaned by AIDS

So many children have lost parents to AIDS, other chronic diseases, trauma, and infections in Africa that children may be split from their siblings and sent to relatives far away from their homes and other members of the family. Older children may be left homeless and begin to live on the streets, become involved in gangs and crime, and/or become addicted to substances such as sniffing glue or petrol, which are cheap and easy to obtain.

This may lead to uncertainty about their identity and lack of knowledge about their parents and background. A child needs a sense of identity and belonging for emotional well-being.

For the HIV-positive parent to plan for his or her child's future — a future without the parent — can be very emotionally painful, and this must be handled with compassion and sensitivity. Many parents find that it is emotionally satisfying to know that their children will be cared for after their death.

Complicated Grief

Grief is defined as complicated when the child is not able to adapt to the loss and when grieving does not lessen with time. Signs of complicated grief may include continued changing behaviour, outbursts of anger and tantrums, depression, sleep disturbances, anorexia, and bodily complaints. Complicated grief is best attended to by professionals such as social workers where available.

Factors predisposing to complicated grief include the lack of a caring adult or family support, lack of ability to express emotions, living with adults who are grieving themselves and do not have the emotional resources to support the child, and increased vulnerability due to poverty and lack of a safe and secure environment. The death of a parent or sibling may bring with it a change of role, as children may be heading households or caring for ill family members and thus have no time to grieve properly.

Adults caring for children may not be able to identify complicated grief and are often uninformed about services that may be available. Teachers may be taught to identify grief-related behaviour, and in South Africa schools are becoming increasingly involved in support of grieving children. Programmes to assist teachers and faith leaders to identify complicated grief, and refer where there is assistance available, have been initiated in some countries. There may be support groups in schools and churches, but often the person facilitating these groups is not qualified to identify complicated grieving. There is a great need for training bereavement counselors in communities, and for education on signs of complicated grief and the resources available to help.

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