Chapter 30

Loss, Separation, and Bereavement

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All children will experience involuntary separations, whether from illness, death, or other causes, from loved ones at some time in their lives. Relatively brief separations of children from their parents usually produce minor transient effects, but more enduring and frequent separation may cause sequelae. The potential impact of each event must be considered in light of the age, stage of development, and experiences of the child; the particular relationship with the absent person; and the nature of the situation.

SEPARATION AND LOSS

Separations may be from temporary causes, such as vacations, parental job requirements, natural disasters or civil unrest, or parental or sibling illness requiring hospitalization. More long-term separations occur as a result of divorce, placement in foster care, or immigration, whereas permanent separation may occur because of death. The initial reaction of young children to separation of any duration may involve crying, such as a tantrum type, protesting type, and a quieter, sadder type. Children's behavior may appear subdued, withdrawn, fussy, or moody, or they may demonstrate resistance to authority. Specific problems may include poor appetite, behavior issues such as acting against caregiver requests, reluctance to go to bed, sleep problems, or regressive behavior, such as requesting a bottle or bed-wetting. School-age children may experience impaired cognitive functioning and poor performance in school. Some children may repeatedly ask for the absent parent and question when the absent parent will return. The child may go to the window or door or out into the neighborhood to look for the absent parent; a few may even leave home or their place of temporary placement to search for their parents. Other children may not refer to the parental absence at all.

A child's response to reunion may surprise or alarm an unprepared parent. A parent who joyfully returns to the family may be met by wary or cautious children. After a brief interchange of affection, children may seem indifferent to the parent's return. This response may indicate anger at being left or wariness that the event will happen again, or the young child may feel, as a result of **magical thinking** (see Chapter 25), as if the child caused the parent's departure. For example, if the parent who frequently says "Stop it, or you'll give me a headache" is hospitalized, the child may feel at fault and guilty. Because of these feelings, children may seem more closely attached to the present parent than to the absent one, or even to the grandparent or babysitter who cared for them during their parent's absence. Some children, particularly younger ones, may become more clinging and dependent than they were before the separation, while continuing any regressive behavior that occurred during the separation. Such behavior may engage the returned parent more closely and help to reestablish the bond that the child felt was broken. Such reactions are usually transient, and within 1-2 weeks, children will have recovered their usual behavior and equilibrium. Recurrent separations may tend to make children wary and guarded about reestablishing the relationship with the repeatedly absent parent, and these traits may affect other personal relationships. Parents should be advised not to try to modify a child's behavior by threatening to leave.

DIVORCE

More sustained experiences of loss, such as divorce or placement in foster care, can give rise to the same kinds of reactions noted earlier, but they are more intense and possibly more lasting. Currently in the United States, approximately 40% of first marriages end in divorce. Divorce has been found to be associated with negative parent functioning, such as parental depression and feelings of incompetence; negative child behavior, such as noncompliance and whining; and negative parent–child interaction, such as inconsistent discipline, decreased communication, and decreased affection. Greater childhood distress is associated with greater parental distress. Continued parental conflict and loss of contact with the noncustodial parent is common.

Two of the most important factors that contribute to morbidity of the children in a divorce include *parental psychopathology* and *disrupted parenting* before the separation. The year after the divorce is the period when problems are most apparent; these problems tend to dissipate over the next 2 years. Depression may be present up to 5 years later, and educational or occupational decline may occur even 10 years later. It is difficult to sort out all confounding factors. Children may suffer when exposed to parental conflict that continues after divorce and that in some cases may escalate. The degree of *interparental conflict* may be the most important factor associated with child morbidity. A continued relationship with the noncustodial parent when there is minimal interparental conflict is associated with more positive outcomes.

School-age children may become depressed, may seem indifferent, or may be extremely angry. Other children appear to deny or avoid the issue, behaviorally or verbally. Most children cling to the hope that the actual placement or separation is not real and only temporary. The child may experience guilt by feeling that the loss, separation, or placement represents rejection and perhaps punishment for misbehavior. Children may protect a parent and assume guilt, believing that their own "badness" caused the parent to depart. Children who feel that their misbehavior caused their parents to separate may have the fantasy that their own trivial or recurrent behavioral patterns caused their parents to become angry at each other. A child might perceive that outwardly

blaming parents is emotionally risky; parents who discover that a child harbors resentment might punish the child further for these thoughts or feelings. Some children have behavioral or psychosomatic symptoms and unwittingly adopt a "sick" role as a strategy they hope will reunite their parents.

In response to divorce of parents and the subsequent separation and loss, older children and adolescents usually show intense anger. Five years after the breakup, approximately 30% of children report intense unhappiness and dissatisfaction with their life and their reconfigured family; another 30% show clear evidence of a satisfactory adjustment; and the remaining children demonstrate a mixed picture, with good achievement in some areas and faltering achievement in others. After 10 years, approximately 45% do well, but 40% may have academic, social, or emotional problems. As adults, some are reluctant to form intimate relationships, fearful of repeating their parents' experience.

Parental divorce has a moderate long-term negative impact on the adult mental health status of children, even after controlling for changes in economic status and problems before divorce. Good adjustment of children after a divorce is related to ongoing involvement with two psychologically healthy parents who minimize conflict and to the siblings and other relatives who provide a positive support system. Divorcing parents should be encouraged to avoid adversarial processes and to use a trained mediator to resolve disputes if needed. Joint-custody arrangements may reduce ongoing parental conflict, but children in joint custody may feel overburdened by the demands of maintaining a strong presence in two homes.

When the primary care provider is asked about the effects of divorce, parents should be informed that different children may have different reactions, but that the parents' behavior and the way they interact will have a major and long-term effect on the child's adjustment. The continued presence of both parents in the child's life, with minimal interparental conflict, is most beneficial to the child.

MOVE/FAMILY RELOCATION

A significant proportion of the U.S. population changes residence each year. The effects of this movement on children and families are frequently overlooked. For children, the move is essentially involuntary and out of their control. When changes in family structure such as divorce or death precipitate moves, children face the stresses created by both the precipitating events and the move itself. Parental sadness surrounding the move may transmit unhappiness to the children. Children who move lose their old friends, the comfort of a familiar bedroom and house, and their ties to school and community. They not only must sever old relationships but also are faced with developing new ones in new neighborhoods and new schools. Children may enter neighborhoods with different customs and values, and because academic standards and curricula vary among communities, children who have performed well in one school may find themselves struggling in a new one. Frequent moves during the school years are likely to have adverse consequences on social and academic performance.

Migrant children and children who emigrate from other countries present with special circumstances. These children not only need to adjust to a new house, school, and community, but also need to adjust to a new culture and in many cases a new language. Because children have faster language acquisition than adults, they may function as translators for the adults in their families. This powerful position may lead to role reversal and potential conflict within the family. In the evaluation of migrant children and families, it is important to ask about the circumstances of the migration, including legal status, violence or threat of violence, conflict of loyalties, and moral, ethical, and religious differences.

Parents should prepare children well in advance of any move and allow them to express any unhappy feelings or misgivings. Parents should acknowledge their own mixed feelings and agree that they will miss their old home while looking forward to a new one. Visits to the new home in advance are often useful preludes to the actual move. Transient periods of regressive behavior may be noted in preschool children after moving, and these should be understood and accepted. Parents should assist the entry of their children into the new community, and whenever possible, exchanges of letters and visits with old friends should be encouraged.

SEPARATION BECAUSE OF HOSPITALIZATION

Potential challenges for hospitalized children include coping with separation; adapting to the new hospital environment; adjusting to multiple caregivers; seeing very sick children; and sometimes experiencing the disorientation of intensive care, anesthesia, and surgery. To help mitigate potential problems, a preadmission visit to the hospital can help by allowing the child to meet the people who will be offering care and ask questions about what will happen. Parents of children <5-6 years old should room with the child if feasible. Older children may also benefit from parents or other family members staying with them while in the hospital, depending on the severity of their illness. Creative and active recreational or socialization programs with child life specialists, chances to act out feared procedures in play with dolls or mannequins, and liberal visiting hours, including visits from siblings, are all helpful. Sensitive, sympathetic, and accepting attitudes toward children and parents by the hospital staff are very important. Healthcare providers need to remember that parents have the best interest of their children at heart and know their children the best. Whenever possible, school assignments and tutoring for hospitalized children should be available to engage them intellectually and prevent them from falling behind in their scholastic achievements.

The psychologic aspects of illness should be evaluated from the outset, and physicians should act as a model for parents and children by showing interest in a child's feelings, allowing them a venue for expression, and demonstrating that it is possible and appropriate to communicate about discomfort. Continuity of medical personnel may be reassuring to the child and family.

MILITARY FAMILIES

More than 2 million children live in military families in the United States, and approximately 50% of them obtain medical care in the community rather than at a military medical facility. Children whose parents are serving in the military may experience loss and separation in multiple ways. These include frequent relocations, relocation to foreign countries, and duty-related separation from parents. The most impactful experiences have been repeated wartime deployments of parents and the death of parents during military service. All branches of the military have increased their focus on preparing and supporting military families for a service member's deployment to improve family coping. Military families composed of young parents and young children are at risk for child maltreatment in the context of repeated or prolonged deployments.

PARENTAL/SIBLING DEATH

Approximately 5–8% of U.S. children will experience parental death; rates are much higher in parts of the world more directly affected by war, AIDS, and natural disasters. Anticipated deaths from chronic illness may place a significant strain on a family, with frequent bouts of illness, hospitalization, disruption of normal home life, absence of the ill parent, and perhaps more responsibilities placed on the child. Additional strains include changes in daily routines, financial pressures, and the need to cope with aggressive treatment options.

Children can and should continue to be involved with the sick parent or sibling, but they need to be prepared for what they will see in the home or hospital setting. The stresses that a child will face include visualizing the physical deterioration of the family member, helplessness, and emotional lability. Forewarning the child that the family member may demonstrate physical changes, such as appearing thinner or losing hair, will help the child to adjust. These warnings combined with simple yet specific explanations of the need for equipment, such as a nasogastric tube for nutrition, an oxygen mask, or a ventilator, will help lessen the child's fear. Children should be honestly informed of what is happening, in language they can understand, allowing them choices, but with parental involvement in decision-making. They should be encouraged, but not forced, to see their ill family member. Parents who are caring for a dying spouse or child may be too emotionally depleted

to be able to tend to their healthy child's needs or to continue regular routines. Children of a dying parent may suffer the loss of security and belief in the world as a safe place, and the surviving parent may be inclined to impose his or her own need for support and comfort onto the child. However, the well parent and caring relatives must keep in mind that children need to be allowed to remain children, with appropriate support and attention. Sudden, unexpected deaths lead to more anxiety and fear because there is no time for preparation, and explanations for the death can cause uncertainty. Examples of this may be death of a parent due to a motor vehicle crash, homicide or suicide, sudden health-related issue such as a myocardial infarction or stroke, or from infection such as the recent COVID pandemic. Providing support to the child is paramount to allow him or her to express sorrow and grief and to have stability in the child's remaining relationships.

GRIEF AND BEREAVEMENT

Grief is a personal, emotional state of bereavement or an anticipated response to loss, such as a death. Common reactions include sadness, anger, guilt, fear, and at times, relief. The normality of these reactions needs to be emphasized. Most bereaved families remain socially connected and expect that life will return to some new, albeit different, sense of normalcy. The pain and suffering imposed by grief should never be automatically deemed "normal" and thus neglected or ignored. In **uncomplicated grief** reactions, the steadfast concern of the pediatrician can help promote the family's sense of well-being. In more distressing reactions, as seen in traumatic grief of sudden death, the pediatrician may be a major, first-line force in helping children and families address their loss.

Participation in the care of a child with a life-threatening or terminal illness is a profound experience. Parents experience much anxiety and worry during the final stages of their child's life. In one study, 45% of children dying from cancer died in the pediatric intensive care unit, and parents report that 89% of their children suffered "a lot" or "a great deal" during the last month of life. Physicians consistently underreport children's symptoms compared with parents' reports. Better ways are needed to provide care for dying children. Providers need to maintain honest and open communication, provide appropriate pain management, and meet the families' wishes as to the preferred location of the child's death, in some cases in their own home. Inclusion of multiple disciplines, such as hospice, clergy, nursing, pain service, child life specialists, social work, and pet therapy, often helps to support patients and families fully during this difficult experience.

The practice of withholding information from children and parents regarding a child's diagnosis and prognosis has generally been abandoned, because physicians have learned that protecting parents and patients from the seriousness of their child's condition does not alleviate concerns and anxieties. Even very young children may have a real understanding of their illness. Children who have serious diseases and are undergoing aggressive treatment and medication regimens, but who are told by their parents that they are okay, are not reassured. These children understand that something serious is happening to them, and they are often forced to suffer in silence and isolation because the message they have been given by their parents is to not discuss it and to maintain a cheerful demeanor. Children have the right to know their diagnosis and should be informed early in their treatment. The content and depth of the discussion needs to be tailored to the child's personality and developmental level of understanding. Parents have choices as to how to orchestrate the disclosure. Parents may want to be the ones to inform the child themselves, may choose for the pediatric healthcare provider to do so, or may do it in partnership with the pediatrician.

A **death**, especially the death of a family member, is the most difficult loss for a child. Many changes in normal patterns of functioning may occur, including loss of love and support from the deceased family member, a change in income, the possible need to relocate, less emotional support from surviving family members, altering of routines, and a possible change in status from sibling to only child. Relationships between family members may become strained, and children may blame themselves or other family members for the death of a parent or sibling. Bereaved children may exhibit many of the emotions discussed earlier as a result of the loss, in addition to behaviors of withdrawal into their own world, sleep disturbances, nightmares, and symptoms such as headache, abdominal pains, or possibly symptoms similar to those of the family member who has died. Children 3-5 years of age who have experienced a family bereavement may show regressive behaviors such as bed-wetting and thumb sucking. School-age children may exhibit nonspecific symptoms, such as headache, abdominal pain, chest pain, fatigue, and lack of energy. Children and adolescents may also demonstrate enhanced anxiety if these symptoms resemble those of the family member who died. Bereavement may be measured by various published scales (Table 30.1). Behavioral patterns of *persistent complex bereavement disorder* are noted in Table 30.2.

Table 30.1 Example Items from the Three Grief Measurement Tools Assessed Through Cognitive Interviewing

CORE BEREAVEMENT ITEMS (CBI)
Do you experience images of the events surrounding your loved one's death? Do thoughts of your loved one make you feel distressed?
Do you find yourself pining for/yearning for your loved one?
Do reminders of your loved one such as photos, situations, music, places, etc., cause you to feel loneliness?
Do reminders of your loved one such as photos, situations, music, places, etc. cause you to cry about your loved one?
Response options: A lot of the time; Quite a bit of the time; A little bit of the time; Never
GRIEF COGNITIONS QUESTIONNAIRE FOR CHILDREN (GCQ-C)
Since my loved one died, I think of myself as a weak person.
I should have seen to it that he/she would not have died.
I blame myself for not having cared for him/her better than I did. It is not nice toward him/her, when I will begin to feel less sad. My life is worthless since he/she died.
Response options: Hardly ever; Sometimes; Always
INTRUSIVE GRIEF THOUGHTS SCALE (IGTS)
(During the past 4 wk) How often did you think about the death of your loved one?
How often did you find yourself thinking how unfair it is that your loved one died, even though you didn't want to think about it?
How often did you have trouble falling asleep because you were thinking about your loved one's death? How often have you had bad dreams related to your loved one's death?
How often did you have trouble doing things you like because you were worrying about how you and your family will get along?
Response options: Several times a day; About once a day; Once or twice a week; Less than once a week; Not at all

From Taylor TM, Thurman TR, Nogela L. Every time that month comes, I remember: using cognitive interviews to adapt grief measures for use with bereaved adolescents in South Africa. *J Child Adolesc Mental Health*. 2016;28(2):163–174, Table 1, p 166.

The presence of secure and stable adults who can meet the child's needs and who permit discussion about the loss is most important in helping a child to grieve. The pediatrician should help the family understand this necessary presence and encourage the protective functioning of the family unit (Table 30.3). More frequent visits to the healthcare professional may be necessary to address these symptoms and provide reassurance when appropriate. Suggested availability of clergy or mental health providers can provide additional support and strategies to facilitate the transitions after the death.

Death, separation, and loss as a result of **natural catastrophes** and **human-made disasters** have become increasingly common events in children's lives. Exposure to such disasters occurs either directly or indirectly, where the event is experienced through the media. Examples of **indirect exposure** include scenes of earthquakes, hurricanes, tsunamis, tornadoes, and terrorist attacks. Children who experience personal loss in disasters tend to watch more media coverage than children who do not. Children without a personal loss watch as a way of participating in the event and may thus experience repetitive exposure to traumatic scenes and stories. The loss and devastation for a child who personally lives through a disaster are significant; the effect of the simultaneous c

Table 30.2 Developmental Manifestations of Persistent Complex Bereavement Disorder in Children and Adolescents: Developmental Considerations and Symptom Manifestation in Youth

CRITERION A	**CHILD HAS EXPERIENCED THE DEATH OF A LOVED ONE**
CRITERION B	
B1: Expression of persistent yearning or longing for the deceased	Children have an evolving understanding of the permanence of death, particularly among young children; behavioral expressions of separation distress from surviving caregivers are common, as are reunification fantasies (i.e., wanting to die to be reunited with the parent in the afterlife)
B2: Intense sorrow or emotional pain	Children focus on the more salient immediate physical environment rather than their own internal state; young children often have difficulties expressing inner mood; overt expressions of emotional pain might be interspersed within seemingly normal mood, which can lead to others incorrectly assuming they are not grieving
B3: Preoccupation with the person who died	Children might become distressed when separated from the deceased parent's belongings; it is common for youth to seek out physical connections to their parent, including sleeping in the parent's bed, or wearing their clothing or jewelry
B4: Preoccupation with the circumstances of the death	Young children might reenact the death through play, sometimes with alternate (i.e., counterfactual) actions that depict what children feel they or others could have done to prevent the death; reenacting might also take the form of drawing disturbing scenes or aspects of the death
CRITERION C	
C3: Difficulties related to positive reminiscing about the deceased	Children's ability to reminisce matures with development and is often facilitated by surviving caregivers
C4: Bitterness or anger related to the loss	Youth might show overall irritability, oppositional behavior, and problem behavior in the context of bereavement; externalizing behaviors are often precipitated by changes to the youth's daily routine that are a result of the parent's absence (including others assuming the deceased parent's roles)
C5: Maladaptive self-appraisals in relation to the deceased or the death	Youth, particularly adolescents, might become preoccupied by a perceived accountability (e.g., blaming others or oneself for their parent's death); in young children, this might manifest as magical thinking that their own thoughts or actions caused their parents to die
C6: Excessive avoidance of reminders of the loss	Avoidance might not always be under a child's control (e.g., a parent might choose not to bring the child to the gravesite, which prevents the child from confronting that reminder)
C7: Desire not to live so that they can be with the deceased	Children and adolescents often experience suicidal ideation as a means of reunification fantasies, and their reduced understanding of the complexities of death might exacerbate this mindset among young children; suicidal ideation associated with reunification fantasies might not be accompanied by intent or planning; adolescents might engage in risk-taking behaviors (e.g., substance use, reckless driving)
C8: Difficulty trusting other people since the death	Children might have difficulty establishing relationships with new caregivers, which is often reflective of difficulty with new life circumstances, rather than lack of trust; youth might also display overt anger or oppositional and defiant behaviors toward the surviving or new caregiver
C9: Feeling alone or detached from others since the death	Youth often report feelings of alienation from other peers who have not experienced a similar loss, particularly when reminders of this difference are salient (e.g., seeing other classmates' parents coming to a school event); children and adolescents might conceal their own grief reactions to protect their caregivers from additional distress
C10: Feeling that life is meaningless or empty without the deceased or the belief that they cannot function without the deceased	Developmental regressions (e.g., regression in toileting or language among young children; loss of study skills or emotion regulation in adolescents) are common, as are disruptions to sleep and appetite patterns; adolescents can show a lack of engagement in preparations for adulthood (e.g., applying to jobs)
C11: Confusion about their role in life or a diminished sense of their identity	Youth can express sadness over lost opportunities they were planning to experience with their deceased caregiver (e.g., riding a bicycle, walking down the aisle at their wedding); adolescents might show disorganization, lack of direction, or both

The letters and numbers refer to the symptom within each diagnostic criterion (e.g., criterion B, 4th symptom). Persistent complex bereavement disorder symptom criteria and descriptions have been adapted to the context of parental death.

From Kentor RA, Kaplow JB. Supporting children and adolescents following parental bereavement: guidance for health-care professionals. *Lancet Child Adolesc.* 2020;4:889–898, p 891.

and personal loss complicates the bereavement process as grief reactions become interwoven with posttraumatic stress symptoms (see Chapter 38). After a death resulting from aggressive or traumatic circumstances, access to expert help may be required. Under conditions of threat and fear, children seek proximity to safe, stable, protective figures.

It is important for parents to grieve with their children. Some parents want to protect their children from their grief, so they put on an outwardly brave front or do not talk about the deceased family member or traumatic event. Instead of the desired protective effect, the child receives the message that demonstrating grief or talking about death is wrong, leading the child to feel isolated, grieve privately, or delay grieving. The child may also conclude that the parents did not really care about the deceased because they seem to have forgotten the person so easily or demonstrate no emotion. The parents' efforts to avoid talking about the death may cause the parents to isolate themselves from their children at a time when the children most need them. Children need to know that their parents love them and will continue to protect them. Children need opportunities to talk about their relative's death and associated memories. A surviving sibling may feel guilty simply because he or she survived, especially if the death was the result of an accident that involved both children. Siblings' grief, especially when compounded by feelings of guilt, may manifest as regressive behavior or anger. Parents should be informed of this possibility and encouraged to discuss it with their children.

Table 30.3 Recommendations for Healthcare Professionals for Helping Children After Bereavement

- Help children and families recognize that there is no correct way to grieve and that every child grieves differently
- Help caregivers recognize that child grief is not the same as adult grief, and children express their grief reactions in very different ways
- Help caregivers understand that the circumstances of the death can play a major role in children's grief reactions, and deaths by homicide or suicide might be especially difficult for children (therefore could require more intensive mental healthcare)
- Empower caregivers by explaining they can be instrumental in facilitating adaptive grief in their children by providing empathy, reassurance, and a listening ear, and talking openly about the deceased person with their child
- Help caregivers to use language accessible to children when talking about the death, meaning that they should use simple and straightforward language that is appropriate for the child's developmental stage, and let the child ask questions as opposed to providing a lot of detailed information
- Provide accurate information to children about the cause of death; children can become preoccupied with thoughts about contagion (e.g., "will I catch cancer too?") or worries about the caregiver's level of suffering (e.g., "did it hurt when my dad had a stroke?"), and healthcare professionals can help children understand the circumstances of the death and assist in alleviating some of these concerns
- Never underestimate the importance of simply bearing witness to a child's grief; our society often sends children messages that it is not okay to talk about their own grief, and in allowing them the space to do that, healthcare professionals can help to both normalize and validate their reactions.

From Kentor RA, Kaplow JB. Supporting children and adolescents following parental bereavement: guidance for health-care professionals. *Lancet Child Adolesc.* 2020;4:889–898, p 896.

DEVELOPMENTAL PERSPECTIVE

Children's responses to death reflect the family's current culture, their past heritage, their experiences, and the sociopolitical environment. Personal experience with terminal illness and dying may also facilitate children's comprehension of death and familiarity with mourning. Developmental differences exist in children's efforts to make sense of and master the concept and reality of death and profoundly influence their grief reactions.

Children younger than 3 years have little or no understanding of the concept of death. Despair, separation anxiety, and detachment may occur at the withdrawal of nurturing caretakers. Young children may respond in reaction to observing distress in others, such as a parent or sibling who is crying, withdrawn, or angry. Young children also express signs and symptoms of grief in their emotional states, such as irritability or lethargy, and in severe cases, mutism. If the reaction is severe, failure to thrive may occur.

Preschool children are in the preoperational cognitive stage, in which communication takes place through play and fantasy (see Chapter 25). They do not show well-established cause-and-effect reasoning. They may feel that death is reversible, analogous to someone going away. In attempts to master the finality and permanence of death, preschoolers frequently ask unrelenting, repeated questions about when the person who died will be returning. This makes it difficult for parents, who may become frustrated because they do not understand why the child keeps asking and do not like the constant reminders of the person's death. The primary care provider has a very important role in helping families understand the child's struggle to comprehend death. Preschool children typically express magical explanations of death events, sometimes resulting in guilt and self-blame ("He died because I wouldn't play with him"; "She died because I was mad at her"). Some children have these thoughts but do not express them verbally because of embarrassment or guilt. Parents and primary care providers need to be aware of magical thinking and must reassure preschool children that their thoughts had nothing to do with the outcome. Children of this age are often frightened by prolonged, powerful expressions of grief by others. Children conceptualize events in the context of their own experiential reality, and therefore consider death in terms of sleep, separation, and injury. Young children express grief intermittently and show marked affective shifts over brief periods.

Younger school-age children think concretely, recognize that death is irreversible, but believe it will not happen to them or affect them, and begin to understand biologic processes of the human body ("You'll die if your body stops working"). Information gathered from the media, peers, and parents forms lasting impressions. Consequently, they may ask candid questions about death that adults will have difficulty addressing ("He must have been blown to pieces, huh?").

Children approximately 9 years and older do understand that death is irreversible and that it may involve them or their families. These children tend to experience more anxiety, overt symptoms of depression, and somatic complaints than do younger children. School-age children are often left with anger focused on the loved one, those who could not save the deceased, or those presumed responsible for the death. Contact with the primary care clinician may provide great reassurance, especially for the child with somatic symptoms, and particularly when the death followed a medical illness. School and learning problems may also occur, often linked to difficulty concentrating or preoccupation with the death. Close collaboration with the child's school may provide important diagnostic information and offer opportunities to mobilize intervention or support.

At **12-14 years of age**, children begin to use symbolic thinking, reason abstractly, and analyze hypothetical, or "what if," scenarios systematically. Death and the end of life become concepts rather than events. Teenagers are often ambivalent about dependence and independence and may withdraw emotionally from surviving family members, only to mourn in isolation. Adolescents begin to understand complex physiologic systems in relationship to death. Because they are often egocentric, they may be more concerned about the impact of the death on themselves than about the deceased or other family members. Fascination with dramatic, sensational, or romantic death sometimes occurs and may find expression in *copycat behavior,* such as cluster suicides, as well as *competitive behavior,* to forge emotional links to the deceased person ("He was my best friend"). Somatic expression of grief may revolve around highly complex syndromes such as eating disorders (see Chapter 41) or conversion reactions (Chapter 35), as well as symptoms limited to the more immediate perceptions (stomachaches). *Quality of life* takes on meaning, and the teenager develops a focus on the future. Depression, resentment, mood swings, rage, and risk-taking behaviors can emerge as the adolescent seeks answers to questions of values, safety, evil, and fairness. Alternately, adolescents may seek philosophic or spiritual explanations ("being at peace") to ease their sense of loss. The death of a peer may be especially traumatic.

Families often struggle with how to inform their children of the death of a family member. The answer depends on the child's developmental level. It is best to avoid misleading euphemisms and metaphor. A child who is told that the relative who died "went to sleep" may become frightened of falling asleep, resulting in sleep problems or nightmares. Children can be told that the person is "no longer living" or "no longer moving or feeling." Using examples of pets that have died sometimes can help children gain a more realistic idea of the meaning of death. Parents who have religious beliefs may comfort their children with explanations, such as, "Your sister's soul is in heaven," or "Grandfather is now with God," provided those beliefs are honestly held. If these are not religious beliefs th[illegible] children will sense the insincerity and experience anxiety rather than

the hoped-for reassurance. Children's books about death can provide an important source of information, and when read together, these books may help the parent to find the right words while addressing the child's needs.

ROLE OF THE PEDIATRIC HEALTHCARE PROVIDER IN GRIEF

The pediatric healthcare provider who has had a longitudinal relationship with the family will be an important source of support in the disclosure of bad news and in critical decision-making, during both the dying process and the bereavement period (see Table 30.3). The involvement of the healthcare provider may include being present at the time the diagnosis is disclosed, at the hospital or home at the time of death, being available to the family by phone during the bereavement period, sending a sympathy card, attending the funeral, and scheduling a follow-up visit. Attendance at the funeral sends a strong message that the family and their child are important, respected by the healthcare provider, and can also help the pediatric healthcare provider to grieve and reach personal closure about the death. A family meeting 1-3 months later may be helpful because parents may not be able to formulate their questions at the time of death. This meeting allows the family time to ask questions, share concerns, and review autopsy findings (if one was performed), and allows the healthcare provider to determine how the parents and family are adjusting to the death.

Instead of leaving the family feeling abandoned by a healthcare system that they have counted on, this visit allows them to have continued support. This is even more important when the healthcare provider will be continuing to provide care for surviving siblings. The visit can be used to determine how the mourning process is progressing, detect evidence of marital discord, and evaluate how well surviving siblings are coping. This is also an opportunity to evaluate whether referrals to support groups or mental health providers may be of benefit. Continuing to recognize the child who has died is important. Families appreciate the receipt of a card on their child's birthday, around holidays, or the anniversary of their child's death.

The healthcare provider needs to be an *educator* about disease, death, and grief. The pediatrician can offer a safe environment for the family to talk about painful emotions, express fears, and share memories. By giving families permission to talk and modeling how to address children's concerns, the clinician demystifies death. Parents often request practical help. The healthcare provider can offer families resources, such as literature (both fiction and nonfiction), referrals to therapeutic services, and tools to help them learn about illness, loss, and grief. In this way the physician reinforces the sense that other people understand what they are going through and helps to normalize their distressing emotions. The healthcare provider can also facilitate and demystify the grief process by sharing basic tenets of **grief therapy**. There is no single right or wrong way to grieve. Everyone grieves differently; mothers may grieve differently than fathers, and children mourn differently than adults. Helping family members to respect these differences and reach out to support each other is critical. Grief is not something to "get over," but a lifelong process of adapting, readjusting, and reconnecting.

Parents may need help in knowing what constitutes **normal grieving**. Hearing, seeing, or feeling their child's presence may be a normal response. Vivid memories or dreams may occur. The healthcare provider can help parents to learn that, although their pain and sadness may seem intolerable, other parents have survived similar experiences, and their pain will lessen over time.

Healthcare providers are often asked whether children should attend the **funeral** of a parent or sibling. These rituals allow the family to begin their mourning process. Children >4 years old should be given a choice. If the child chooses to attend, the child should have a designated, trusted adult who is not part of the immediate family and who will stay with the child, offer comfort, and be willing to leave with the child if the experience proves to be overwhelming. If the child chooses not to attend, the child should be offered additional opportunities to share in a ritual, go to the cemetery to view the grave, tell stories about the deceased, or obtain a keepsake object from the deceased family member as a remembrance.

In the era of regionalized tertiary care medicine, the primary care provider and medical home staff may not be informed when one of their patients dies in the hospital. Yet, this communication is critically important. Families assume their primary care provider has been notified and often feel hurt when they do not receive some symbol of condolence. Because of their longitudinal relationship with the family, primary care providers may offer much needed support. There are practical issues, such as the need to cancel previously made appointments and to alert office and nursing staff so that they are prepared should the family return for a follow-up visit or for ongoing health maintenance care with the surviving siblings. Even minor illnesses in the surviving siblings may frighten children. Parents may contribute to this anxiety because their inability to protect the child who has died may leave them with a sense of guilt or helplessness. They may seek medical attention sooner or may be hypervigilant in the care of the siblings because of guilt over the other child's death, concern about their judgment, or the need for continued reassurance. A primary care visit can do much to allay their fears.

Clinicians must remain vigilant for risk factors in each family member and in the family unit as a whole. Primary care providers, who care for families over time, know bereft patients' premorbid functioning and can identify those at current or future risk for physical and psychiatric morbidity. Providers must focus on symptoms that interfere with a patient's normal activities and compromise a child's attainment of developmental tasks. Symptom duration, intensity, and severity, in context with the family's culture, can help identify **complicated grief** reactions in need of therapeutic attention (see Table 30.2). Descriptive words such as "unrelenting," "intense," "intrusive," or "prolonged" should raise concern. Total absence of signs of mourning, specifically an inability to discuss the loss or express sadness, also suggests potential problems.

No specific sign, symptom, or cluster of behaviors identifies the child or family in need of help. Further assessment is indicated if the following occur: (1) persistent somatic or psychosomatic complaints of undetermined origin (headache, stomachache, eating and sleeping disorders, conversion symptoms, symptoms related to the deceased's condition, hypochondriasis); (2) unusual circumstances of death or loss (sudden, violent, or traumatic death; inexplicable, unbelievable, or particularly senseless death; prolonged, complicated illness; unexpected separation); (3) school or work difficulties (declining grades or school performance, social withdrawal, aggression); (4) changes in home or family functioning (multiple family stresses, lack of social support, unavailable or ineffective functioning of caretakers, multiple disruptions in routines, lack of safety); and (5) concerning psychologic factors (persistent guilt or blame, desire to die or talk of suicide, severe separation distress, disturbing hallucinations, self-abuse, risk-taking behaviors, symptoms of trauma such as hyperarousal or severe flashbacks, grief from previous or multiple deaths). Children who are intellectually impaired may require additional support.

TREATMENT

Suggesting interventions outside the natural support network of family and friends can often prove useful to grieving families. Bereavement counseling should be readily offered if needed or requested by the family. Interventions that enhance or promote attachments and security, as well as give the family a means of expressing and understanding death, help to reduce the likelihood of future or prolonged disturbance, especially in children. Collaboration between pediatric and mental health professionals can help determine the timing and appropriateness of services.

Interventions for children and families who are struggling to cope with a loss in the community include gestures such as sending a card or offering food to the relatives of the deceased and teaching children the etiquette of behaviors and rituals around bereavement and mutual support. Performing community ser

charitable organizations, such as fund-raising in memory of the deceased, may be useful. In the wake of a disaster, parents and older siblings can give blood or volunteer in search and recovery efforts. When a loss does not involve an actual death (e.g., parental divorce, geographic relocation), empowering the child to join or start a "divorced kids' club" in school or planning a "new kids in town" party may help. Participating in a constructive activity moves the family away from a sense of helplessness and hopelessness and helps them find meaning in their loss.

Psychotherapeutic services may benefit the entire family or individual members. Many support or self-help groups focus on specific types of losses (sudden infant death syndrome, suicide, widow/widowers, AIDS) and provide an opportunity to talk with other people who have experienced similar losses. Family, couple, sibling, or individual counseling may be useful, depending on the nature of the residual coping issues. Combinations of approaches may work well for children or parents with evolving needs. A child may participate in family therapy to deal with the loss of a sibling and use individual treatment to address issues of personal ambivalence and guilt related to the death.

The question of **pharmacologic intervention** for grief reactions often arises. Explaining that medication does not cure grief and often does not reduce the intensity of some symptoms (separation distress) can help. Although medication can blunt reactions, the psychologic work of grieving still must occur. The physician must consider the patient's premorbid psychiatric vulnerability, current level of functioning, other available supports, and the use of additional therapeutic interventions. Medication as a first line of defense rarely proves useful in normal or uncomplicated grief reactions. In certain situations (severe sleep disruption, incapacitating anxiety, intense hyperarousal), an anxiolytic or antidepressant may help to achieve symptom relief and provide the patient with the emotional energy to mourn. Medication used in conjunction with some form of psychotherapy, and in consultation with a psychopharmacologist, has optimal results.

Children who are **refugees** and may have experienced war, violence, or personal torture, while often resilient, may experience posttraumatic stress disorder if exposures were severe or repeated (see Chapters 15.3 and 38). Sequelae such as depression, anxiety, and grief need to be addressed, and mental health therapy is indicated. Cognitive-behavioral therapy, use of journaling and narratives to bear witness to the experiences, and use of translators may be essential.

SPIRITUAL ISSUES

Responding to patients' and families' spiritual beliefs can help in comforting them during family tragedies. Offering to call members of pastoral care teams or their own spiritual leader can provide needed support and can aid in decision-making. Families have found it important to have their beliefs and their need for hope acknowledged in end-of-life care. The majority of patients report welcoming discussions on spirituality, which may help individual patients cope with illness, disease, dying, and death. In addressing spirituality, physicians need to follow certain guidelines, including maintaining respect for the patient's beliefs, following the patient's lead in exploring how spirituality affects the patient's decision-making, acknowledging the limits of their own expertise and role in spirituality, and maintaining their own integrity by not saying or doing anything that violates their own spiritual or religious views. Healthcare providers should not impose their own religious or nonreligious beliefs on patients, but rather should listen respectfully to their patients. By responding to spiritual needs, clinicians may better aid their patients and families in end-of-life care and bereavement and take on the role of healers.

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