CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Supporting the Grieving Child and Family: Clinical Report

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The death of someone close to a child often has a profound and lifelong effect on the child and results in a range of both short- and long-term reactions. Pediatricians, within a patient-centered medical home, are in an excellent position to provide guidance to caregivers and to offer assistance and support to grieving children of all ages and their families. This clinical report offers practical suggestions on how to talk with grieving children to help them better understand what has happened and its implications. An understanding of guilt, shame, and other common reactions as well as an appreciation of the role of secondary losses and the unique challenges facing children in communities characterized by chronic trauma and cumulative loss will help the pediatrician to address factors that may impair children's adjustment and to identify complicated mourning and situations when professional counseling is indicated. Advice on how to support children's participation in funerals and other memorial services and to anticipate and address grief triggers and anniversary reactions is provided so that pediatricians are in a better position to advise caregivers and to offer consultation to and collaborate with professionals in schools, early education and child care facilities, and other child congregate care sites. Pediatricians often enter their profession out of a profound desire to minimize the suffering of children and may find it personally challenging to bear witness to the distress of children who are acutely grieving. The importance of professional preparation and self-care is, therefore, emphasized, and resources are recommended.

INTRODUCTION

At some point in their childhood, the majority of children* will experience the death of a close family member or friend.[1,2] Approximately 1 in

*This report is intended to address grieving children of all ages. Throughout this report, the word "children" is used to represent infants, preschool-aged and school-aged children, adolescents, youth, and young adults, unless otherwise indicated.

abstract

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20 children in the United States experiences the death of a parent by the age of 16.[3] Despite the high prevalence of bereavement among children, many pediatricians are uncomfortable talking with and supporting grieving children.[4] The coronavirus disease 2019 pandemic highlighted the enormous impacts of grief and loss and was coupled with unique aspects, such as cumulative loss and grieving in the context of social isolation that affected virtually everyone. These same factors are present, however, for some children even outside the context of a pandemic, especially children in groups that historically have been marginalized or disadvantaged.

Bereavement is a universal and normative experience. However, this does not minimize the impact of a loss. The death of someone close to a child often has a profound and lifelong effect on the child and may result in a range of both short- and long-term reactions. Children and families may experience grief after other forms of loss than death, including loss of a parent through divorce, deployment, deportation, or incarceration. Pediatricians, within a patient-centered medical home, are in an excellent position to provide support and guidance to families before, during, and after a loss and can provide assistance and support in a number of areas, including the following:

- exploring and confirming that children understand what has occurred and what death means, based in part on their developmental stage;
- supporting the family by educating them about the developmentally informed understanding of the grieving process and with advice and support on related issues;
- helping to identify prolonged or severe guilt, fear, worry, or depressive symptoms or other grief reactions that suggest the need for further evaluation and referral;
- providing reassurance to children who become concerned about their own health or those of family members;
- providing effective interventions to grieving children and families in the office to address common grief reactions;
- informing families about local resources that can provide additional assistance; and
- offering advice on funeral attendance of children.

Pediatricians also can play an important role in supporting parents and other caregivers after the death of a child, even in the absence of surviving siblings.[4–6] In addition, children may experience grief in response to a range of other losses, such as separation from parents because of deployment, incarceration, deportation, or divorce, which may be helped by similar caring strategies. Much of the practical guidance provided in this clinical report may be applicable, with modification, to situations of other types of losses, but this clinical report focuses on grief caused by death (ie, bereavement).

This clinical report is a revision of an earlier clinical report that introduced some of the key issues that pediatricians should consider in providing support to grieving children.[7] Guidance is available elsewhere regarding how to support families faced with the impending or recent death of their child,[4,8] including practical advice on how to approach notification of parents about the death of their child in a hospital setting[8,9] or in the unique context of a disaster.[10] Because traumatic events often involve loss, complementary information on providing psychosocial support in the aftermath of a crisis can be found in a recent clinical report,[11] which may be particularly relevant to pediatricians providing care in emergency departments and intensive care settings.

IDENTIFYING CHILDREN'S LOSS EXPERIENCES

In a busy pediatric practice, it is likely that a pediatrician interacts with a child who is grieving a death virtually every week, if not every day. But many children who are grieving show few outward signs during an office visit. From an early age, children learn that questions or discussion about death make many adults uncomfortable; they learn not to talk about death in public. In the context of a recent death, children may also be reluctant to further burden grieving family members with their own concerns. Children's questions about the impact of a personal loss can be quite poignant and/or frame the experience in concrete and direct terms that underscore the immediacy and reality of the loss to adults (eg, "If Mommy died, does that mean that she won't be here even for my birthday? How can I live the rest of my life without her?"). Adolescents who are in a better position to appreciate the secondary losses and other implications of a significant loss may raise concerns that surviving adults may not have yet appreciated (eg, "I don't know if I ever will feel comfortable having my own children when I grow up, without Mom there to help me."). When children ask such questions or make similar comments, surviving family members may become tearful and/or obviously upset. Children may misinterpret these expressions of grief triggered by their questions as evidence that the questions themselves were hurtful or inappropriate. They subsequently may remain silent and grieve alone, without support. In addition, when children lose a parent or other close family member, they are often fearful that others they count on for support may also die and leave them all alone. Children may find it particularly unsettling to observe their surviving caregivers struggling and often respond to their surviving parents' demonstrations of grief by offering support or assistance (eg, "Don't worry Daddy, I can help do many of the things Mommy used to do; we are going to be okay."), rather

than asking for help themselves, which may convince surviving caregiver(s) that the child is coping and has no need for assistance. For this reason, it is important for pediatricians to offer to speak with children privately after a family death to identify their understanding, concerns, and reactions without children feeling that they need to protect surviving caregivers.

Caregivers who are struggling with their own personal grief may be unaware or unable to recognize or accept their children's grief. As a result, children in this situation may be forced to grieve alone, postponing expressing their grief until a time when it feels safer, or seeking support elsewhere, such as at school or after-school programs where they can talk about their feelings and concerns with adults who have personal distance from the loss.

Young children, in particular, may not yet understand the implications of the death for them or their family. Children and their families may wish to seek advice but view death as a normative experience that does not warrant professional assistance and may not realize that their pediatrician may be interested in helping and able to assist them. During an incidental pediatric office visit, children may be reluctant to raise the topic because they worry that they will start crying or otherwise feel uncomfortable. They may be afraid to start a discussion in the pediatric office or at school because they worry that once they start to cry, they will be unable to compose themselves by the end of an office visit or a conversation at school. Children may also express their grief indirectly through their behavior or attempt to address their feelings through play. Grief is, in many ways, a personal experience. Older children and adolescents, especially, may elect to keep their feelings and concerns to themselves unless caring adults invite and facilitate discussion. Special considerations are needed for children with intellectual and neurodevelopmental disabilities, with explanations geared to their developmental and cognitive level. Children who have limited ability to communicate verbally may express their grief indirectly through nonspecific behaviors. These are among the many reasons why pediatricians may be unaware of a death involving a close family member or friend of one of their patients.

Pediatricians can increase the likelihood that children and families will bring significant losses to their attention by directly informing families, often during the initial visit and periodically thereafter, that they are interested in hearing about major changes in the lives of patients and their families, such as deaths of family members or friends, financial or marital concerns of the family, planned or recent moves, traumatic events in the local community or neighborhood, or problems or concerns at school or with peer relationships. A comment, modified depending on developmental or cultural factors, such as the following can be included in new patient visits: "Our practice is here to assist you with both medical concerns as well as stressful events, such as the death of someone close to you, when upsetting changes are occurring, or if there is something that has happened in the community that you feel may be impacting you or your family." At subsequent visits, pediatricians can ask whether any major changes or potential stressors at home, at school, or within the community have occurred or are anticipated.[12] Practices that respond to these needs as they arise in families by inviting conversations, expressing concern, and offering information and referral create an atmosphere in which families are more likely to disclose their occurrence and actively seek assistance and support.

INITIATING THE CONVERSATION

Pediatricians and other caring adults may worry that asking children about the recent death of someone close to them may upset them. In the immediate aftermath of a major loss, the loss is almost always on survivors' minds. Although a question about the death may lead to an expression of sadness, it is the death itself, and not the question, that is the cause of the distress. Inviting children to express their feelings allows them to express their sadness; it does not cause it. In contrast, avoiding the subject may create more problems. Children may interpret the silence as evidence that adults are unaware of their loss, feel that their loss is trivial and unworthy of comment, are disinterested in their grief, are unwilling or unable to assist, or view the child as unable to cope even with support.[13] Initiating the conversation with the bereaved child and family may be uncomfortable, even for an experienced pediatrician. The following are strategies to help the pediatrician approach this task[14]:

- Express your concern. It is okay to be tearful or simply to let them know you feel sorry someone they care about has died.
- Be genuine; children can tell when adults are authentic. Do not tell children you will miss their grandfather if you have never met him; instead, let them know that you appreciate that he was important to them, and you feel sorry they had to experience such a loss.
- Listen and observe; talk less. Simply being present while the child is expressing grief and tolerating the unpleasant affect can be very helpful.
- Invite discussion using open-ended questions such as "How are you doing since your mother died?" or "How is your family coping?"
- Offer practical advice, such as suggestions about how to answer questions that might be posed by peers or how to talk with teachers about learning challenges.
- Offer appropriate reassurance. Do not minimize children's concerns but let them know that over time you

do expect that they will become better able to cope with their distress.
- Communicate your availability to provide support over time. Do not require children or families to reach out to you for such support, but rather, make the effort to schedule follow-up appointments and reach out by phone or e-mail periodically.

Adults are often worried that they will say the wrong thing and make matters worse. In the context of talking with a patient who has recently experienced a death, caregivers may wish to consider the following suggestions[14]:

- Although well intentioned, attempts to "cheer up" individuals who are grieving are usually neither effective nor appreciated. Anything that begins with "at least" should be reconsidered (eg, "at least he isn't in pain anymore," "at least you have another brother"). Such comments may minimize professionals' discomfort in being with a child who is grieving but do not help children express and cope with their feelings.
- Do not instruct children to hide their emotions (eg, "You need to be strong; you are the man of the house now that your father has died.").
- Avoid communicating that you know how they feel (eg, "I know exactly what you are going through."). Instead, ask them to share their feelings.
- Do not tell them how they ought to feel ("You must feel angry.").
- Avoid comparisons with your own experiences. When adults share their own experiences in the context of recent loss, it shifts the focus away from the child. If your loss is perceived by the child as less important, the comparison can be insulting (eg, "I know what you are going through after the death of your father. My cat died this week."). If your experience appears worse (eg, "I understand your grandfather died. When I was your age, both my mother and father died in a car accident."), the child may feel compelled to comfort you and be reluctant to ask for help.

The use of expressive techniques, such as picture drawing or engaging children in an unrelated activity such as play while talking with them, may be helpful, especially with young children or children who appear reluctant to address the topic in direct conversation.[13] Children's reluctance to talk may be because of their own lack of clarity about their feelings or lack of language or emotional expressive capacity. Offering to talk alone with grieving children may increase their comfort in sharing their distress without worrying about upsetting grieving parents or caregivers. Similarly, it is helpful for pediatricians to offer to speak with parents and caregivers alone about their own concerns and to advocate for them to get appropriate support for their own needs.[11]

Pediatricians can also provide written information to families about how to support grieving children (eg, *After a Loved One Dies: How Children Grieve and How Parents and Other Adults Can Support Them*, which is freely available and can be accessed through the coping and adjustment Web page of the American Academy of Pediatrics at https://www.aap.org/disasters/adjustment).[15] Books written specifically for younger children that help them develop a better understanding of death or that help children and adolescents cope and adjust with a personal loss can be found through recommendations of a children's librarian or at bookstores. Pediatricians can identify a few books to recommend and, ideally, may even choose to stock their offices with a couple of copies to lend to families. It is important to ensure that materials are appropriate for the cultural, religious, and social context of the grieving child.

CHILDREN'S DEVELOPMENTAL UNDERSTANDING OF DEATH

Before the development of object permanence, which develops in the second half of the first year of life, infants are unable to comprehend and experience permanent loss and truly grieve. But as children develop object permanence during the second half of the first year of life, they begin to acquire the ability to appreciate the possibility of true loss. It is, therefore, not coincidental that peek-a-boo emerges during this time period as a game played by children across different cultures, wherein the child shows heightened concern at separation and joy at reunion, as if "playing" with the idea of loss. Infants and toddlers play this game repeatedly as they try to understand and deal with the potential of loss. It has been suggested that peek-a-boo is one of many games that children play that might allude to loss or death. In fact, "peek-a-boo" is translated literally from Old English as "alive-or-dead." Parents who worry that it is too early to raise the topic of death with their preschool- or even school-aged children likely do not realize that they began communicating with their children about loss at an early age.

Research has shown that there are 4 concepts that children come to understand that help them make sense of, and ultimately cope with, death: irreversibility, finality (nonfunctionality), causality, and universality (inevitability).[15–20] On average, most children will develop an understanding of these concepts, outlined in Table 1, by 5 to 7 years of age. Personal loss or a terminal illness before this age has been associated with a precocious understanding of these concepts[20]; education has been shown to accelerate children's understanding as well.[21] The death of a pet in early childhood can be used as an opportunity to help young children both understand death and learn to express and cope with loss.

Understanding the concepts of death can be viewed as a necessary precondition, but not necessarily sufficient,

TABLE 1 Component Death Concepts and Implications of Incomplete Understanding for Adjustment to Loss
Irreversibility: death is a permanent phenomenon from which there is no recovery or return
• Example of incomplete understanding: the child expects the deceased to return, as if from a trip
• Implication of incomplete understanding: failure to comprehend this concept prevents the child from modifying personal ties to the deceased, a necessary first step in successful mourning
Finality (nonfunctionality): death is a state in which all life functions cease completely
• Example of incomplete understanding: the child worries about a buried relative being cold or in pain; the child wishes to bury food with the deceased
• Implication of incomplete understanding: may lead to preoccupation with physical suffering of the deceased and impair readjustment
Inevitability (universality): death is a natural phenomenon that no living being can escape indefinitely
• Example of incomplete understanding: the child views significant individuals (ie, self, parents) as immortal
• Implication of incomplete understanding: if the child does not view death as inevitable, he or she is likely to view death as punishment (either for actions or thoughts of the deceased or the child), leading to excessive guilt and shame
Causality: the child develops a realistic understanding of the causes of death
• Example of incomplete understanding: the child who relies on magical thinking is apt to assume responsibility for death of a loved one by assuming that bad thoughts or unrelated actions were causative
• Implication of incomplete understanding: tends to lead to excessive guilt that is difficult for the child to resolve
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for acceptance and adjustment. Children at a very young age can understand that death is irreversible; indeed, even toddlers come to learn "all-gone." But accepting that someone about whom you care deeply will never return is difficult even for adults. Pediatricians can counsel parents to help children understand these concepts and assess children's comprehension directly through simple questions. Parents can be encouraged to be patient with children's repetitive questions after a loss, which may occur over an extended period of time. For young children, such questions may reflect attempts to develop a more complete understanding over time as cognitive development progresses.

Misinformation or misconceptions can impair children's adjustment to loss. Literal misinterpretations are common among young children. For example, children may become resistant to attending a wake after being told that their parent's body will be placed in the casket; adults often assume this is because of a fear of dead bodies. But some children, when told that the "body" is placed in one location, may conclude that the head is placed elsewhere; their reluctance to attend the wake may be attributable to a fear of viewing their parent decapitated. It is best not to assume the reasons for children's worries or hesitation but instead ask what they are thinking about. Young children also may have difficulty understanding why families would choose to cremate a family member after death. Providing developmentally appropriate explanations for parents and other caregivers to use to address common questions can be helpful and reassuring (eg, explaining to preschool-aged children that once people die, their body stops working permanently and they no longer are able to move, think, or feel pain, which is why it is okay to cremate the body, or use high temperatures to turn the body into ashes).

To minimize misinterpretations, it is best to avoid euphemisms; especially with younger children, it is important to use the word "dead" or "died." For example, a young child told that a family member is in eternal sleep may become afraid of going to sleep himself. Religious explanations can be shared with children of any age according to the wishes of their caregivers. But because religious concepts tend to be abstract and, therefore, are more likely to be misunderstood by young children, it is important to also share with children factual information based on the physical reality. For example, a young child told only that a brother died "because he was such a good baby God wanted him back at his side" may begin to fear attending church (if this is viewed as "God's home") and misbehave whenever brought to religious services.

Children with intellectual disabilities will generally benefit from explanations geared toward their level of cognitive functioning, followed by questions to assess the degree of comprehension and to probe for any misunderstandings. Caregivers of children with neurodevelopmental disorders, such as autism spectrum disorder, may benefit from advice on how to identify when these children are communicating their feelings and needs as well as how to provide additional support to promote coping. Children unable to communicate verbally may show their grief through nonspecific signs or behaviors, such as weight loss or head banging. To provide support after a death, parents and other caregivers can draw on the strategies and approaches that have worked with their children in the past to provide comfort when faced with other stressors and to explain challenging concepts.

ADOLESCENTS

Adolescents may have a mature conceptual understanding of death, but they still experience challenges adjusting to

the death of a close family member or friend.[22] This is especially true if the individual who died was an important attachment figure and caregiver who provided nurturing and emotional support for the adolescent and would have helped buffer other stressors that the child may experience later in life. Although they are capable of rational thinking, adolescents, like adults, nonetheless, benefit from additional explanation and discussion in addition to emotional support. Although they often turn to peers for support and assistance in many situations, after the death of a close family member or friend, they can benefit from the additional physical and emotional presence of adults. Unfortunately, many adolescents receive limited explanation or support after a death. Often, surviving caregivers rely on them to take on more adult responsibilities, such as contributing to the care of younger siblings and performing more chores within the home, and may count on them to serve the role of a confidante and source of emotional support for the caregivers themselves. Pediatricians may be able to assist in such cases by encouraging adult caregivers to identify their own support, such as through faith-based organizations, community-based support groups or professional counseling, and encouraging the adults to avoid depending on adolescents to take on adult responsibilities that are not appropriate to their developmental level and/or that interfere with the adolescent's personal development.

Juniors or seniors in high school are at a point in their development when they may be particularly vulnerable to difficulties in coping with the death of a close family member or friend. This is a time of heightened academic demands, and the common short-term negative effect on academic productivity may be compounded by the high level of academic scrutiny characteristic of applying to college. Completing high school and leaving family to pursue their own education or career is a challenging transition for adolescents who choose to pursue postgraduate education and often involves stress and ambivalence. A recent death can exacerbate academic and personal challenges. Youth anticipating leaving home for school or a career may feel guilty about leaving other family members who are grieving or worry that they will have difficulty coping when separated from their family, friends, and familiar supports. These young people may arrive in college to face peers who are unaware of their loss, unfamiliar with how best to provide them with support, and focused on pursuits and activities that seem incongruous with their grief. The food, people, and settings that normally provide these young people solace and comfort may be lacking at a time when they are most needed. Pediatricians can support these adolescents by staying connected with them during the transition and helping them and their families identify supports and resources at college and in their family's community.[14] Similar challenges also face youth that choose not to pursue postgraduate education but need to transition to new work settings and/or living independently.

GUILT AND SHAME

Because of the egocentrism and magical thinking that are characteristic of young children's understanding of causality, children will often assume that there was something they did, did not do, or should have done that would have prevented the death of someone close to them and develop guilt over a death. Even older children, and indeed adults, often feel guilty when there is no logical, objective reason for them to feel responsible for a death. People may assume some responsibility because it helps them believe that, by taking actions they failed to take before, they can prevent the future deaths of others about whom they care deeply and feel more in control. For example, if a child assumes that the reason his father died was because he attended a friend's party rather than staying home to monitor his father, he can reassure himself that his mother will be okay as long as he never leaves the home at night again. The alternative to this kind of thinking is accepting that we have limited influence over tragic events but that reality leaves many feeling helpless. It is frightening to realize someone else we care about could die at any time, no matter what we do. But assuming fault for a death in this manner does not prevent future loss, and the resulting guilt contributes to further distress. Consideration by the pediatrician of referral is indicated in situations in which children's actions clearly contributed to the cause of death (eg, a child who accidentally discharges a firearm that results in the death of someone) or when children persist in feeling responsible (whether or not such guilt is logical). In the context of ongoing support, children can be helped to either dismiss illogical guilt or come to forgive themselves for unintended actions they believe have contributed in some way to the death.

Children are also more likely to feel guilty about a death when the preexisting relationship with the deceased was ambivalent or conflicted. The relationship between adolescents and their parents often has some element of such ambivalence or conflict as the adolescent strives for independence, and conflict is more likely to be present if the deceased had a chronic mental or physical illness or problem with substance use or had been abusive, neglectful, or absent (eg, incarcerated or deployed). Guilt of other family members may also lead to difficulties; for example, it can distort the relationships between parents and surviving children after the death of a sibling.[23]

It is helpful for pediatricians to approach children who have lost a close family member or friend presuming that guilt may be present, even when there is no logical reason for it. Pediatricians can explain that they know

there is nothing that the child did, failed to do, or could have done to change the outcome but wonder if the child ever believes that he or she somehow contributed to the death as many children do in similar situations. They can explain that feeling bad does not mean you did anything bad and feeling guilty does not mean you are guilty. When pediatricians help children express their guilt associated with a death, it allows children to begin to challenge their faulty assumptions about personal responsibility and promotes a refocusing on the child's feelings about the loss.

Children also may experience guilt over surviving after a sibling died or feeling relief after a death that followed a lengthy illness. In the setting of a protracted illness, family members and friends often experience anticipatory grieving. They can imagine the death and experience graduated feelings of loss, but when it becomes overwhelming, they can reassure themselves that their family member or friend is still alive. Anticipating the death allows them to accomplish some of the "work" of grief before the death actually occurs. But anticipating death is a painful process, and at some point, many individuals in this situation will wish for the death to occur. Although they may couch this in terms of hoping for the person who is dying to be able to end his or her suffering, the death would also end some of their own emotional suffering as they anticipate the death of a family member or friend and free them of their responsibility to focus much of their time and efforts on the needs of the person who is critically ill. This situation can result in further guilt and complicate the grieving process.[8]

When children assume that the cause of the death was the result of the actions, inactions, or thoughts of the person who died, they may feel ashamed of the person who died and/or the death and reluctant to talk with others about their loss. Shame is also likely to complicate bereavement when the death is somehow stigmatized, such as death from suicide or resulting from criminal activity or substance use. This shame further isolates grieving children from the support and assistance of concerned peers and adults.

Suicide is often complicated by both guilt and shame among survivors. As a result, discussion about the cause of death is often limited, and children may struggle to understand the cause or circumstances of the death. Open communication helps prevent suicide from becoming a "family secret," which may further disrupt the grieving process. If the explanations are too simplistic, concerns may be increased. For example, if children are told only, "Your uncle killed himself because he was very, very sad," they will likely notice that extended family members and friends, who are overwhelmed with grief, may look "very, very sad" and worry that they too will kill themselves. A preferable explanation might aim to convey that suicide is usually the result of underlying depression or other mental health problems; it may also be related to alcohol or other substance use. It is important to emphasize that suicide is not generally a logical "choice" made by someone who is thinking clearly and able to consider a range of solutions to problems. In addition, children should be encouraged to communicate when they are distressed or feeling depressed, informed about where they can go for advice and assistance, and instructed not to keep in confidence when peers or others communicate to them that they are considering self-harm.[24] Sample scripts and language for discussing suicide with children at different developmental levels, prepared by the National Center for School Crisis and Bereavement, can be used by schools to respond to a death by suicide of a student or member of the school staff (freely available at www.schoolcrisiscenter.org).

SECONDARY AND CUMULATIVE LOSSES

Although children generally show a remarkable resiliency and ability to adjust to the death of someone close to them, nonetheless, they do not "get over" a death in 6 months or a year. Rather, they spend the rest of their life accommodating the absence. In fact, many find the second year more difficult than the first. The first year after the death is filled with many anticipated challenges: the first holiday or birthday without a close family member or friend or the first father-daughter dance after the father's death. Expectations typically are reduced (ie, the child expects to feel sad at the first special holiday without someone close), and multiple supports are usually in place. When these special occasions are still not joyful in the second year, children may wonder if they will ever be able to experience joy again. Unfortunately, by this point in time, the support they may have received from extended family, teachers, coaches, and others at school and in the community has probably already ended. However, the sense of loss is persistent, and without proper support, it may be perceived as overwhelming. Maintaining support for children and families is important well beyond the initial period of grief.

When children experience a death of someone close to them, they lose not only the person who died (ie, the primary loss) but also everything that person had contributed or would have contributed to their life (ie, secondary losses). Common secondary losses include the following:

- change in lifestyle (eg, altered financial status of the family after the death of a parent);
- relocation resulting in a change in school and peer group;
- less interaction with friends or relatives of the person who died (eg, friends of a child's sister no longer visit after the sister dies);
- loss of shared memories;

- decreased special attention (eg, a child may no longer value participating in sports activities without his parent there to cheer for him);
- decreased availability of the surviving parent (who may need to work more hours or who becomes less available emotionally because of depression); and
- a decreased sense of safety and trust in the world.

Relationships that seemed incidental may take on new meaning after they are no longer available. For example, after the death of his sister, a younger brother may now miss the advice and guidance provided by his sister's boyfriend, who no longer visits. Other losses may not become apparent until years later. A 5-year-old girl experiencing the death of her grandmother who was her primary caregiver may not realize until many years later that she has lost her grandmother's advice and support as she faces puberty or her first date, or on the first night her newborn infant cries inconsolably. At each new milestone, the loss of someone for whom we care deeply is redefined and grief is revisited. When children experience a death at a young age, they may also not fully understand the death or its implications. Each new developmental stage, as cognitive development advances and experience widens, may prompt a resurfacing of their grief and be accompanied by questions that permit the child to come to a more mature understanding of the death and its implications.

Children experiencing foster care, adoption, and kinship care routinely experience some degree of loss of the parent(s) or caregiver(s) from their lives even if they are still alive. When death has occurred, they generally benefit from additional support.

In communities of color and other groups marginalized by discrimination and systemic racism, deaths often occur at higher rates. When children in these communities and groups grieve, their grief may be complicated by experiences of inequity in their families and communities. Too often these communities are also lacking in children's bereavement support programs. Pediatric health care professionals can partner with others within the health care system (such as pediatric departments or hospitals), schools, and nonprofit organizations to advocate for the establishment of children's bereavement centers or programs within the community that are positioned to meet the broad range of intersecting service needs.

Subsequent losses and stressors also add to the challenge of adaptation for all children. Children who have experienced traumatic events or significant losses in the context of sufficient support and internal capacity to cope may experience post-traumatic growth and emerge with increased resiliency and new skills to cope with future adversity. These children may shift their life goals to align more with public service; place a higher priority on family, friends, spirituality, and helping others; or become more empathic.[11,13] But in communities that are characterized by high rates of violence, poverty, and frequent deaths of peers and young family members, such supports are generally not present or are insufficient to meet the heightened need. Children in such environments do not somehow "get used to death" or become desensitized. Rather, these losses make them progressively more vulnerable to future stresses and loss. Children in these circumstances often come to perceive that adults in their communities are unlikely to ensure their safety or provide support for their grief and may, therefore, not seek assistance from these adults because they doubt it will be offered.

GRIEF TRIGGERS AND ANNIVERSARY REACTIONS

Grief triggers evoke sudden reminders of the person who died that can cause powerful emotional responses in children who are grieving. Although they are most common in the first few months after the death, they may happen months or years later, although the strength of the emotions generally lessens with time. Some triggers, such as a Mother's Day activity in class or a father-daughter dance at school, are easier to identify, but grief triggers can be ubiquitous and often difficult to anticipate. A child may pass by a stranger wearing the same perfume as her aunt or hear a song that her grandfather used to sing and be reminded of the loss. Parents can work with teachers to both minimize likely triggers in school settings and create a "safety" plan wherein students know they can leave the classroom if necessary. If children know that they can leave if they need to, they are less likely to feel overwhelmed or afraid they will cry in class. As a result, they will rarely need to exit and are more able to remain within the classroom and engaged in the classwork.[14]

Anniversaries of the death, birthdays of the deceased, holidays, special events, and major transitions (eg, changing schools, graduating high school, moving homes) are also times when a close family member or friend's absence will be acutely felt. Pediatricians can help the family find ways to meaningfully honor these events. The medical home is uniquely well suited to provide ongoing periodic bereavement support. Pediatricians can invite children and their families to reach out for assistance and advice as children adjust to the loss over time. However, many individuals who are grieving may not anticipate the challenges posed by anniversaries or events or may feel uncomfortable imposing on the physician for advice for what they believe to be a normative and universal experience. Pediatricians can, instead, schedule follow-up appointments to coincide with such timed events (eg, just before the start of a new school year; just before the first-year anniversary of the death), when modest changes in the timing make it practical, or can call, write, or e-mail a patient or family periodically to check in and let

the child and family know of their continued availability and interest. When the pediatrician lets the family know he or she is still concerned and available, it increases the chances that the child or family will seek advice and assistance when needed. Pediatricians interested in providing significant direct bereavement support for children and families within their practice can explore the use of appropriate coding, including coding by time, to maximize payment for these services.

FUNERAL ATTENDANCE

Children, like adults, often benefit from participating in funerals, wakes, and other memorial or commemorative activities after the death of a close family member or friend. It provides them with an opportunity to grieve in the presence of family and friends while receiving their support and, as appropriate to the family, solace from their spiritual beliefs. Parents and other caregivers sometimes exclude children from funerals and wakes for fear that the experience may be upsetting or because they, themselves, are grieving and unsure whether they can provide appropriate support. Children who are excluded from memorial or funeral services often resent not being able to participate in a meaningful activity involving someone they care deeply about and may wonder what is so terrible that is being done to the deceased that it is not suitable for them to view. What they imagine is likely to be far worse than the reality.

It is best to invite children to participate in wakes, funerals, or memorial services to the extent they wish. Begin by providing basic information in simple terms about what children can expect from the experience. For example, include information about whether there will be an open casket and anticipated cultural and religious rituals (eg, guests may be invited to place some dirt on the coffin at the gravesite), as well as how people may be expected to behave (eg, some people may be crying and very upset; humorous stories and memories may be shared). Ask children what additional information they would like and what questions they might have. Children should not be forced or coerced to participate in particular rituals or to attend the funeral or wake. If older children who had a very close relationship with the deceased (eg, teenagers whose parent has died) indicate they do not want to attend the funeral, it is helpful to explore the reason for their not wishing to attend and ask them to describe what accommodations might be made in the plans to meet their needs (eg, they prefer not to attend the wake but will attend the funeral service). But, as with all true invitations, the decision is ultimately left to the child. Families can work with children to identify alternate ways for them to recognize the death, such as a private visit to the funeral home once the casket has been closed or a visit to the gravesite after the burial. All children can be invited to make meaningful but developmentally appropriate decisions about the service of an immediate family member; they may be permitted to select a flower arrangement or a picture of the parent to be displayed at the wake.

It can be helpful to assign an adult whom the child knows well but who is not personally grieving (eg, a teacher, babysitter, or relative who is close to the child but less familiar with the deceased) to accompany and monitor the child throughout the services. If the child is fidgeting or appears distressed, the adult can suggest they go for a walk and inquire about how the child is coping with the experience. If the child prefers to stand outside of the room and hand out prayer cards, that level of participation can be accommodated without disrupting the experience for other grieving family members (ie, the child would be less able to stay outside of the room if being watched by the mother who feels it important to stand by her husband's coffin throughout the wake). Older children and adolescents may wish to invite a close friend to sit with them during the service or assist with greeting guests as they approach the room. Suggestions on how to address the needs of children related to commemoration and memorialization involving a crisis, especially in a school setting, can be found elsewhere, for example, in the publications cited here.[11,14]

CULTURAL SENSITIVITY

Different cultures have a range of traditional practices and rituals as well as expectations around how members of their culture typically mourn the death of a family member or close friend. In addition, when children of racial, ethnic, or other groups that historically have been marginalized grieve, their grief may be complicated by experiences of inequity in their families and communities. Although it is helpful for pediatricians to know something about these cultural and racial differences, it is important to remember that the fundamental experience of grief is universal.

Knowledge of the common practices of a particular culture may not accurately predict how a family or individual from that culture will behave. Many families have mixed backgrounds and/or have been exposed to different cultures through their communities or schools. Parents sometimes have different beliefs or practices from their children. Families or individuals may choose to follow practices of a different culture if they seem to align better with their current preferences. Assumptions about how someone ought to mourn in a particular culture may result in a stereotype that could cloud our perceptions and make us miss opportunities to be helpful. It is best for pediatricians to ask families what they feel would be most helpful for their family or for individuals within the family.

The best approach is to be present, authentic, and honest. Approach all children and their families with an open mind and heart and be guided by what you see, hear,

and feel. The following are questions that may assist in this process:

- "Can you tell me how your family and your culture recognize and cope with the death of a family member?"
- "How does this fit with your own preferences at this time?"
- "Can you help me understand how I can best be of help to you and your family?"

WORKING WITH SCHOOLS

Children typically experience at least temporary academic challenges after the death of a close friend or family member. The effect the loss has on learning may first appear weeks or even months later. Some children may even respond to a death by overachieving in school. Children with learning problems that predated the loss may experience a marked worsening.

In general, it is best for the family to anticipate at least brief difficulties in learning and concentration and to establish a proactive relationship with the school to coordinate supports at school with those within the home. If schools wait for academic failure to become apparent, then school becomes a source of additional distress rather than a potential support. Instead, academic expectations should be modified as needed and supports put into place in anticipation of a possible need.[14]

Caregivers and educators can work together to identify the level of academic work that feels appropriate and achievable at a particular point of time in the recovery process after a major loss. Some modifications that may be considered include the following:

- adapting assignments (eg, allow grieving students to prepare a written presentation if they feel uncomfortable with an oral presentation; substitute smaller projects for a large project that may feel overwhelming in scope);
- changing the focus or timing of a lesson (eg, excuse grieving students from a lesson on substance use if their sibling recently died of a drug overdose or consider postponing it to later in the semester);
- reducing and coordinating homework and extracurricular activities so that the student is able to meet expectations for what is being required; or
- modifying or excusing the student from tests or placing more weight on grades achieved before the death.

The goal is to maintain reasonable expectations while providing the support and accommodations so that the student can achieve at that level and be prepared for successful advancement to the next grade level.[14]

Pediatricians can help provide training to schools about how best to support grieving students and provide consultation after a death has occurred involving a member of the school community.[11,14,25–27] The Coalition to Support Grieving Students was formed to develop a set of resources broadly approved by 10 of the leading professional organizations of school professionals to guide educators and other school personnel in supporting and caring for their grieving students. There are now more than 125 organizations in the Coalition, including the American Academy of Pediatrics. The resources are available at no charge to the public at www.grievingstudents.org. The video training modules feature expert commentary, school professionals who share their observations and advice, and bereaved children and family members who offer their own perspective on living with loss. Handouts and reference materials oriented for classroom educators, principals or administrators, and student support personnel that summarize the training videos, as well as a range of additional resources, can be downloaded from the Web site. Although developed for use by educators, the materials are applicable for the professional development of pediatric health care professionals as well. Many are also appropriate for other sites where child congregate care is provided, including early learning centers, preschools, and in-home day care settings. Those caring for children younger than school age similarly benefit from the support and training that can be provided by pediatricians.

COMPLICATED MOURNING AND INDICATIONS FOR REFERRAL

In the immediate aftermath of a death, the reactions of children and adults can be quite extreme and varied. It is best to avoid the tendency to judge or try to categorize such acute reactions as either "normal" or "abnormal." If children or adults appear to be at risk for harming themselves or others, action should be immediately taken to preserve safety. It is important for pediatricians to be aware of community resources for bereavement support. These resources may include the following:

- bereavement support groups, programs (including those within children's hospice programs, which often support grieving children independent of whether the death involved a patient in their hospice program), and camps, which provide important opportunities for peer-to-peer support (a listing of local services and resources for grieving children can be found at https://elunanetwork.org/national-bereavement-resource-guide/resources/ and https://nacg.org/find-support/);
- school-based mental health and support professionals (including school counselors, nurses, psychologists, and social workers), programs, and services;
- counselors who are interested and qualified in counseling children who are grieving; and

- other mental health professionals trained to counsel grieving children who are also experiencing depression, anxiety, or trauma symptoms.

As noted previously, adults in the family may benefit from their own support so that they do not depend unduly on their children for emotional support and so they are better able to discern and address the needs of their grieving children.

Grief from the death of a friend, including when a romantic relationship was involved, or close family member can dominate children's lives in the immediate aftermath of the loss, causing disinterest in engaging in previously enjoyed activities, compromising peer relationships, interfering with the ability to concentrate and learn, causing regressive or risk-taking behavior (such as substance use or premature sexual behavior), or creating a challenge to healthy social and emotional development. But with time and adequate support, grieving children learn that their lives in the absence of the deceased, although permanently altered, nonetheless, can be meaningful and increasingly characterized by moments of satisfaction and joy. Children who instead experience complicated mourning may fail to show such adjustment over time.[28] They may experience difficulty with daily functioning at school or at home that persists months after the death. They may become preoccupied with thoughts about the deceased or develop nonadaptive behaviors, such as tobacco, alcohol, or other substance use; promiscuous sexual behavior; or delinquent or other risky behaviors. They may show deep or sustained sadness or depression. Referral for counseling or consultation with a qualified child mental health provider should be considered for complicated mourning and should be obtained immediately if children are perceived to be at risk for self-harm or harm to others.

PROFESSIONAL PREPARATION AND SELF-CARE

Pediatricians often enter the profession because of a desire to help children grow, develop, and be healthy and happy. Understandably, pediatricians can find it difficult to witness children's distress as they grieve the death of someone about whom they care deeply. Many pediatricians have received limited training about how to support grieving children. It is difficult to believe you are helping people when they remain in such distress. You want to help people feel "better," but when they freely express their sorrow in the immediate aftermath of a death, it is difficult to know that you are helping them ultimately adjust and cope. Following up with children and their families over time and actively inquiring about how they are continuing to adjust will help the pediatrician support and observe the course of recovery and understand his or her role in that process. Professional preparation and education are helpful; resources are available on various professional Web sites (eg, the American Academy of Pediatrics at www.aap.org/disasters/adjustment; the Coalition to Support Grieving Students at www.grievingstudents.org; or the National Center for School Crisis and Bereavement at www.schoolcrisiscenter.org). Pediatricians can also seek out and request professional development training through professional meetings, through grand rounds, from other continuing medical education venues, and via retreats and psychosocial rounds in hospital settings.

Children's grief may also trigger reminders of loss and other reactions in pediatricians. It may remind adults of their own losses or raise thoughts or concerns about the well-being of those they love. During the coronavirus disease 2019 pandemic, pediatricians were faced with supporting large numbers of grieving children and their families while they themselves were likely grieving personal losses—underscoring the need for professional self-care. Children's grief is often unfiltered and pure; their questions are direct and poignant. It is difficult to witness a child's grief and not feel an effect personally. In fact, not being affected should not even be an expectation or a goal. Nonetheless, it is important for pediatricians to monitor their reactions and feelings and limit their support to what they feel ready and able to provide to any particular family at that point in time. If the family is in need of additional supportive services, the pediatrician can seek the assistance of a professional colleague in the office or through referral to someone in the community.

It is important for pediatricians to examine and understand their personal feelings about death to be effective in providing support to children who have experienced a personal loss or who are faced with their own impending death. Often, this understanding will involve an awareness of the effects of deaths of patients on pediatricians' professional and personal lives. The culture in medicine needs to acknowledge that it is understandable to feel upset when bearing witness to something that is upsetting. As professionals, pediatricians should offer support to our colleagues and seek out and accept support for ourselves. Pediatricians who do provide support to grieving children and families often have a meaningful and lasting impact. A relatively modest effort to provide compassion and support can have a dramatic effect. It can help reduce the amount of time grieving children feel confused, isolated, and overwhelmed. Pediatricians will not be able to take away the pain and sorrow (which should not be viewed as the goal), but they can significantly reduce the suffering and minimize the negative effects of loss on children's lives and developmental courses.

Pediatricians within a patient-centered medical home are in an excellent position to provide guidance to caregivers and to offer assistance and support to children and families who are grieving. They can ensure their

professional approaches and practice settings are grief-sensitive and can:

- talk with grieving children and advise caregivers on how to help children of all developmental abilities better understand and cope with the loss;
- approach the situation with an open mind and heart and strive to be culturally sensitive;
- help identify and address guilt, shame, and other troubling reactions and make referrals when grief becomes complicated;
- be aware of the unique challenges of children from groups and communities that historically have been marginalized and disadvantaged;
- offer resources within their practices and communities, including children's bereavement programs, centers, and camps for peer-to-peer support;
- provide periodic support and assistance beginning soon after the death and continuing throughout the longer recovery period; and
- understand and manage their personal reactions to promote professional self-care and decrease compassion fatigue.

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