



CLINICAL REPORT

Supporting the Family After the Death of a Child

abstract

FREE

The death of a child can have a devastating effect on the family. The pediatrician has an important role to play in supporting the parents and any siblings still in his or her practice after such a death. Pediatricians may be poorly prepared to provide this support. Also, because of the pain of confronting the grief of family members, they may be reluctant to become involved. This statement gives guidelines to help the pediatrician provide such support. It describes the grief reactions that can be expected in family members after the death of a child. Ways of supporting family members are suggested, and other helpful resources in the community are described. The goal of this guidance is to prevent outcomes that may impair the health and development of affected parents and children. *Pediatrics* 2012;130:1164–1169

INTRODUCTION

The death of an infant, child, or adolescent, from any cause, has a devastating effect on the family. For parents, the loss of a child defies the natural order. In our era, parents do not expect to bury their children. The death of a child or adolescent also often means there is a sibling or siblings who experience their own significant loss. The pediatrician is in a position to help family members cope, both with the immediate loss and then the ongoing effect of the child's death. Because of the general good health of children in our society, pediatricians are often unfamiliar with how to deal with the death of a child, however. Or they may feel that addressing this event is too emotionally painful. This report identifies the most important issues to be considered and suggests ways the pediatrician can and should help.

PARENTAL GRIEF

The death of a child of any age is extremely painful for parents. Parents have an obligation and a strong emotional need to protect their children from harm. Most parents experience a profound sense of guilt when harm comes to their child, even if through no fault of their own. Parents invest much of their hopes and wishes for the future in their children. All of these factors lead to a devastating grief that is much longer lasting than most people realize.¹ The depth of parental grief often shocks and surprises others. It is common for grieving parents to be unable to function for varying times after their child's death. They may spend days in bed, away from work, and unable to carry out

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KEY WORDS

child death, family support, grief, pediatrician, parents, siblings

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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household tasks. It is common for parents to have great difficulty eating and sleeping. The thought that life is not worth living is frequent, as are thoughts that one might be “going crazy.”

ISSUES RELATED TO THE CIRCUMSTANCES OF THE DEATH

Death as the Result of Chronic Illness or Disability

When a child or adolescent's death results from chronic illness or disability, it is likely that the pediatrician has been involved in the patient's care and may have a long-standing relationship with the family. Although the family may have anticipated the death, the grief will still likely be profound. Even when the child has had severe disability or has suffered, the parents' sense of grief and loss is not usually diminished. When there has been a long-standing relationship with the family surrounding the child's illness or disability, the family also may suffer from the loss of the relationship with the pediatrician. Under these circumstances, the pediatrician's continuing involvement with the family may be especially important.

Sudden, Unexpected Death

Injuries are the single most common reason for death in children and adolescents. In adolescents, suicide and homicide are also a common cause of death. Pediatricians may not immediately be aware of the death in such circumstances. If there is a brief period of survival after the event, the pediatrician may be involved; however, these deaths often occur in the emergency department. If this situation is the case, the emergency physician should inform the pediatrician of the death, including the details of the last hours of care.^{2,3} If not actually witnessed by the parents, these details will often be what haunts the

parents' thoughts in the months after the death. Pediatricians may hear about the death of a child or adolescent who was one of their patients from the news or from their office staff or other parents in their practice. Although the pediatrician was not involved at the time of the death, if there has been a relationship with the family and if there are surviving siblings who are still patients in the practice, the pediatrician has an important role in supporting the family.

Infant Death

In the case of infant death, many physicians fail to appreciate the intense attachment to the fetus and infant and the extent to which parents and other family members invest in that infant's imagined future. The grief at this loss is intense, and the surviving siblings also may be deeply affected. The physician should recognize the depth of these feelings and be prepared to provide the kind of support outlined in this statement.

Helpful Responses and Those That Hurt

The most helpful response after a child or adolescent death is to provide an opportunity to meet with the parents, face to face, and to just listen, responding in ways that encourage the parents to talk. Frequently, in the context of an unexpected death, physicians fail to respond at all. This failure to respond may contribute to the family's pain. Many physicians find the thought of losing a child so terrible that they avoid contact with the grieving parents rather than confront their own fears. Others find it difficult to be with parents who are crying or showing their grief in other ways. Physicians often hold the mistaken belief that talking about the death will be harmful because such talk will reawaken and prolong the parents'

grief.⁴ Quite the contrary, grieving parents report that acknowledging their grief is important, and they seldom forget the pain of a friend, family member, or physician who fails to make contact after such a loss.⁵ If pediatricians have a relationship with a family, they should always contact the parents when they learn of the death of a child in that family, including the pediatrician who hears about the death from the news or from others in the community. Such contact should be more than attendance at a viewing or a funeral. At such formal times of grieving, personal contact is not possible, and parents are usually in shock and unable to ask the questions that may be on their minds. The most helpful response is a face-to-face visit.⁶ The purpose of such an encounter is to acknowledge the death and allow the parents to talk. The pediatrician might say, simply, “I'm so sorry to hear about _____'s death. What a terrible loss for you and your family.” Attempts to alleviate the grief by providing advice are usually ineffective and may be hurtful. Expressions of religious interpretation may or may not be appropriate and should be tailored to what the pediatrician knows of the family's beliefs. Comments made to parents of children with disabilities, such as “he/she is better off now,” are often perceived as diminishing the value of the child. Some parents, however, may voice this thought themselves.

Duration of Grieving

Many people are surprised at how long parents may grieve the loss of a child. The period of a year of grieving is acknowledged by many religions and cultural practices, but commonly, parents experience significant grief for much longer. Parents frequently report waves of grief that include reliving the traumatic details of the injury or visions of the person suffering the final stages of a fatal illness.

Anniversaries of the death and important dates, such as the child's birthday, bring recurring waves of grief, often for several years. Family events, such as graduations, marriages, and births, reawaken grief. These events are reminders of the hopes and dreams shattered by the child's death. Eventually, and the period of time varies greatly, parents describe a gradual pattern of change. They no longer relive the experiences at the time of death, and they are able to remember common and happy events in the child's life with less pain and even with pleasure. This change is, however, usually measured in years. Parents frequently report that their greatest fear is that the child will be forgotten, so failing to mention or talk about the child who has died confirms these fears.

Helping During Prolonged Grief

Every parent grieves in his or her own way, and the pediatrician should not expect a prescribed timetable of grieving. Parents find it painful to hear a statement such as, "You should get over it and get on with your life." Yet such statements are frequently made. Self-help support groups, such as The Compassionate Friends and Bereaved Parents USA (see Resources section), are specifically designed for parents whose children have died and provide some of the best help for this prolonged grieving process.⁷ These peer-led support groups provide an atmosphere in which it is possible to talk about the loss without the pressure to "get over it." Also, most parents are comforted by an environment in which others have been through a similar experience and in which they meet those who have survived this devastating loss. Descriptive studies confirm that many parents resolve their grief by talking about their loss in an accepting environment.⁴ Family members who are discouraged from expressing their grief

may find it more difficult to get past the most painful part of their grieving and function effectively. Pediatricians are encouraged to learn about the support groups in their community and how they function. They can then refer parents who might benefit from such groups (see Resources).

Special Circumstances

The death of a child, no matter what the cause, is devastating. But there are some circumstances that make this loss particularly difficult. When the death occurs by suicide or through the child's use of alcohol or drugs, the guilt experienced by parents can be particularly strong. Homicide or injuries that are caused by negligence, such as by drunk driving, produce intense anger. The grief also may be especially intense if the parent's actions may have contributed to the death, such as in situations in which supervision was lacking or if the parent was driving when an injury occurred. Parents in these circumstances may require special help through counseling or therapy. If the cause of a child's death might be filicide, special circumstances beyond the scope of this statement must be addressed.

Complicated Grief, Medication, and Grief Counseling

In this report, the term "complicated grief" refers to the situation when grief is so intense and/or prolonged that the pediatrician believes that professional mental health evaluation or treatment is required. It is difficult to specify either the symptoms or the circumstances when this point is reached, but a few general guidelines can be given. Complicated grief occurs most frequently when the parent is already experiencing a psychiatric problem, or the parent may have had a psychiatric disorder in the past. Most obviously, when a parent is already experiencing

depression, the death of his or her child is likely to exacerbate that problem. Other psychiatric disorders also may worsen with such a death. Another situation that is known to result in a more serious grief reaction is the death of a child when the parent-child relationship has been a troubled one⁸; however, grief (including intense and prolonged grief, as described previously) is a normal reaction to the loss of a child. In most situations, medication is not needed and can be counterproductive. If, however, the pediatrician judges the grief to be especially intense and debilitating, medication may be needed, and a referral to a mental health specialist should be considered.

Grief counseling is available and/or provided under a variety of circumstances. In situations of injury death in which a number of people have been killed, such as in an airplane crash, grief counselors may provide help in the immediate aftermath. Also, in most communities and at most hospitals, grief counseling groups meet, usually for a prescribed period of time, typically lasting from 6 to 8 weeks. Such groups usually are not designed just for parents who have lost children. Although these groups are helpful to many parents, they do not address the long-term issues mentioned previously. Grief counselors can be especially helpful when they are trained to recognize the complicated grief described previously and can make appropriate referrals.

SIBLINGS

Siblings in a family in which an infant, child, or adolescent has died are sometimes called "the forgotten mourners."⁹ This phrase acknowledges that the grief of siblings is often neglected because parents are the focus of grieving within the family. The pediatrician is in a unique position to provide support to siblings

who are in their practice, both at the time of death of their brother or sister and in the context of the sibling's ongoing health care. What follows are suggestions on how to provide this type of care.

Initially, particularly in the case of sudden, unexpected death, the problem may be that parents may not be able to provide ongoing support to their surviving children in the midst of their own grief. For very young siblings for whom the need for parental support is great, this problem may be acute. Members of the extended family may be in the position to help once the need is identified. When not available, however, other social services may need to be recruited to provide support. Older siblings often experience an ongoing lack of emotional support and feel abandoned by their grieving parents. The pediatrician may be in the best position to assess these issues and identify other resources if needed.

The way siblings respond to the death of a brother or a sister of any age varies depending on the developmental age of the sibling, and this response changes as the sibling matures. The reactions to death in the family and the changes that occur during development are discussed elsewhere in the pediatric literature¹⁰; however, there are special issues associated with sibling loss that are less well known and are reviewed here.

Survivor Guilt

Survivor guilt in siblings is common, especially in situations of unexpected death. Guilty feelings may be especially strong in siblings who have experienced intense sibling rivalry. Before the death, the sibling may have had negative feelings about the deceased, or there may have been harsh words spoken during angry arguments. The sibling may have harbored thoughts

wishing that harm would come to his or her brother or sister. These thoughts and words may haunt the surviving sibling. Such thoughts and memories may be emotionally crippling unless talked about in counseling or dealt with in therapy.

Overprotection

Parents commonly fear that their surviving child or children will also die. These fears may lead to serious overprotection of surviving siblings, such as restricting age-appropriate activities. Behavior problems in these siblings may stem from the need to break free from stifling overprotection. Pediatricians should be sensitive to this possibility and should counsel parents under such circumstances.

Idealization and the Replacement Child

Parents and other family members frequently idealize the deceased child. Parents often create shrines to memorialize the child, which may reinforce this idealization. Siblings, especially younger ones, may be jealous and resent this picture of the idealized child. The surviving sibling may feel he or she cannot live up to that ideal and may respond with rebellious behavior. Parents also may come to view a surviving sibling, particularly a younger one, as a replacement for the child who died.¹¹ In this situation, the family member projects on to the surviving sibling his or her hopes and wishes for the child who died. The sibling may sense the parents' feelings and rebel against these wishes and hopes, especially if they are unrealistic. If pediatricians recognize these dynamics, they can be discussed with the parents, and suggestions can be made to address the sibling's feelings.¹² A referral for therapy may be needed if the problem persists.

Assuming the Parental Role

It is especially common for older siblings to assume a parental role when parents are absorbed with their own grief. Although this reaction may be adaptive in the early months of the parents' grief journey, it may become maladaptive as the sibling matures. The pediatrician should look for this situation and help the parent and surviving sibling to relinquish this distortion of family roles.

General Issues of Sibling Grief

One's siblings play a special role in a child's growth and development. Siblings share family secrets, and no one else in a child's life may share that experience. Siblings also have a special role to play in protecting each other in the wider environment of school and playground. Surviving siblings may experience a profound sadness at the loss of this special relationship and may find it helpful to talk about this aspect of their loss.

Providing Sibling Support

If a surviving sibling is in the pediatrician's practice, the clinician should find a way to follow that sibling's emotional development and intervene when problems are detected. One suggestion is to place a picture of the deceased child in the sibling's chart as a reminder whenever that sibling is seen in ongoing health care. A helpful approach is to raise the issue of the brother's or sister's death at well-child visits. The surviving sibling's feelings and thoughts will change with time. The pediatrician should be aware that siblings may refuse to talk about their deceased brother or sister at first. The pediatrician should honor this resistance but be persistent in raising the issue, because this reaction often changes over time.

Some self-help support groups provide support for siblings who are old enough

to benefit from talking to other young people who have suffered a similar loss. Support for siblings may also be provided by schools, religious organizations, and groups such as scouts or other organizations. Knowledge of these and other such services in one's community allows the pediatrician to tap other sources of support (see Resources).

SUMMARY

The death of an infant, child, or adolescent is a devastating experience for the family. The pediatrician is in a special position to help families through their grief experience. The ultimate goal of such support is the prevention of problems that may result from such trauma. The following are suggestions for pediatricians regarding this support.

1. Expect that grief after the loss of a child is intense and long lasting.
2. Recognize that failing to acknowledge the death of an infant, child, or adolescent who was a patient can contribute to the family's pain. A telephone call or a face-to-face visit with the parent(s) of a patient who has died is encouraged.
3. Follow up with and provide guidance to surviving siblings who are still patients. Providing guidance to siblings requires recognition of the special issues experienced by grieving siblings.
4. Understand that the duration of grieving within a family after the loss of a child is longer than many expect and is usually measured in years.

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5. Recognize the power of self-help support groups in helping parents get through the prolonged grief after their child's death. Be aware of the presence of such groups in the community and make referrals when indicated.
6. Be aware that when the death of a child or adolescent is by suicide, through the use of alcohol or drugs, or through homicide, the grief is especially intense and is accompanied by intense guilt and/or anger. Consider referral for counseling or therapy in these cases.
7. Be aware that complicated grief is more likely when the parent has a preexisting psychiatric problem or when there was a troubled parent-child relationship before death. In such cases, referral to a mental health specialist may be indicated. Most intense and prolonged grief is normal, however, and the use of medication is usually not helpful.

RESOURCES

The Compassionate Friends

A national self-help support organization with >600 local chapters. Many local chapters have special groups for siblings. National office telephone number (toll free): 877-969-0010; Web site: www.compassionatefriends.org.

SHARE

Support for those touched by the death of an infant through miscarriage, stillbirth, or newborn death. Web site: www.nationalshare.org.

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BEREAVED PARENTS OF THE USA (BP/USA)

Provides support, care, and compassion for bereaved parents, siblings, and grandparents. Web site: www.bereavedparentsusa.org.

SURVIVORS OF SUICIDE (SOS)

Support for those who have lost a loved one to suicide. Web site: www.survivorsofsuicide.com.

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