Supporting the Family After the Death of a Child

abstract

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. 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...
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. 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. 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. 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. 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. 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. 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 one; 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.” 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 on-
going health care. What follows are sugges-
tions on how to provide this type of care.

Initially, particularly in the case of
sudden, unexpected death, the prob-
lem 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 sup-
port 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 sup-
port. 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 pedi-
atric literature19; 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 experi-
enced 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 sur-
viving child or children will also die.
These fears may lead to serious over-
protection 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. Pedia-
tricians should be sensitive to this pos-
sibility 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 re-
force this idealization. Siblings, es-
pecially younger ones, may be jealous
and resent this picture of the ideal-
zied 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
sibling. Such thoughts and memories
may stem from the need to break free
from stifling overprotection. Pedia-
tricians should be sensitive to this pos-
sibility and should counsel parents
under such circumstances.

Assuming the Parental Role
It is especially common for older sib-
lings 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 sur-
viving sibling to relinquish this distor-
tion of family roles.

General Issues of Sibling Grief
One’s siblings play a special role in a
child’s growth and development. Sib-
lings 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 pedi-
atrian’s practice, the clinician should
find a way to follow that sibling’s emo-
tional 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 resis-
tance 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.

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.

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BEREAVED PARENTS OF THE USA (BP/USA)


SURVIVORS OF SUICIDE (SOS)

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

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