National Hospice and Palliative Care Organization

National Hospice and Palliative Care Organization

Palliative Care Resource Series

COMMUNICATING WITH A CHILD EXPERIENCING THE DEATH OF A LOVED ONE: DEVELOPMENTAL CONSIDERATIONS

Marilyn A. Fisher, M.D., M.S.

CASE STUDY

Maria's parents were anxiously awaiting the birth of her new little sister. Preparations had been made as they got ready for the new baby. Maria's bedroom received a fresh coat of pink paint and her furniture had been re-arranged. Her bed was pushed against the wall and her bookcase and toy box were crammed into one half of the room. The other half of Maria's room was now occupied by a crib, a changing table, an extra-large trashcan with a lid, and a bunch of bags and boxes. Juvenile decals of hot pink giraffes and lemon yellow hippos were plastered on the wall near the crib.

While her parents were thrilled in anticipation of Sofia's arrival, six-year-old Maria was not so sure that this was a good thing. She didn't relish the idea of sharing her room with a baby. Maria remembered her two-year-old brother, Jack, crying at all hours of the night when he was a baby. She remembered the awful, smelly messes he would make, and still makes, in his diaper. And, Jack didn't even have to share a room with Maria.

It might be fun to have a little sister someday, but Maria didn't feel quite ready for that now. On the night her mom and dad went to the hospital, Grammy came to stay with Maria and Jack. Grammy gave Maria and Jack their goodnight kisses and said that when they awakened in the morning, they would have a brand-new baby sister.

The next morning, when she got out of bed, Maria found Grammy sitting in the kitchen in her pajamas. Grammy's hair was a mess and she was talking on the phone and crying. Grammy explained to Maria that something was dreadfully wrong with baby Sofia. Sofia wouldn't be coming home and she was going to die.

Maria was not sure what all of that meant, but she could see that it caused Grammy to be very sad. Maria felt guilty and ashamed for having had bad thoughts about Sofia. Surely, her bad thoughts had caused this to happen. Later, Dad came home to give Maria and Grammy more information, and he was crying. When Jack saw Grammy and Dad crying, he began to cry without even understanding the cause of their sadness.

Maria felt guilty and ashamed that her bad thoughts had caused Grammy, Dad, and Jack to cry. She wanted reassurance that her mom was alright and that, maybe tomorrow, her world would continue on as it had been before Sofia was born. Maria also felt guilty and ashamed about being a little bit glad that she wouldn't be sharing her room with a noisy, smelly baby. But she kept that thought to herself.

In a few days, Maria's mom came home for a little while to sleep and shower. But, mostly, Mom and Dad spent their time at the hospital with Sofia. Grammy stayed home with Maria and Jack. Maria wondered if, because Sofia was dying and never coming home, her parents were always going to be at the hospital. She wondered if Grammy would take care of her and Jack from now on.

Maria was not allowed to go to the hospital with her parents. Secretly, she imagined that Sofia was a giant monster baby who required both Mom and Dad to change her giant smelly diapers. She hoped that soon Mom and Dad wouldn't have to spend every waking moment at the hospital, and that they would have time to play with her. She hated Sofia for taking Mom and Dad away from her.

When Maria awakened the next morning, she was surprised to find that she had wet her bed.

UNDERSTANDING A CHILD'S ABILITY TO COMPREHEND DEATH

A child's ability to comprehend death is limited by the child's neurodevelopmental level. In general, this comprehension is dependent upon the child's age. While neurodevelopmental maturity is a continuum, neurodevelopmental processing of death may be divided into the following 4 major age categories (Schuurman DL, DeCristofaro J, 1999)

Up to 3 years

- Children in this age category are egocentric. They believe that the world revolves around them.
- They share their stories (with regard to death and other life experiences) with family and strangers alike, without discretion.
- They lack the cognitive ability to grasp the abstract concept of the "forever-ness" of death and see it as a reversible condition.
- Even though they may not possess the vocabulary necessary to express their grief, children in this age range will often exhibit their grief through their movement and physical activity/play. In their artwork and play, they may demonstrate how they will "save" the person who has died.
- Children in this age category may reflect the emotions demonstrated by others without understanding why such emotions exist. For example, in the scenario above, Jack began to cry when he saw his dad and Grammy crying, without feeling grief or understanding why the others were crying.
- If adults can acknowledge the words and play of the grief-stricken child, he will feel as though he is being heard, understood, and respected. Routine is important to young children and pro vides security in the midst of chaos and crisis.

4 – 7 years

- Children under approximately 8 years of age cannot comprehend the idea of permanent death, but they can appreciate the idea of someone being gone permanently.
- They may not understand the term "death" or "to die." A concrete definition of death needs to be provided to them. In the scenario, Maria thought that death meant that Sofia would never come home and that her parents would have to spend their waking hours at the hospital for ever after. Maria's family would have been appropriate in telling Maria that a dead person can't move, have a heartbeat, breathe, play, laugh, eat, pee, poop, sleep, think, or anything.
- Children in this age range try to make sense of the death and try to link cause and effect. Still somewhat egocentric, they may exhibit "magical thinking," believing that they are somehow responsible for the death. Maria believed that her ambivalence towards having Sofia share both her bedroom and her parents' attention was the reason for Sofia's death. Adults should provide reassurance to the child that nothing that she may have thought, said, or done was the cause of the loved one's death.

- Children should be offered the opportunity to visit/see the dying or deceased person, as what they imagine may be worse than reality. Maria imagined that her sister was a baby monster. A visit to the hospital may have helped.
- Having improved language skills, children in this age range may ask many questions regarding how and why the death occurred; adults need to encourage them to ask these questions. The supportive adult must be available, physically and emotionally, to answer a child's questions, and to welcome even more questions, as well as to discuss feelings about the deceased. There are many children's books available to assist adults with these conversations.
- Adults must take care in their description of how the death occurred; an attempt to reassure a child that the death was painless ("Sofia died peacefully in her sleep.") could make the child terrified to go to sleep or to sleep alone, for fear that she will also die. This is why it is important to include sleep in the list of activities that a dead person cannot perform.

8-11 years

- Children in this age range are better able to understand the abstract concept of death as final.
- These children may worry about their own mortality, or that of other loved ones.
- They may develop somatic symptoms, sometimes reflecting the symptoms of their deceased or sick loved one.
- Some children may also feel a sense of responsibility for the death.
- Their emotions may range from sadness to anger to despair to fear to relief.
- Since they didn't have a choice about the person dying, children should be offered choices with regard to how they wish to express and process their grief. This may involve being offered an informed choice about visiting the dying person, or seeing the deceased after death, attending the funeral, etc.
- Photographs or possessions of the deceased may be offered. The child may choose which of these mementos is most important to her in supporting her grieving process, and what she will do with these items.
- Children within this age range, and beyond, may keep the spirit of the deceased alive by assuming preferences and mannerisms of the deceased.

12+ years

- Adolescents have strong connections to their peers and life outside of the home. However, their peer group is generally unable to appreciate their friend's grief at the loss of a sibling. Despite feeling alone and unsupported by their peers and, perhaps, unsupported at home as well, adolescents, in particular, will make efforts to appear and act normal, and to appear and act no different from their peers.
- Common adolescent emotions in the aftermath of a sibling death include anger, depression, anxiety, and guilt.
- Some adolescents experiencing loss report an increased level of maturity, improvement in academics, deeper appreciation for life and living life at its fullest, less risk-taking, ability to better express affection towards those in their lives, higher moral values, and a sense of a greater purpose in life (Balk, 1983; Forward & Garlie, 2003). The tendency towards overachieving may be due to a desire to make their parents happy again.
- Alternatively, the child may act out in negative ways, seeking attention and proof that her parents still love her. This behavior may be precipitated by the grieving parents immortalizing the deceased child, or being physically or emotionally unavailable for the grieving child.

THE GRIEVING FAMILY

Because the grieving process is both an individual and a family process, a child's death disrupts the entire family function, alters the way surviving siblings interact with each other and with their parents, and changes family members' individual self-expectations as well as expectations that the family has for itself as a unit (Detmer & Lamberti, 1991).

- A surviving child may feel that her parents are no longer physically or emotionally available for her. Thus, unsupported in their grief and disconnected from their family, surviving children may feel that they no longer belong to the family unit.
- Relationships between siblings are unique because siblings often spend a large part of their lives together. Siblings are friends, confidantes, playmates, role models, and protectors. Siblings use each other as points of influence in defining their own personal identities. Since their histories are often inextricably entwined, survivors of sibling death essentially lose a part of themselves (Devita-Raeburn,2004).
- After the death of a sibling, survivors often feel an ongoing sense of attachment with their dead sibling (Hogan & DeSantis, 1992). This may include:
  - (1) relationship-building - desiring to have a better relationship with the deceased, wishing to continue a shared relationship;
  - (2) analyzing - trying to understand reasons and circumstances for the death;
  - (3) trying to catch-up with the deceased by, depending on religious beliefs, asking the deceased what heaven is like, how the deceased is doing up there, as if he/she is still alive, but far away;
  - (4) reaffirming—loving and missing the sibling;
  - (5) influencing—seeking guidance from the deceased sibling, feeling that the sibling is watching over the survivor;
  - (6) reuniting—anticipating reunion in heaven, depending on religious beliefs.

- The depth and nature of emotional closeness that existed between siblings prior to the death will influence the surviving child's grief processes (Davies, 1995). In relationships where the sibling relationship was ambivalent or conflictual, or marked by one-sided ambivalence, as in Maria's case, the connection to the dead sibling may be disturbing or frightening.
- Surviving siblings may express their internal pain in a variety of external ways: crying, withdrawing, regression, attention-seeking (positive and/or negative), psychosomatic complaints, nightmares, fear of going to sleep or of the dark, etc. The fact that Maria wet her bed exhibits elements of regressive behavior.
- As the surviving sibling advances to new neurodevelopmental levels, her thinking becomes more abstract. She will need to re-process her old grief with her new neurodevelopmental skills. She will need parental or professional assistance and support for this (Packman, et al, 2006).

Parents generally play a major role in assisting grieving children to cope and adapt to the loss of a sibling. Sibling loss, however, has been described as a double loss. Surviving siblings, attempting to cope with a sibling's death, will seek support from their parents. However, their parents are generally consumed by their own grief and do not possess the emotional wherewithal to provide support for their grieving children.

Grief of the surviving siblings is often unacknowledged, unsupported, and not validated, as friends and family will hug and offer condolences, time and attention to the parents, but not to the siblings. Parental distress may be so intense that the (also suffering) children will attempt to protect their parents by hiding external manifestations of their own grief. Some will never mention the deceased in the parents' presence, since they believe such things will upset their parents even more (Horsley & Patterson, 2006).

Open communication within the family regarding the death is crucial if healing is to occur. When children do not feel free to express their feelings or to talk about the deceased, they will feel unsupported and alone in their grief, and may suffer for years to come. When and if the family is unable to provide the support necessary for grieving surviving siblings, it may be time for professional assistance.

REFERENCES

Balk D, 1983. Adolescents' grief reactions and self-concept perceptions following sibling death: A study of 33 teenagers. Journal of Youth & Adolescence, 12, 137-159.

Davies B, 1995. Toward siblings' understanding and perspective of death. In: E. Grollman (Ed.), Bereaved children and teens: A support guide for parents and professionals (pp. 61-74). Boston: Beacon Press

Detmer CM, Lamberti JW, 1991. Family grief. Death Studies, 15, 363-374.

Devita-Raeburn E, 2004. The empty room: Surviving the loss of a brother or sister at any age. New York: Scribner.

Forward DR, Garlie N, 2003. Search for new meaning: Adolescent bereavement after the sudden death of a sibling. Canadian Journal of School Psychology, 18(1-2), 23-53.

Hogan N, DeSantis L, 1992. Adolescent sibling bereavement: An ongoing attachment. Qualitative Health Research, 2, 159-177.

Horsley H, Patterson T, 2006. The effects of a parent guidance intervention on communication among adolescents who have experienced the sudden death of a sibling. American Journal of Family Therapy, 34(2), 119-137.

Packman W, Horsley H, Davies B, Kramer R, 2006. Sibling bereavement and continuing bonds. Death Studies, 30, 817-841.

Schuurman DL, DeCristofaro J, 1999. After a parent's death: Group, family, and individual therapy to help children. In: Webb NB. (Ed.), Play therapy with children in crisis: Individual, group and family treatment (2nd ed), 173-196. New York: Guildford Press.