

- Article III. **Use of interdisciplinary resources.** Because of the complexity of care, no one clinician can provide all of the needed services. The team members may include primary and subspecialty physicians, nurses in the hospital/facility or for home visits, the pain management team, psychologists, social workers, pastoral ministers, schoolteachers, friends of the family, and peers of the child. The child and family should be in a position to decide who should know what during all phases of the illness process.
- Article IV. **Acknowledgment and support provisions for caregivers.** The death of a child is difficult to accept and understand. The primary caregivers of the child, family, and friends need opportunities to address their own emotional concerns. Siblings of the child who is dying react emotionally and cognitively, based on their developmental level. Team meetings to address thoughts and feelings of team members are crucial. Soon after the death of the child, the care team should review the experience with the parents and family and share their reactions and feelings. Institutional support may include time to attend funerals, counseling for the staff, opportunities for families to return to the hospital, and scheduled ceremonies to commemorate the death of the child.
- Article V. **Commitment to quality improvement of palliative care through research and education.** Hospitals should develop support systems and staff to monitor the quality of care continually, assess the need for appropriate resources, and evaluate the responses of the patient and family members to the treatment program. Issues often arise over less than completely successful attempts to control the dying child's symptoms or differences between physicians and family members in the timing of the realization that death is imminent. Consensus results in better palliative care from the medical and psychosocial perspective.

Hospice care is a treatment program for the end of life, providing the range of palliative care services by an interdisciplinary team, including specialists in the bereavement and end-of-life process. Typically, the hospice program uses the adult Medicare model, requiring a prognosis of death within 6 months and the cessation of curative efforts for children to receive hospice services. Recently some states have developed alternative pediatric models where curative efforts may continue while the higher level of coordinated end-of-life services may be applied.

BEREAVEMENT

Bereavement refers to the process of psychological and spiritual accommodation to death on the part of the child and the child's family. **Grief** has been defined as the emotional response caused by a loss, including pain, distress, and physical and emotional suffering. It is a normal adaptive human response to death. Palliative care attends to the grief reaction. Assessing the coping resources and vulnerabilities of the affected family before death takes place is central to the palliative care approach.

Parental grief is recognized as being more intense and sustained than other types of grief. Most parents work through their grief. Complicated grief, a pathologic manifestation of

continued and disabling grief, is rare. Parents who share their problems with others during the child's illness, who have had access to psychological support during the last month of their child's life, and who have had closure sessions with the attending staff, are more likely to resolve their grief.

A particularly difficult issue for parents is whether to talk with their child about the child's imminent death. Although evidence suggests that sharing accurate and truthful information with a dying child is beneficial, each individual case presents its own complexities, based on the child's age, cognitive development, disease, timeline of disease, and parental psychological state. Parents are more likely to regret not talking with their child about death than having done so. Among those who did not talk with their child about death, parents who sensed their child was aware of imminent death, parents of older children, and mothers more than fathers were more likely to feel regretful.

COGNITIVE ISSUES IN CHILDREN AND ADOLESCENTS: UNDERSTANDING DEATH AND DYING

The pediatrician should communicate with children about what is happening to them, while respecting the cultural and personal preferences of the family. A developmental understanding of children's concepts of health and illness helps frame the discussion with children and can help parents understand how their child is grappling with the situation. Piaget's theories of cognitive development, which help illustrate children's concepts of death and disease, are categorized as sensorimotor, preoperational, concrete operations, and formal operations.

For very young children, up to 2 years of age (sensorimotor), death is seen as a separation, and there is probably no concept of death. The associated behaviors in grieving children of this age usually include protesting and difficulty of attachment to other adults. The degree of difficulty depends on the availability of other nurturing people with whom the child has had a good previous attachment.

Children from 3 to 5 years of age (preoperational) (sometimes called the *magic years*) have trouble grasping the meaning of the illness and the permanence of the death. Their language skills at this age make understanding their moods and behavior difficult. Because of a developing sense of guilt, death may be viewed as punishment. If a child previously wished a younger sibling to have died, the death may be seen psychologically as being caused by the child's wishful thinking. They can feel overwhelmed when confronted with the strong emotional reactions of their parents.

In children ages 6 to 11 years of age (late preoperational to concrete operational), the finality of death gradually comes to be understood. Magical thinking gives way to a need for detailed information to gain a sense of control. Older children in this range have a strong need to control their emotions by compartmentalizing and intellectualizing.

In adolescents (≥ 12 years of age) (formal operations), death is a reality and is seen as universal and irreversible. Adolescents handle death issues at the abstract or philosophical level and can be realistic. They may also avoid emotional expression and information, instead relying on anger or disdain. Adolescents can discuss withholding treatments. Their wishes, hopes, and fears should be attended to and respected.