

## CULTURAL, RELIGIOUS, AND SPIRITUAL CONCERNS ABOUT PALLIATIVE CARE AND END-OF-LIFE DECISIONS

Understanding the family's religious/spiritual or cultural beliefs and values about death and dying can help the pediatrician work with the family to integrate these beliefs, values, and practices into the palliative care plan. Cultures vary regarding the roles family members have, the site of treatment for dying people, and the preparation of the body. Some ethnic groups expect the clinical team to speak with the oldest family member or to only the head of the family outside of the patient's presence. Some families involve the entire extended family in decision making. For some families, dying at home can bring the family bad luck, whereas others believe that the patient's spirit will become lost if the death occurs in the hospital. In some traditions, the health care team cleans and prepares the body, whereas, in others, family members prefer to complete this ritual. Religious/spiritual or cultural practices may include prayer, anointing, laying on of the hands, an exorcism ceremony to undo a curse, amulets, and other religious objects placed on the child or at the bedside. Families differ in the idea of organ donation and the acceptance of autopsy. Decisions, rituals, and withholding of palliative or lifesaving procedures that could harm the child or are not in the best interests of the child should be addressed. Quality palliative care attends to this complexity and helps parents and families through the death of a child while honoring the familial, cultural, and spiritual values.

## ETHICAL ISSUES IN END-OF-LIFE DECISION MAKING

Before speaking with a child about death, the caregiver should assess the child's age, experience, and level of development; the child's understanding and involvement in end-of-life decision making; the parents' emotional acceptance of death; their coping strategies; and their philosophical, spiritual, and cultural views of death. These may change over time, and the use of open-ended questions to repeatedly assess these areas contributes to the end-of-life process. The care of a dying child can create **ethical dilemmas** involving **autonomy**, **beneficence** (doing good), **nonmaleficence** (doing no harm), truth telling, confidentiality, or the physician's duty. It is extremely difficult for parents to know when the burdens of continued

medical care are no longer appropriate for their child. The beliefs and values of what constitutes quality of life, when life ceases to be worth living, and religious/spiritual, cultural, and philosophical beliefs may differ between families and health care workers. The most important ethical principle is what is in the **best interest** of the child as determined through the process of **shared decision making**, **informed permission/consent** from the parents, and **assent** from the child. Sensitive and meaningful communication with the family, in their own terms, is essential. The physician, patient, and family must **negotiate** the goals of continued medical treatment while recognizing the burdens and benefits of the medical intervention plan. There is no ethical or legal difference between withholding treatment and withdrawing treatment, although many parents and physicians see the latter as more challenging. Family members and the patient should agree about what are appropriate **do not resuscitate** (also called DNR) orders. Foregoing some measures does not preclude other measures being implemented, based on the needs and wishes of the patient and family. When there are serious differences among parents, children, and physicians on these matters, the physician may consult with the **hospital ethics committee** or, as a last resort, turn to the legal system by filing a report about potential abuse or neglect.

## Suggested Reading

- American Academy of Pediatrics: Committee on Bioethics Fallat ME, Glover J: Professionalism in pediatrics: statement of principles, *Pediatrics* 120(4):895–897, 2007.
- American Academy of Pediatrics: Committee on Psychosocial Aspects of Child and Family Health: The new morbidity revisited: a renewed commitment to the psychosocial aspects of pediatric care, *Pediatrics* 108(5):1227–1230, 2001.
- Bloom B, Cohen RA: Summary health statistics for U.S. children: National health interview survey, 2006, National Center for Health Statistics, *Vital Health Stat* 10(234):1–79, 2007.
- Flores G, Tomany-Korman SC: Racial and ethnic disparities in medical and dental health, access to care, and use of health services in US children, *Pediatrics* 121(2):e286–e298, 2008.
- Gluckman PD, Hanson MA, Cooper C, et al.: Effect of in utero and early-life considerations on adult health and disease, *N Engl J Med* 359(1):61–73, 2008.
- Hamilton BE, Martin JA, Ventura SJ: Births: preliminary data for 2006, *Natl Vital Stat Rep* 56(7):1–18, 2007.
- National Center for Health Statistics: *Health, United States, 2007: with chartbook on trends in the health of Americans*, Hyattsville, MD, 2007.