The definition of palliative care is difficult and subject to interpretation. “Palliative” comes from the Latin adjective, meaning “tending or serving to cloak” and “relieving or soothing the symptoms of a disease or disorder without effecting a cure.” “Care” comes from the Latin noun, meaning “attentive assistance or treatment to those in need.”

These definitions seem simple enough. A search of the meaning of “palliative care” on the Internet brings up thousands of choices that are varied and unique. Common descriptive definitions of palliative care include quality of life, symptom relief, and control of pain and symptoms. Palliative care is not strictly hospice or end-of-life care, although this is an extremely important part of the whole piece.

In a very broad definition, palliative care is what pediatric care providers do every day when seeing even non-critically ill children in daily pediatric practices. Pain and suffering are relieved through the diagnosis and treatment of a problem, usually resulting in the cure of the ailment (eg, a urinary tract infection). In addition, attention is paid to the child’s developmental, emotional, and spiritual needs, while caring for the concerns, fears, and needs of parents, siblings, and other members of the child’s family.

When a more serious diagnosis is made, such as childhood cancer, all these aspects are repeated, being more attune to their immediate importance. However, the unique aspect of pediatric palliative care is that it often reaches over a period of days to months to years, providing a journey where the goals and directions are for initial cure or aggressive treatment, all the while initiating attempts at attainment of childhood growth and maturity, developmental milestones, and a high functioning life.

The path may shift, drift, and change over time. Sometimes, the direction of care is more goal-focused, while other times the direction is toward relieving specific symptoms, especially pain. Ultimately, palliative care involves end-of-life issues, but the true comprehensive pediatric care provider employs palliative care practices throughout the entire journey.

The subtle change in direction of a child’s illness may not be obvious at first. A child or adolescent with cerebral palsy and severe developmental delay may begin having more admissions for pneumonia, the remission of leukemia is not achieved, or the dyspnea from cystic fibrosis foretells respiratory failure on the horizon. At this point a paradigm shift occurs, with a need for realistic goal-setting, conversations about options, new or different treatments to relieve symptoms, all in the context and framework of the child’s developmental, spiritual, and emotional world. Pediatric palliative care is not only hospice care, but is care of a child and their family when a life-altering or life-shortening diagnosis is made.

Early in my clinical years, I remember a mother’s words as her son lay critically ill in the intensive care unit. She said, “But children do not die.” We cannot ignore the sobering fact that this statement is false, confusing, and misleading to parents or pediatric care providers. Statistics from 2008 reveal that more than 28,000 children died in the United States, perinatal mor-
tality has not been eliminated, and 5% of children are born annually with some form of birth defect.¹

Children are not immune to death in their daily lives. Television and video games are full of violence. Much of that violence spills over into many children’s daily lives with witness of real acts of homicide, loss, grief, and death. It is estimated that 7% of children will lose one parent to cancer by the time they are 18 years old. In many urban areas of the United States, a large population of children are orphans, losing parents to HIV/AIDS infection. Family members of a victim of a traumatic death have a higher rate of subsequent mortality (10% compared to 7%) in their lifetime.³

All children at some time will experience the loss of a pet, grandparent, parent, sibling, or close family friend. The tools to help this child grieve, in an age-appropriate manner, are part of our obligation of care for these children; it is necessary to revisit these issues as this person grows into adolescence and young adulthood.

The care of children experiencing loss falls within the very broadest definition of palliative care. Taking time to help and assist our young patients as they cope with death and dying, whether of themselves or another cherished family member, are important skills for a pediatrician, equivalent to knowing the cause and treatment of pharyngitis, bone pain, or seizure disorders.

Pediatric multidisciplinary teams already practice team principles in the care for children and adolescents with myelomeningocele; sickle cell disease; cystic fibrosis; developmental delay and cerebral palsy; hematology/oncology conditions; craniofacial defects; and genetic disorders. Pediatric palliative care programs formally began in the 1990s and have evolved to become successful pediatric care teams consisting of multidisciplinary providers. Pediatric palliative care fellowships have slowly emerged, with the discipline now recognized by the American Board of Pediatrics.

In this issue of Pediatric Annals, we review and discuss several palliative care topics: treatment of pain; unique aspects of neonatal deaths; the paradigm shift when care changes from cure to palliation; bereavement; grief in the context of the developmental stages of children; and most importantly, care for the medical caregivers. Knowing that one has made a difference in the last days of a child’s life can be a gratifying yet draining process. This issue provides tools for the palliative care journey; making sure that part of that path includes respite for the care team as well.

**REFERENCES**


doi: 10.3928/00904481-20110412-02
about the guest editor

Kathryn S. Moffett, MD, received a BS from Dickinson College in Carlisle, PA. She then served as a chemist for Wyeth Laboratories from 1982 to 1984 before attending the Penn State University in Hershey, PA. Her training included pediatric residency at Children’s Hospital Medical Center in Akron, OH, where she was also chief resident in pediatrics. She did her fellowship training in Pediatric Infectious Diseases at Emory University and served 6 weeks at the International Center for Diarrhea Disease Research Hospital, Bangladesh (ICDDR-B) in 1994.

She worked at East Tennessee Children’s Hospital in Knoxville, TN, and Pinnacle Health Systems in Harrisburg, PA, before joining the faculty at West Virginia University in 1998. While in Harrisburg, Dr. Moffett became a part of the Cystic Fibrosis (CF) care team and has continued to care for CF patients at WVU. In 1999, she became the Center Director for the Mountain State CF Center. In 2004, Dr. Moffett attended the Harvard Course on Palliative Care. She is board certified in Pediatrics and Pediatric Infectious Diseases. In 2008, Dr. Moffett became Section Chief for Pediatric Infectious Diseases.

Dr. Moffett consults on the pediatric wards for Cystic Fibrosis, Infectious Diseases, and Pediatric Palliative Care, with teaching of residents and medical students. In addition, she teaches medical students/residents/fellows in the outpatient clinic (CF and infectious diseases).

Dr. Moffett is host of Doctors-on-Call, a local public television program, and the West Virginia Health Report, a television news report. Her research interests include CF, with ongoing clinical trials in CF. She also leads a 15-member team in CF care and quality improvement, vaccines in children, and medical ethics and palliative care of chronic diseases in children.