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Charlotte's Web: Lessons we can learn from a pig and a spider

Approximately 50,000 children younger than 19 years die each year in the United States from trauma, lethal congenital conditions, extreme prematurity, heritable disorders, or acquired illness.¹ At any one time, an estimated 10 million children in the United States are living with chronic and life-threatening conditions.² Many people are affected for every child with a serious or terminal illness. A grim diagnosis is like a pebble tossed into the pond of a child's life. The ripples spread out further and further, symbolizing the many relationships and people whose lives are touched by the child's condition.

When caring for seriously ill children, the clinician's initial treatment plan customarily focuses on curative measures. Tragically, the time may come when treatment is not able to substantially alter the course of the illness. At this point, the focus gradually shifts to measures to enhance quality of life.

The provision of palliative or "comfort" care has traditionally been used predominantly in the setting of terminal illness and has been equated with hospice care, especially for adults. A distinction is now made between palliative care and hospice care in which palliative care is an integrated model of care offered at diagnosis and continued through the course of illness, whether the outcome ends in cure or death.

The American Academy of Pediatrics cautions that rigid distinctions between curative, life-prolonging, and palliative interventions may hinder the appropriate provision of palliative care to children, especially those with a terminal condition.³ Parents, children, and even health care providers may equate hospice or palliative care with "giving up" or believing that there is "no more hope."

We need to be able to speak with children and their families honestly and compassionately during their terribly stressful times. To prepare ourselves for these conversations, we need information about children's age-related understanding of death, the elements of pain and symptom control, and the psychosocial aspects of life-threatening illnesses. Furthermore, because caring for seriously ill children has a profound effect on so many others, additional aspects of care include addressing the spiritual concerns of the family, being sensitive to the pain and experience of siblings, and knowing ways to provide comfort and follow up with bereaved families.

Primary care providers may be unfamiliar or uncomfortable with counseling or managing a child and family in a palliative-care situation.³ PAs who work in pediatrics most likely have established relationships with seriously ill chil-

dren and their families and can play a valuable role in the course of these families' experiences.

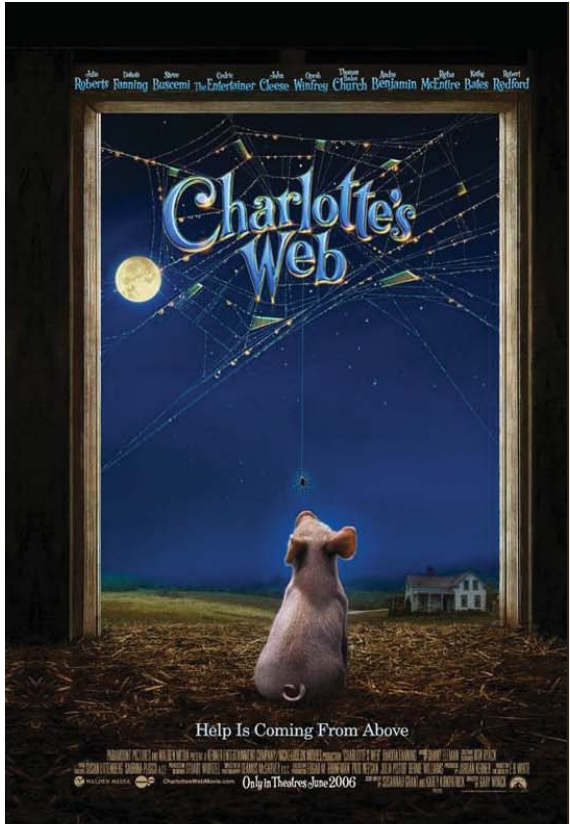
As part of this caring process, it is important for us to evaluate our own knowledge and comfort level and to assess what we can bring of our own experience and understanding to difficult conversations. Exposure to creative works, such as books and movies, and the opportunity to discuss them with colleagues can help us improve our listening skills, increase our empathy, and develop a greater sensitivity to the diverse issues surrounding the serious illness or death of a child. It can also provide a sense of accomplishment and aptitude in providing high-quality patient care.

JAAPA is sponsoring its third session in the medical humanities at the upcoming annual physician assistant conference in Atlanta, using the 2006 live-action film adaptation of *Charlotte's Web* (and E.B. White's 1952 book) to spur discussion of important aspects of caring for sick children. As many of you probably know, White's story is about a pig named Wilbur who is saved from being slaughtered by the actions of an intelligent spider named Charlotte. Considered to be a classic of children's literature, the story of these two friends has been understood for decades by both children and adults to show the inevitability of death within the cycle of life. We all lose loved ones in our lives. The story's universal message of hope and compassion, through the love and support of family and friends, can be interwoven into both our personal and professional relationships, providing a special understanding of life's lessons when caring for our patients.

As with all communication, guidance and practice help improve skills. This is especially critical during conversations with children and their families about life-threatening and terminal conditions. We encourage you to watch the movie (or read the book) *Charlotte's Web* before the annual conference in Atlanta and to begin formulating your ideas about your own feelings when it comes to having these difficult discussions with children and their families. It's amazing what a pig and a spider can teach us about endings and new beginnings. JAAPA

REFERENCES

1. Xu J, Kochanek KD, Tejada-Vera B. Deaths: preliminary data for 2007. *National Vital Statistics Report*. 2009;58(1). http://www.cdc.gov/nchs/data/nvsr/nvsr58/nvsr58_01.pdf. Accessed March 3, 2010.
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3. American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. *Pediatrics*. 2000;106(2):351-355.



At AAPA's 2010 Annual Conference
in Atlanta:

WHAT CHARLOTTE'S WEB CAN TEACH US ABOUT CARING FOR SICK CHILDREN

A JAAPA-sponsored session in
the medical humanities

WHAT CHARLOTTE'S WEB CAN TEACH US ABOUT CARING FOR SICK CHILDREN

A JAAPA-sponsored session
in the medical humanities

Monday, May 31, 2010
3 to 4:45 PM

FACULTY

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Members of the JAAPA
editorial board



PAs are invited to learn more about caring for seriously ill children and their families at this year's medical humanities session. We will use the live-action adaptation of *Charlotte's Web*, E.B. White's classic story of Wilbur, the pig, who is saved by an intelligent spider named Charlotte from being slaughtered, as a launching point to discuss ways to improve communication with patients and families when a child has a life-threatening or terminal illness.

Charlotte's Web, a story for all ages, demonstrates the inevitability of the cycle of life, made easier to understand and accept with the closeness and support of family. Charlotte spins words in her web that have a basic message of love, in a time of both endings and new beginnings.

During the session, we will explore speaking with critically ill children about their condition, given their age and stage of development; discussing grave diagnoses with the child's family; and planning on ways to manage death, grief, and bereavement. Ultimately, we will discover how to better understand the experience of seriously ill children and families and how we can respond to them more effectively.