

# Delivering Bad News

Difficult Conversations with Long-Term Consequences

The responsibility for delivering news of a dire prognosis or impending death is unavoidable for clinicians who care for children. No communication is more painful than telling parents that their child will die. How healthcare providers deliver bad news and engage parents in end-of-life decisionmaking has been shown to influence parents' ability to cope during the child's dying process and to affect the quality of their longterm bereavement. This profound responsibility challenges healthcare providers to continually refine their communication skills.

# **Difficulty of Communication**

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Personal feelings influence the communication of bad news. Healthcare providers often struggle with the recognition of their inability to cure the child and their own feelings of inadequacy. Clinicians who deliver bad news must deal with their feelings as well as the family's expression of strong emotion during the discussion. Realization may slow parents' ability to process what is communicated to them verbally and nonverbally.

Two other factors, the time frame of the discussion and the intensity of elicited emotion vary across care settings and play a pivotal role in successful communication. In the context of cancer treatment or chronic illness, there may be time to schedule a series of family conferences to inform parents as an illness progresses, prognosis alters and treatment goals change. In the emergency department or intensive care unit (ICU), however, discussion may be condensed to one difficult conversation with little opportunity to establish a trusting relationship and to anticipate parents' wishes and personal values.

#### Learned Skills

Communication skills can be learned from expert mentors who model how to lead the emotionally charged conversations surrounding the death of a child. Training programs that teach best practices, incorporate video case studies and illustrate techniques for enhancing verbal and nonverbal communication are now incorporated into many medical school curricula. Communication workshops also are available at national medical conferences and self-directed online training programs.

# **Ethical Considerations**

Ethical questions may arise when differing values suggest conflicting courses of action. In some instances, a gap exists between parental expectations and the limitations of medical reality. Parents in their role as advocate for their child may insist on maintaining or escalating life support and may have unrealistic expectations about possible outcome and the miracles of modern technology. Bridging the gap between expectations and medical necessity is best accomplished by developing a relationship of trust and exploring the family values and expectations that influence parental choices.

Consultation from the ethics committee may be useful to deal with parents' misunderstanding of optimal goals of care for their child. Harnessing the power of active listening may contribute to success. By learning what the family understands about their child's illness or injury and understanding their priorities, misunderstanding may be decreased. Artful listening requires time and training. Engaging the expertise of an ethics consult may contribute to the resolution of an impasse in end-of-life decision-making.

# Interventions Before the Child's Death Influence Outcomes

Bereavement is a normal adaptive process to the loss of a child. Interventions during the final phase of life can facilitate adjustment and may be tailored to fit the circumstances of the death, the age of the child, family dynamics and the type of care setting. Effective interventions include:

- Help the parents stay connected to the child. Keep the role of parent as normal as possible as they care for the child during this time.
- Facilitate ongoing communication between the child and family members and with healthcare providers. Nonjudgmental listening as the family gradually accepts the reality of impending death helps to normalize their emotional reactions. Encouraging parents to say what needs to be said to the child may decrease regrets after the death.
- If appropriate, adjust the circumstances surrounding the dying child to reflect the goals, values and wishes of the patient and family. Discussion of choices empowers the



family to create an experience in tune with their personal goals and values.

- Create opportunities for positive memories of the child with photos, handprints, videotapes and drawings.
- Provide information about supportive community resources, including professional grief counselors and nonprofessional support groups.
- Recognize that siblings, grandparents and friends are grieving the loss and direct to appropriate agencies.'

Skillful communication of bad news deserves emphasis in medical education, clinical practice and research. It is a learned skill with potential to impact the quality of end-oflife treatment decisions, family satisfaction with care and long-term outcomes of bereavement.

1. Davies. B., Orloff, SF, & Toce, S. (2004) Bereavement. Palliative Care for Infants, Children and Adolescents: A Practical Handbook. Editors. Brian Carter and Marcia Levetown. John Hopkins University Press

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#### Suggestions for Breaking Bad News

- Provide privacy and seating in a quiet environment.
- Invite the family to include the individuals they depend upon for support.
- Call the child by name and ask parents to tell you in their own words what they understand about their child's condition.
- Speak slowly and avoid medical jargon or abbreviations. Write down the name of the illness or condition.
- Nonverbal communication is a powerful part of this discussion. Make eye contact, sit down at the same level of the family.
- For support, include nurses, social workers, chaplain or others known to the family.
- Acknowledge emotions, expect tears and anticipate their need for additional time to process information and ask questions.
- Express recognition of the child's unique value as an individual and to his family.
- Learn to tolerate silence.
- Provide contact information for follow-up.<sup>2</sup>

#### Resources

- SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer by Walter Baile, Robert Buckman and colleagues. The Oncologist, 2000. Vol. 5, No. 4, 302-311.
- Palliative Care for Infants, Children, and Adolescents: A Practical Handbook. 2004. by Brian Carter and Marcia Levetown, Eds. John Hopkins University Press.

#### Training

- Initiative for Pediatric Palliative Care (IPPC), Communication training, Two-day workshop, online training in development at www.ippcweb.org/
- The EPEC Project, Education in Palliative and End of Life Care, training material, workshops and online programs, may be tailored to oncology or other care settings at www.epec.net/EPEC/Webpages/

2. Communicating with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information by Marcia Levetown and the Committee on Bioethics. Pediatrics. 2008.121.1441-1460.

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