Hope is the thing...
The challenges of communicating hope

By Maureen Horgan, LICSW

Children with life-threatening conditions and their families hold hope as a guiding principle in their decision making and daily living. Hope sustains. Palliative care providers can hold this hope and walk with families as they face changes amidst their hope. This article describes why joining in hope builds trust and provides practical approaches to dialogue that promotes hope while introducing palliative care concepts and eliciting goals of care.

The trick is, “just tell us the truth about what you think is going to happen, give it your best shot, and then let go...” These words of wisdom come from a bereaved mother who faced the devastating news of a cancer diagnosis and the eventual death of her daughter. She went on to say in her bereavement, “Are you afraid you will destroy our hope? We create our hope. You are not a limiting factor in our sustaining hope.”

The clinical “trick” that this mother and families desire clinicians to practice is this: being present with compassion while disclosing prognosis and all treatment options, including palliative care options. Talking about prognosis and palliative treatment options does not steal hope from patients and parents; in fact, it seems that it just isn’t possible to take away their hope. The prospect of relinquishing the hope for a cure and focusing exclusively on the final phase of life is simply too difficult for most families. It is the responsibility of every palliative care team member to meet families in that hope to assure best care.

To define hope is beyond the bounds of this article, but it is essential to acknowledge that hope is extremely personal, is culturally expressed, and varies from person to person even within the same family system. The hope that families carry and embrace has new beginnings and endings from time of diagnosis into remission and/or bereavement. Wherever a family is in their journey they deserve to be surrounded and accompanied in their hope.

Joining with a family in their hope is an essential initial step for palliative care providers and a natural extension of the palliative care approach, which focuses on preventing and relieving suffering and supporting the best possible quality of life. Hope is “part of the package” that comes in some shape or form for each member of a family with a child with a serious illness. Moments of hopelessness occur in families across illness and into bereavement, and it is essential to use sound clinical assessment in those situations. Often they are simply moments; they are not the general undercurrent or overriding experience of the family.

The palliative care team can be champions with families in their hope by building trusting relationships grounded in compassionate listening and honest sharing of difficult information. Research suggests that truth-telling and compassionate listening build rapport and support hope. “Hope and Prognostic Disclosure” (2007) found no evidence that prognostic disclosure makes parents less hopeful. The study found that disclosure of prognosis by the physician can support hope, even when the prognosis is unclear. Parents want accurate, clear, and timely information even if clinicians state that the situation is uncertain (Field & Behrman, 2003). Realistic perceptions of prognosis have the potential to transform hope — perhaps into a meaningful end-of-life period for the child and family.

STRATEGIES: Communicating Hope with Words

Various strategies exist for clinicians when supporting families in their hope. The initial meeting is an essential time to lay a foundation that clearly identifies a joining together in hope. It is not uncommon at a first meeting for a parent to apologetically state, “We are hoping for a miracle.” This statement is an opportunity to join and promote that hope with a statement such as, “As you think about your child’s illness, can you tell me more about what you are hoping for? I would like to hope right along with you.” If the child...
Uncertain prognosis in pediatric patients is a signal to initiate palliative care

Pediatric health care professionals’ most frequently cited barrier to optimal end-of-life care is uncertain prognosis, followed in importance by family unwillingness to accept that the child’s illness is not curable, a recent study has found. However, the introduction of palliative care may help turn these barriers into opportunities to improve care.

“[P]ediatric providers must realize that uncertainty may be unavoidable and inherent in the care of seriously ill children,” write the study authors in Pediatrics, the official journal of the American Academy of Pediatrics.

“An uncertain prognosis can create opportunities for enhanced communication while families restructure their understanding and garner strength,” they suggest. Introducing discussion of palliative care early in the disease course can allow the family the needed time to “try on” the “what ifs” of a possible poor outcome and absorb the difficult choices they may later face.

Further, if not dealt with openly, uncertainty may delay initiation of the psychosocial support and the respite from suffering that a palliative care approach offers.

Investigators analyzed the questionnaire responses of 81 physicians and 117 nurses on the pediatric staff of an academic children’s hospital in California during early 2002. Respondents were asked to indicate the frequency with which 26 previously identified barriers interfered with their provision of optimal end-of-life care.

**COMMON BARRIERS**

Barriers most commonly reported as “frequently or almost always” encountered were:

- Uncertain prognosis (54.6 percent)
- Family not ready to acknowledge incurable condition (51.1 percent)
- Language barriers (47.3 percent)
- Time constraints (47.1 percent)

**UNCOMMON BARRIERS**

Barriers rarely interfering with optimal care (n = 14) reported by most respondents included:

- Parental discomfort with the possibility of hastening death (occasionally or never, 75.9 percent)
- Staff members’ fear of patient addiction (occasionally or never, 92 percent)

These barriers differed from those reported to be of greatest concern to providers of adult palliative care, the authors note. Such barriers to adult care as fear of addiction, of hastening death, or of legal action were most often reported in this study as occurring only occasionally or never.

“Differences in barriers between pediatric and adult palliative care underscore the need to investigate the unique circumstances involved in providing palliative care to children,” they write.

However, more than 30 percent of respondents identified a cluster of eight barriers as “frequently or almost always” occurring. These related to problems with communication or to lack of education in end-of-life pain management or palliative care. Such barriers included family preferences for more life sustaining treatment than was desired by staff (40.6 percent) and insufficient knowledge of palliative care (31 percent).

 Physicians were more likely than nurses to perceive cultural differences and conflict concerning treatment goals as barriers to optimal care. The authors suggest that this may be because physicians spend less interactive time with patients, yet are responsible for communicating treatment options, then shaping and reconciling the goals of care.

The authors stress the need for more widespread training in pediatric palliative care and for addressing the funding and staffing constraints often inherent in many clinical practice settings in this country.

“We must teach providers that palliative care and end-of-life issues for children can be addressed sensitively and supportively with family and staff members, even early in the course of a life-threatening illness,” they state.

“Our findings validate the specialized time, expertise, and resource requirements essential for providing care to children with life-threatening conditions as they near the end of life,” they conclude.

**Source:** “Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers,” Pediatrics; February 2008; 121(2):282-288. Davies B, Sehring SA, Partridge JC, Cooper BA, Hughes A, Philp JC, Amidi-Nouri A, Kramer RF; Department of Family Health Care Nursing; School of Nursing; Department of Pediatrics; and School of Medicine, University of California, San Francisco; and University of California, San Francisco, Children’s Hospital.

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is present, an inquiry such as, “what are you hoping/wishing for” invites them into the conversation and instills that your primary focus is on their identified goals.

Eliciting and establishing goals of care is essential throughout the course of palliative care treatment. Meyer and colleagues share specific recommendations that invite conversation, introduce the possibility of death, elicit goals of care, and talk about what families might expect.

Inquiries that illicit information, build trust and build upon hope include:

◆ “As you think about your child’s illness, what are your hopes?”
◆ “As you think about your child’s illness, what are your worries?”
◆ “I know you are hoping that the disease will be cured and I am hoping for that too. But I would also like to know more about your hopes and goals if a time comes when a cure is not possible.”
◆ “Would it be helpful to talk about what to expect as your child’s illness gets worse? Although we cannot predict exactly what will happen, most children with this illness eventually develop ________. If that happens, our goal will be to help him feel as comfortable as possible. We can use _________ to help control his discomfort.”

STRATEGIES: Self Awareness

The provision of palliative care and the process of holding hope with families is an art form that involves attentive communication, patience, the investment of time, and a great deal of practice. Paying careful attention to the words we choose is essential with families, the teams we collaborate with, and within our own team context. Incorporating attention to our choice of words and the following practice strategies may also support the goal of joining with families in their diverse hopes.

Practice non-judgment. A simplistic starting point is refraining from using the term “denial” in any context related to the pediatric families we serve. As we work to assist families in re-framing their hope we can also benefit from re-framing the notion of “denial” into the notion of “extreme hope.” Given the phenomenal nature of grief and complex nature of death in the pediatric population, the concept of denial does not build a framework of support and collaboration that is essential for excellence in care.

Practice family-centered care. Refrain from pushing your own agenda. An example of this practice, especially when introducing palliative care and hospice services, is refraining from pushing conversations about end-of-life planning details (ex., funeral planning) and signing DNR/POLST/AND orders. Coordinating care, especially in the home, requires a great deal of attention to detail and anticipatory guidance. Initial guidance and support need not focus on end-of-life details in most situations (patient does not appear to be actively dying). When a team has had the opportunity to develop relationship with the family over time, the team should consider who might best initiate a conversation about end of life based upon the level of trust that has been developed across the team disciplines.

Promote personal control and truth-telling. Deferring to parental expertise builds trust while also supporting parents and the child in their sense of control. “You know [child’s name] best, tell me what changes you’ve noticed and what you’ve done that has helped.” It is essential to assume that every parent is the expert on their child and then to build upon their knowledge base. Children sometimes, in their efforts to protect their parents and community, may decline sharing their truth or knowledge of their situation (that they are going to die) with their family. Offering the child the opportunity to engage a variety of professionals, including social work, spiritual care, comfort therapy, hospice aide, and child life, may provide a pathway for the child to engage in expressing his or her truth with a chosen clinician and then potentially with the family.

Advance directives for children

For children under the age of 18 years, Aging with Dignity has introduced a booklet designed to guide the expression of a child’s care preferences in the event of serious illness. While not a legal document, “My Wishes” encourages communication of choices of site of care, pain management, and information sharing.

The layout fosters personal expression, with spaces for drawing or pasting pictures, writing stories, or adding thoughts to care selections. There is a full page on what the child would want the medical team to know about them, and how they wish to be treated by doctors and nurses.

Children can sign and date the form, and there is a page for family, friends, and physicians who have read “My Wishes” to sign, also. However, it is recommended that the document be revisited and updated yearly, or as preferences change. For those children who are unable to communicate, families are encouraged to use the document for conveying their wishes for their child.

These documents can be ordered for a nominal charge on the organization’s website, along with a video edition of “Five Wishes” and other resources. The booklet “Next Steps,” for example, serves as a patient guide to discussing serious illness with family and physicians, and includes a section entitled “How to Talk with Doc.” For more information, visit www.agingwithdignity.org.
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Hope in Bereavement

Supporting parents in their hope, into bereavement, affirms the idea of continuing a life-long bond with their child. The fundamental belief that the purpose of grief is to let go of the deceased in order to move on and form new attachments is the antithesis of many bereaved people’s experience. Anne Finkbeiner’s (1996) findings demonstrate unequivocally that, far from letting go of their dead child, bereaved parents strive to find ways of sustaining a life-long bond with their child. Families hope throughout their child’s illness to sustain life and the physical and emotional union of relationship. That same hope seems to thrive into bereavement, as family members nurture and create life-long bonds with their deceased children.

As palliative care providers, we can best support families when we join as champions in their hope, at time of initial contact and throughout their care, by supporting them in their changing hopes. “(We) are not limiting factors in their sustaining hope.” Joining in hope requires practice, patience, collaboration, attention to word choice, consideration of our personal and professional agenda, and the genuine intention to provide care that focuses on the best possible quality of life for the entire family. This intention is a core guiding principle of pediatric palliative care, and will be your guide in your journey with children and families living into their death.

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