Communication in Palliative Care: Words Matter

Brian S. Carter, MD
Professor of Pediatrics – UMKC School of Medicine
Children’s Mercy Hospital-Kansas City
Bioethics Center & Division of Neonatology
George Bernard Shaw

“The single biggest problem in communication is the illusion that it has taken place.”
ABSTRACT

Health care communication is a skill that is critical to safe and effective medical practice; it can and must be taught. Communication skill influences patient disclosure, treatment adherence and outcome, adaptation to illness, and bereavement. This article provides a review of the evidence regarding clinical communication in the pediatric setting, covering the spectrum from outpatient primary care consultation to death notification, and provides practical suggestions to improve communication with patients and families, enabling more effective, efficient, and empathic pediatric health care.

*Pediatrics* 2008;121;e1441-e1460

DOI: 10.1542/peds.2008-0565
A *word fitly spoken* is like apples of gold in settings of silver.
“Words are things. You must be careful...Some day we’ll be able to measure the power of words. I think they are things. They get on the walls. They get in your wallpaper. They get in your rugs, in your upholstery, and your clothes, and finally in to you.”
That's Awesome!

C.S. Lewis

“Don't use words too big for the subject. Don't say *infinitely* when you mean very; otherwise you'll have no word left when you want to talk about something really infinite.”
At the Right Time... When is that?
Table 1 – Communicating with Children & Families About Integrating Palliative Care

<table>
<thead>
<tr>
<th>Beginning the conversation</th>
<th>‘What is your understanding of what is ahead for your child?’</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Would it be helpful to talk about how his or her disease may affect him or her in the months and years ahead?’</td>
</tr>
<tr>
<td></td>
<td>‘As you think about what is ahead for your child, what would you like to talk about with me? What information can I give you that would be helpful to you?’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Introducing the possibility of death</th>
<th>‘I am hoping that we will be able to control the disease, but I am worried that this time we may not be successful.’</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Although we do not know for certain what will happen for your child, I do not expect that your child will live a long and healthy life, most children with this disease eventually die because of the disease.’</td>
</tr>
<tr>
<td></td>
<td>‘I have been noticing that your child seems to be sick more and more often. I have been hoping that we would be able to make him or her better, but I am worried that his or her illness has become more difficult to control and that soon we will not be able to help him or her to get over these illnesses. If that is the case, he or she could die of his or her disease.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Eliciting goals of care</th>
<th>‘As you think about your child’s illness, what are your hopes?’</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘As you think about your child’s illness, what are your worries?’</td>
</tr>
<tr>
<td></td>
<td>‘As you think about your child’s illness, what is most important to you right now?’</td>
</tr>
<tr>
<td></td>
<td>‘You mentioned that what is most important to you is that your child be cured of his or her disease. I am hoping for that too. But I would also like to know more about your hopes and goals for your child’s care if the time comes when a cure is not possible.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Introducing palliation</th>
<th>‘Although I hope that we can control your child’s disease for as long as possible, at the same time I am hoping that he/she feels as good as possible each day.’</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Although it is unlikely that this treatment will cure your child’s disease, it may help him or her to feel better, and possibly to live longer.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Talking about what to expect</th>
<th>‘Would it be helpful to talk about what to expect as your child’s illness gets worse?’</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Although we cannot predict exactly what will happen to your child, most children with this disease eventually have [difficulty breathing]. If that happens to your child, our goal will be to help him or her feel as comfortable as possible. We can use medications to help control his or her discomfort.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Talking to children</th>
<th>‘What are you looking forward to most of all?’</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Is there anything that is worrying you or making you feel afraid?’</td>
</tr>
<tr>
<td></td>
<td>‘Is there anything about how you are feeling that is making you feel worried or afraid?’</td>
</tr>
</tbody>
</table>

Adapted from [6].

Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis.
Mack, Jennifer; Wolfe, Joanne
DOI: 10.1097/01.mop.0000193266.86129.47
<table>
<thead>
<tr>
<th>Examples of Questions and Statements About Dying at Approximate Age</th>
<th>Thoughts That Guide Behavior</th>
<th>Developmental Understanding of Dying</th>
<th>Strategies and Responses to Questions and Statements About Dying</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1-3 y</strong></td>
<td>&quot;Mommy, after I die, how long will it be before I’m alive again?&quot;</td>
<td>Limited understanding of accidental events, of future and past time, and of the difference between living and nonliving.</td>
<td>Maximize physical comfort, familiar persons, and favorite toys. Be consistent. Use simple physical contact and communication to satisfy child’s need for sense of self-worth and love.</td>
</tr>
<tr>
<td></td>
<td>&quot;Daddy, will you still tickle me while I’m dead?&quot;</td>
<td>Death is often viewed as continuous with life. Life and death are often considered alternate states, like being asleep and being asleep, or coming and going.</td>
<td>&quot;I will always love you.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;I hope the food is good in heaven.&quot;</td>
<td>The child often believes that he or she somehow caused the death, or views it as a punishment. Death is like an external force that can get you and may be personified (eg, the boogeyman).</td>
<td>&quot;You are my wonderful child and I will always find a way to tickle you.&quot;</td>
</tr>
<tr>
<td><strong>3-5 y</strong></td>
<td>&quot;I’ve been a bad boy, so I have to die.&quot;</td>
<td>Concepts are crude and irreversible. The child may not distinguish between reality and fantasy. Perceptions dominate judgment.</td>
<td>Correct the child’s perception of illness as a punishment. Maximize the child’s presence with his or her parents. Children at this age may be concerned about how the family will function without them. Help parents accept and appreciate the openness of these discussions. Reassure the child and help parents lessen the guilt that the child may feel about leaving by using honest and precise language.</td>
</tr>
<tr>
<td></td>
<td>&quot;I hope the food is good in heaven.&quot;</td>
<td>The child sees death as temporary and reversible and not necessarily universal (only old people die). Because of their egocentrism, the child often believes that he or she somehow caused the death, or views it as a punishment. Death is like an external force that can get you and may be personified (eg, the boogeyman).</td>
<td>&quot;When you die, we will always miss you, but we will know you are with us and that you are in a safe, wonderful place [perhaps with another loved one who has died].&quot;</td>
</tr>
<tr>
<td><strong>5-10 y</strong></td>
<td>&quot;How will I die? Will it hurt? Is dying scary?&quot;</td>
<td>The child begins to demonstrate organized, logical thought. Thinking becomes less egocentric. The child begins to problem-solve concretely, reason logically, and organize thoughts coherently. However, he or she has limited abstract reasoning.</td>
<td>Be honest and provide specifics if they are requested. Help and support the child’s need for control. Permit and encourage the child’s participation in decision making.</td>
</tr>
<tr>
<td></td>
<td>&quot;I’m afraid if I die my mom will just break down. I’m worried that when I die, I’ll miss my family, or forget them or something.&quot;</td>
<td>The child begins to understand death as real and permanent. Death means that your heart stops, your blood does not circulate, and you do not breathe. It may be viewed as a violent event. The child may not accept that death could happen to himself or herself or anyone he or she knows but starts to realize that people he or she knows will die.</td>
<td>&quot;We will work together to help you feel comfortable. It is very important that you let us know how you are feeling and what you need. We will always be with you so that you do not need to feel afraid.&quot;</td>
</tr>
<tr>
<td><strong>Adolescents</strong></td>
<td>10-13 y</td>
<td>Thinking becomes more abstract. Incorporating the principles of formal logic. The ability to generate abstract propositions, multiple hypotheses, and their possible outcomes becomes apparent.</td>
<td>Help reinforce the adolescent’s self-esteem, sense of worth, and self-respect. Allow and respect the adolescent’s need for privacy, but maintain his or her access to friends and peers. Tolerate the teenager’s need to express strong emotions, and feelings. Support the need for independence, and permit and encourage participation in decision making.</td>
</tr>
<tr>
<td></td>
<td>&quot;I’m afraid if I die my mom will just break down. I’m worried that when I die, I’ll miss my family, or forget them or something.&quot;</td>
<td>The child begins to understand death as real, final, and universal. It could happen to him or her or family members. The biological aspects of illness and death and details of the funeral may begin to interest the child. The child may see death as a punishment for poor behavior. The child may worry about who will care for him or her if a parent or caregiver dies. He or she needs reassurance that he or she will continue to be cared for and loved.</td>
<td>&quot;Though I will miss you, you will always be with me and I will rely on your presence in me to give me strength.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;This is so unfair! I can’t believe how awful this cancer made me look.&quot;</td>
<td>A more mature and adult understanding of death develops. Death may be viewed as an enemy that can be fought against. Thus, dying may be viewed by the teenager as a failure, as giving up.</td>
<td>&quot;I can’t imagine how you must be feeling. You need to know that despite it all, you are doing an incredible job handling all of this. I’d like to hear more about what you are hoping for and what you are worrying about.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;I just need to be alone!&quot;</td>
<td>Thinking becomes more abstract. Adolescence is marked by risk-taking behavior that seems to deny the teenager’s own mortality. At this age, the teenager needs someone to use as a sounding board for his or her emotions.</td>
<td>&quot;I can’t imagine how you must be feeling. You need to know that despite it all, you are doing an incredible job handling all of this. I’d like to hear more about what you are hoping for and what you are worrying about.&quot;</td>
</tr>
<tr>
<td></td>
<td>&quot;I can’t believe I’m dying. . . . What did I do wrong?&quot;</td>
<td>A more mature and adult understanding of death develops. Death may be viewed as an enemy that can be fought against. Thus, dying may be viewed by the teenager as a failure, as giving up.</td>
<td>&quot;I can’t imagine how you must be feeling. You need to know that despite it all, you are doing an incredible job handling all of this. I’d like to hear more about what you are hoping for and what you are worrying about.&quot;</td>
</tr>
</tbody>
</table>
What Do Parents Say?

Mother of child with cancer: When information was presented, the doctors always gave us the choice to either go with us and tell him, or just have us tell him.

They gave us the option too, that . . . [if] the infection could clear up, then Frank had the option to do the third one. That's what Frank is hoping for, and we agree with Frank. We believe it's Frank's life, even though as parents you want to do everything in the world . . . You still want to do whatever you can. You still get up every morning and you keep praying and hoping because miracles happen.
What Do Pediatricians Do?

Thompson LA, Knapp C, Madden V, Shenkman E. Pediatricians’ Perceptions of and Preferred Timing for Pediatric Palliative Care. *Pediatrics* 2009;123:e777–e782

### What’s Known on this Subject?

- National experts recommend integrating palliative care with curative therapies for children with life-limiting illnesses.
- Studies have noted barriers to referral for palliative care in general, but none investigated whether, when, or how pediatricians refer patients across a spectrum of diseases.

### What This Study Adds

- Most respondents define palliative care as hospice care and refer children once curative therapy has been forgone, despite citing a need for services throughout a child’s life.
- Pediatricians have not readily adopted the expansive definition of palliative care in practice.
Bad News

• Deliver it?
  – Pizza is delivered; so is the mail

• Break it?
  – News Feeds, TV/Internet all give “breaking news”

• Give it?
  – Here it is, its yours now...

• Bear it?
  – Lean into it, shoulder the burden with the patient/family
    – Requires empathy and presence
With the Right Person - Physician(s)


N=253 responders
Greg Mortenson

“When you take the time to actually listen, with humility, to what people have to say, it's amazing what you can learn. Especially if the people who are doing the talking also happen to be children.”
In the Right Manner

The death of a child is perhaps the worst tragedy a family ever has to endure. The communication that occurs among children, parents, and healthcare professionals at the end of a child’s life must be grounded in caring and compassionate relationships. More is at stake here than the addition of behavioral skills to the practitioner’s repertoire. . . . We need to step out of a narrowly defined professional role to show our more “human” side.

“I think healthcare professionals have to be pretty good readers of people.” —Parent

“By me knowing my child, that’s why you have to listen to hear what I’m saying about my child. I know my child better than you do.” —Grandparent/guardian

“[Her physician’s ability] to be able to show that humanness with her . . . was something I’ll always remember.” —Parent
Isaiah 50:4

The Lord Yahweh has given me the tongue of those who are taught, that I may know **how to sustain** with words **him who is weary:** he wakens morning by morning, he wakens my ear to hear as those who are taught.
William Shakespeare

“Mend your speech a little, Lest you may mar your fortunes.”
Antoine de Saint-Exupéry

“I shall look at you out of the corner of my eye, and you will say nothing. *Words are the source of misunderstandings.*”
“it’s important to make sure that we’re talking with each other in a way that heals, not in a way that wounds.”
“We speak not only to tell other people what we think, but to tell ourselves what we think. Speech is a part of thought.”

Dr. Oliver Sacks

Transparency in Thought
Kahlil Gibran

“For thought is a bird of space, that in a cage of words may indeed unfold its wings but cannot fly.”
Henry David Thoreau

“Speech is for the convenience of those who are hard of hearing; but there are many fine things which we cannot say if we have to shout.”
“Communication is truth; communication is happiness. To share is our duty; to go down boldly and bring to light those hidden thoughts which are the most diseased; to conceal nothing; to pretend nothing; if we are ignorant to say so; if we love our friends to let them know it.”

Virginia Woolf
It’s not a technology thing...

Edward Murrow

“The newest computer can merely compound, at speed, the oldest problem in the relations between human beings, and in the end the communicator will be confronted with the old problem, of what to say and how to say it.”
“Anything that’s human is mentionable, and anything that is mentionable can be more manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary.

The people we trust with that important talk can help us know that we are not alone.”
Of Course, There are Certain Words to Avoid or That Require Deeper Exploration

- “Futility”  “Better”  “Hope”
- “Quality of Life”
- Suffering
- Doing *everything*
- “We can do this…”

- And framing matters, too...is your glass ½ full of ½ empty?
Henry Winkler

“Assumptions are the termites of relationships.”
Fyodor Dostoyevsky

“Much unhappiness has come into the world because of bewilderment and things left unsaid.”
Words are heavy like stones.
If birds talked they could not fly.

- Native American Proverb