To Show Our Humanness — Relational and Communicative Competence in Pediatric Palliative Care

by David Browning

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. These relationships require particular skills, knowledge and attitudes that are not fully addressed in many approaches to communication training currently available to practitioners. This essay proposes elements of a pedagogy for relational and communicative competence in pediatric palliative care that is rooted in ethical and ethnographic principles.

Recently, a much-needed effort has been undertaken to improve the quality of healthcare for children and families with life-threatening conditions (Field and Behrman 2002). Several studies have examined the experience of families and what went well or poorly in their experiences with practitioners during their child's illness (Contro et al. 2002, Meyer et al. 2002, and Wolfe et al. 2000). The illness and death of a child is one of the most difficult tragedies a family will ever have to bear. What happens between families and healthcare professionals during these excruciatingly difficult times?

> Clinicians, usually previously unknown to the family, can be quickly drawn into the family's inner circle of support. Reasons for this may include the clinicians' expertise, availability, and familiarity with the hospital culture, in the context of the family's emotional needs and vulnerability (Meyer et al. 2002).
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> One of the most striking findings in these studies was how a single event could cause parents profound and lasting emotional distress. Parents recounted incidents that included insensitive delivery of bad news, feeling dismissed or patronized, perceived disregard for parents' judgment regarding the care of their child, and poor communication of important information. Such an event haunted them and complicated their grief even years later (Contro et al. 2002).

How have hospitals and other healthcare institutions responded to this kind of data? One response has been to design and implement communication training programs aimed at improving the skills practitioners bring to the difficult conversations they must have with children and families. These programs are often successful in producing measurable changes in practitioners' behaviors.

Any improvements in this challenging and neglected area should be applauded. It is clear, however, from research conducted with family members that more is at stake here than the addition of behavioral skills to the practitioner's repertoire. There are times when children and family members need to sense that their professional caregivers acknowledge and, at times, share their suffering. At other times, they need their practitioners to step out of a narrowly defined professional role to reveal a more "human" side. The following vignette is evidence of this point:

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

Our daughter loved Halloween. She was trick-or-treating at sixteen with her younger sister. Loved it! So she decided she was going to dress up as a doctor for her doctor. The staff was more than happy to help her. They got her a white robe and a stethoscope and a tongue depressor and she waited around the corner for her doctor to appear. And he comes down the hall and she pops out in her white outfit and says, "Now, I'm the doctor today."

So she takes him and he just never missed a beat. He was not Mr. Warm, but he totally reacted to the situation in the greatest way. He allowed her to be in control. She escorts him into the examination room and she proceeds to give him all the neurological tests he gives her. "Touch your nose, walk this line, say the following letters after me." He did all that and we videotaped him. He was okay with the videotaping and with her playing that role (Mother, interviewed in Browning 2002).

The dimensions of this relationship are difficult to quantify and difficult to reduce to discrete, objective communication behaviors between clinicians and patients or families.

What would it look like to teach the art and science of communication in this broader relational context? What should be the conceptual framework within which that teaching would occur? This essay proposes elements of a pedagogy for relational and communicative competence in pediatric palliative care that is rooted in ethical and ethnographic principles.

The Ethical Frame

Children and families struggling with life-threatening illness come into contact with practitioners at times of enormous vulnerability. The challenge to the practitioner is, at root, an ethical one. This ethical claim on the practitioner occurs not at the level of principles and abstractions, but at the level of everyday interactions with children and families.

> The doctor is involved in a constant stream of choices of an ethical kind, which are made at the local level of his or her interaction with the patient and which bear on its most minute aspects. . . . Ethics is what happens in every interaction between every doctor and every patient (Komesaroff 1995).

The willingness of practitioners to be fully present to children and families at the end of life cannot be left to chance; nor can individual practitioners be allowed to "opt in" or "opt out" of engaging with children and families in their suffering.

> The encounter between professional and patient is such that one party, the professional, is not free to avoid entering; that is, by the very nature of the act of profession the nurse or doctor has stated a readiness to be "caught by the claim of the Other." To reconstruct bioethics toward a focus on the relationship of nurse-patient or doctor-patient as an embodied, empathic responsiveness is imperative. Such an ethical responsiveness occurs as we come face to face with our patients, and in so doing we come face to face with ourselves (Bergum 1992).

The work of communicating with children and families at the end of life places special demands on practitioners, not the least of which is an obligation to nurture relationships that can hold within their embrace both vulnerability and suffering: that which is experienced by our child patients and their families, and that which we experience within ourselves.

The Ethnographic Frame

Communication among practitioners, children, and families occurs in a social and cultural context. An ethnographic approach brings to the communication process an appreciation of the centrality of culture, broadly defined, in shaping thought, feeling, and experience. It also involves an ethical commitment to understand human experience as it is lived, felt, and understood by others. Borrowed primarily from the field of anthropology, the ethnographic perspective is being used increasingly by theorists and practitioners in the fields of healthcare and human services as a useful framework to inform clinical practice. (Browning 2003, Kleinman 1989, Laird 1998, and Krakauer 2000).

> What this stance most fundamentally is about is figuring out how, when entering the experience of another individual or group of individuals, to be as unfettered as possible with one's own cultural luggage — how to leave at home one's powerful cultural assumptions and to create the conversational spaces wherein the voices of the "other" can emerge (Laird 1998, p. 30).

An ethnographic perspective views biomedicine both as a particular "way of knowing" and as a distinct culture with its own traditions, rules, and customs. The language and culture of biomedicine is one in which nurses and physicians are expected to be fluent, and in which ill children and their families must have at least a rudimentary mastery. In establishing relationships with children and families, clinicians must be capable of "having a foot in both worlds" and of becoming "bicultural" in their encounters with families. With this stance, the practitioner endeavors to enter the culture of each family, albeit partially, in order for communication to be successful.

Elements of a Framework

What, then, are the central features of an approach to relational and communicative competence grounded in an ethical and ethnographic framework?

The practitioner must be capable of alternating between the stance of expert and the stance of learner. The modernist approach to medicine places practitioners, especially physicians, firmly in the position of expert. This approach may be quite useful and necessary from the standpoint of making available to children and families specialized professional expertise, but it can be counterproductive when the invitation at hand is to engage on a human-to-human level. This human-to-human form of contact is facilitated by a kind of "informed not-knowing" (Laird 1998, Anderson and Goolishian 1992) in which the practitioner learns effective ways of getting to know children and families by honoring their expertise over the narratives of their lives.

"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

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> Listen. Just listen and just dig deeply what they're saying. . .That's the kind of doctor to be. Not just a doctor that understands big words, doctor talk, whatever. Because they got to meet all kinds, like me. They got to understand me. . . I'm the one here with my child. I could read her face. . .You got to listen to what I'm saying about my child (Mother, interviewed in Browning 2002).

Effective communication takes place when practitioners can move fluidly between their position as experts and their position as curious and respectful fellow human beings.

Such relationships must be shaped by mutuality and reciprocity. The language of communication skills training in palliative care reveals a unidirectional view of difficult conversations with families.

The idea of "breaking bad news" emphasizes the importance of having the right "strategy" when approaching families, and tends to emphasize a single, rehearsed communication event. These approaches often give too little attention to the relational foundation of mutuality and reciprocity that is integral to holding difficult conversations.

The construct of "delivering" bad news conveys an even starker message of detachment and one-way communication on the part of the practitioner. Mail is delivered. Pizza is delivered. A frightening diagnosis or prognosis should never be "delivered." It should be broached in the context of a relationship of mutuality and reciprocity. Such communication best occurs in an ongoing relationship with a practitioner over time, but the principles of relational competence apply equally to the vicissitudes of a single encounter.

> When we was in the waiting room, the surgeon, he came out and he explained to us how serious it was. He even told us how long she might live. . . . To me, he was just like part of us at that moment. And I really appreciate him for that. Because that was the beginning of it and that would have been the most important part right there . . . the way he handled it, the way he took care of it. . . He even got a little room off to the side for us to go in by ourself for a minute.
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> That particular surgeon, I'll never, never forget him. I can just picture him, the way he present himself, the way he express himself, the body movements, the caring. I mean he just let you know . . . you can just feel it (Grandmother/guardian, interviewed in Browning 2002).

To assert the values of mutuality and reciprocity in relationships among practitioners, children and families is not to argue that such relationships are equal in terms of power (Brody 1993). In fact, it is especially in light of the inevitability of power differentials that practitioners are ethically obliged to strive for whatever degree of mutuality and reciprocity is possible. One form of that obligation is to speak in language that is familiar and understandable to children and families.

> I say it's a very important situation when the doctor come and show care and concern of what they're doing and how they're going about the situation. And keeping you informed of the situation, what is being done. . . . It's like myself. I don't always speak correctly in everything I say. So I don't want you to use that against me that I don't understand everything that you [are] saying, if you get one of those big words out to me, you know, throw it that way. But if you give me time I might understand what you [are] saying (Grandfather/guardian, interviewed in Browning 2002).

"Sometimes I might not understand your doctor language. . . . but if you break it down, I can understand."
—Grandparent/guardian

Self-awareness and reflective practice on the part of the practitioner are central to compassionate communication with children and families. Theories and methods in healthcare necessarily focus on the patient and, in the case of pediatrics, on the patient in the context of the family. However, effective communication and relationship building require that an equivalent gaze be aimed toward the practitioner. This requirement means cultivating a level of self-awareness and willingness to reflect on one's practice on multiple levels, including cognitive, emotional, spiritual, and physical. For example, in the clinical context, practitioners need to be aware of the impact that their theories and assessment procedures have on their interactions with children and families.

> There were lots of times for my brother and sister, especially my brother, where they were sort of left to themselves just because there was no other way to do it. So it's sort of like this Catch-22 where you're worried about your sibling but jealous at the same

time and wondering, where do I fit in this picture?

From a healthcare perspective you need to go in there waiting to see what they bring to you and not bringing what you have. Seeing what the family makeup is and seeing the different roles people have in the family and then supporting them any way that you can, versus bringing your structure into their home, because it doesn't tend to work very well (Sibling, interviewed in Browning 2002).

The capacity to reflect on one's own ways of thinking, feeling, fearing, hoping, and embodied living can provide a rich and highly relevant source of data for clinicians as they seek to communicatie effectively with children and families. Developing this capacity for reflection may seem like an inordinate burden on practitioners already stressed to their limits by the complex and incessant demands of the healthcare professions. The emotional and spiritual burden for clinicians of not developing such a capacity, however, may be even greater.

"[Her physician's ability] to be able to show that humanness with her . . . was something I'll always remember." —Parent

The experience of the professional caregiver is as relevant to the communication process as the experience of the child and family. An ethnographic approach provides the starting point for recognizing the parallel suffering, and parallel efforts at meaning making, of practitioners alongside patients and family members.

An observation from child psychology can help explain the double suffering of sickness. Infants are found to engage in so-called parallel play, during which the play of one infant has nothing to do with the play of a neighboring infant. Only as the infant matures is he or she capable of joining another child in true play, an activity that, by being shared, achieves cooperative meaning. Similarly, doctors and patients sometimes engage in parallel suffering. Both patient and doctor suffer, but their suffering is isolated from one another. As a consequence, the suffering of both patient and doctor is needlessly intensified. Not uncommonly, the doctor or the patient is blamed for the suffering of the other. The isolation, wordlessness, and blame of parallel suffering hurt all who are involved: the doctor, the nurse, the patient, the family, and all who must witness the pain of any of the participants (Charon 1997).

The modernist emphasis on practitioner expertise and objectivity routinely makes invisible the potential suffering of clinicians who choose to move closer to the suffering of children and families (Browning 2003, Rushton 1993). This invisibility lays the groundwork for burnout and compassion fatigue and will only be remedied when professional and organizational structures aee transformed in ways that acknowledge and respond to caregiver suffering.

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.

Conclusion

Making time available, finding a quiet place to talk, maintaining eye contact, sitting instead of standing, learning to be empathic. All of these are

important tools in the complicated and challenging endeavor of communicating well with children and families at the end of a child's life. But our tools will only do their job well if we understand and embrace the relational context in which we use them. The parents and other family members whose voices appear in this essay, convey a clear message to healthcare professionals about what more we need to do. We need to become good readers of children and families, and to bring to our reading a full measure of respect, curiosity, humility, and reflection. We need to see parents as experts, because they know their children better than we do. We need to take a close look at our doctor language and learn how to break it down in order to meet families where they are. We need, above all, to be willing to show our humanness to children and families, just as they so readily show their humanness to us.

Acknowledgment

The author wishes to thank Elaine Meyer, PhD, project director of the Program to Enhance Relational and Communication Skills (PERCS) at Children's Hospital Boston for her thoughtful collaboration on the ideas expressed in this article. The author has received funding from the Argosy Foundation, Nathan Cummings Foundation, and the Open Society Institute's Project on Death in America.

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