Facing Decisions about Life and Death — Communication with Parents

by Marcia Levetown

How can healthcare professionals, most of whom have never personally been confronted with such tragic situations, best help parents and their children make decisions about life and death that will minimize the suffering of children and their parents? Research studies and the professional experience of those attuned to these problems can be instructive. This paper reviews and gives advice about the communication between healthcare professionals and parents and children facing life and death.

As parents, we make many decisions on behalf of our children. We feel unprepared for many of these every day decisions: what kind of discipline will most effectively form the person I want my child to become? What is the right age to assign chores? Should I let my son play football? When should I allow my child to date? Yet these difficult decisions pale in comparison to the decisions that some parents face.

Some parents must decide whether the burdens of continued attempts to prolong life are outweighed by the child's suffering: whether the child would benefit more from increased efforts to be at home, to be comfortable, or even to achieve personal goals rather than continue to use precious final days, weeks, or months pursuing the prolongation of life at any cost.

These difficult decisions are encountered by parents of teen drivers, parents of unexpectedly premature newborns, and children born with congenital defects; parents of children who have endured treatments for cancer or other illnesses that seemed to be working, but now are not; and children who are chronically ill, often from severe neurologic dysfunction.

In the first of these scenarios, parents of previously healthy or unexpectedly ill children are faced with the need to make urgent decisions that seem out of context. They were expecting a healthy child that would outlive them, survive to become parents themselves, and productive members of society. The suddenness of the transformation from being the parent of a healthy child to becoming the parent of a child who is dying is understandably difficult to endure. A range of emotional reactions can be expected, including anger, feeling overwhelmed and paralyzed, or the need to intellectualize, suppressing normal emotional responses for a time.

Parents in the second of these scenarios have lived with their child's chronic illness, hoping that their child would be cured (in the case of the oncology patient), or praying for an unlikely miracle, adapting to the realities of a different quality of life and becoming accepting of that reality. Many have learned to live with predictions of imminent death that were incorrect. These parents, too, have

a difficult task. Even for them, the reality of the end seems unbelievable, and, yes, sudden. No parent should have to face these decisions feeling uninformed, alone, unsupported, or rushed.

How can healthcare professionals, most of whom have never personally been confronted with such tragic situations, best help parents and their children make decisions that will minimize the suffering of children and their parents? Research studies and the professional experience of those attuned to these problems can be instructive. This paper reviews and gives advice about communication between healthcare professionals and the parents of children facing life and death.

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Communication, an essential tool in healthcare professions, is almost never overtly addressed in training (Greenberg et al. 1999); yet poor communication can plague bereaved parents for the remainder of their lives (Field and Berman 2002).

First and foremost, children and families need respect. Respect is the foundation; it makes communication possible and ensures parents that their concerns have not gone unnoticed or unshared. Respect can be reflected in myriad ways. Respect for parents is evidenced by

- choosing carefully the manner in which we will communicate,
- affirming that the parent has done an excellent job caring for the child,
- acknowledging the impact of the illness or condition on the entire family system as well as the larger community,
- recognizing that the decisions parents make are loving and correct, and worthy of the care team's support,
- committing ourselves to the continuity and streamlining of care, and
- appreciating the personal and spiritual crises that emerge as a result of the potential death of one's child.

But if good communication begins with respect, it also requires imagination — the realization that each of us may one day be on the receiving end of such news. It is not difficult to imagine that our intellectual processing would be impaired by extreme emotions, or that the foreignness of the hospital environment would likely contribute to feelings of surrealism. Plain speaking would be, for most of us, the only way to achieve effective communication. Life and death decision making must be viewed as a process that undergoes remodeling as friends and family give advice and as new information emerges regarding the child's response to therapy over time.

Respectful and empathic communication unfolds according to seven important steps.

Create the Right Environment

Within practical limits, ask the parents about their preferred time to talk and whom they would like to have present for the discussion. Ask whether they would like to have their child present, or if they would prefer to speak to the child after the larger meeting. Take time — much can be accomplished in five to ten minutes, but longer is better. Sit down, and look parents in the eye, unless this gesture is culturally inappropriate. In the latter case, avert your eyes and check in occasionally to see how they are responding.

Other ways to develop rapport include using the child's name and acknowledging the child as an individual with importance and value. This rapport is often achievable by commenting on the child's positive attributes (in the case of an infant), or by inquiring about his or her personality or achievements (in the case of an older child).

It is also important to notice and address symptoms (Garwick et al. 1995). Consider the following example:

> Five month-old Marissa was dying of an unusual disorder that involved stiffening of her lungs. Rapport with her angry mother was rapidly established by a new clinician who noted Marissa's obvious difficulty breathing (120 times a minute, causing Marissa to be exhausted and covered in sweat). "Have you noticed Marissa is breathing funny?" the clinician asked, followed by, "Does that bother you?" And finally, "I can help her with that, but there are some risks I need to tell you about."

Find a private environment with indirect or soft lighting, if available. Avoid rooms with large desks or tables; if these are unavoidable, intimacy can be achieved by sitting at the corner of the furniture, close enough to touch the parents. Invite the parents to sit next to each other and their supporters. Do not overwhelm them with white coats and new faces. Have tissues available. If x-rays will be shown, ensure that a light-box is available.

Inquire about the style the parents prefer for receiving information; some prefer a detailed accounting of every option; others prefer to know only what they need for today (unpublished interview data 2001). Bring pen and paper to summarize or illustrate ideas legibly. Consider tape recording the meeting. A recorded interview can be made available for later review and accurate information dissemination (Levinson 1997). It will not increase liability risks; rather, these risks decrease with improved communication (Levinson 1997).

Develop a Mutual Understanding of the Goals of Care

Ask the parents what they understand about what is happening to their child. Clarify misconceptions and provide the "big picture" (Todres and Jellinek 1994). Parents and family often do not care about lab results and machines. Instead they need to know what goals of care are achievable, and what other goals may be hoped for, though unattainable. They need to understand the potential outcomes of care as these relate to degrees of benefit and burden, and they will want to know about their child's ultimate degree of impairment and ability to participate in life. Parents need us to acknowledge uncertainty, when it is present; and to be clear, when certainty exists. Consider the following case:

> A profoundly neurologically impaired nine-year-old, nonverbal, quadriplegic child recurrently arrived in the intensive care unit after full cardiac arrest caused by aspiration pneumonitis (stomach contents in his lungs). Despite surgical and pharmacologic therapy to prevent this common complication of severe brain dysfunction, the child's care providers were unable to prevent this recurring cylce of events.
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> When his guardians were asked what they hoped to achieve with his medical care, they responded, "We want him to be all better." A response of, "Can you tell me what you mean by 'all better'?" was countered with "We want him to talk, play, and go to school like his brothers."
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> This hoped-for outcome was not achievable. Empathy and clarity of achievable goals must follow such a response. "I wish that were possible." (Follow with appropriate silence). "However, there is no surgery, no medicine and no amount of love — because you clearly love him very much — that can make that happen.
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> The best we can hope for is to return him to the state he was in prior to this episode of

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pneumonia. Is that a goal that is desirable for (patient's name) and your family?" Invite the parents to explain in their own words what is happening and what goals of care can be achieved.

Provide New Information Effectively

Avoid all technical terms and medical jargon, but give clear and critical information in the manner that the parents prefer. Place the new information in the context of progress toward goals, or decreasing likelihood of a positive outcome. Use pie charts to illustrate percent chances, and the child's imaging studies or slides next to studies of healthy children of that age to illustrate the child's pathology. Avoid using exam table paper, paper towels, or napkins as stationery.

When parents ask "How long does he have to live?", provide a range of time, indicating as appropriate that it could be minutes to hours, hours to days, or days to weeks. Understand that they are trying to determine the urgency of gathering family and friends, taking time off from work, and managing for their other children. The following case shows how quickly effective information can help parents know what they want for their child.

> Adam was a four-week-old premature infant. He had been born at thirty-two weeks' gestation, generally a hopeful size portending a good outcome. He had, however, contracted a devastating infection of his brain, Group B Streptococcal meningitis, and would not survive. He looked like a normal baby (if one ignored the ICU, ventilator, monitors, and central lines). He slept most of the time, but would never wake up or have any volitional movements. This devastating news was most easily illustrated by showing his brain MRI next to one of a "normal" thirty-six-week gestation infant. Once the parents saw this vivid illustration of the damage and understood its implications, they no longer desired to continue the life-sustaining therapies that they had "demanded" only minutes before.

Ensure that the short and long-term burdens and benefits of each treatment option are clearly explained. Include information about the likelihood of success in achieving hoped-for outcomes and the possibility of undesired outcomes. If time-limited trials are indicated, be clear about the time frame and set an appointment to meet again to review the child's response to therapy and the implications for new goals of care (AAP and ACOG 1995). The following case illustrates the importance of clarity about outcomes.

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> Marissa's severely compromised state may have been the result of the inexorable course of her underlying illness, with a recently escalating speed of decline, or it may have been due to a superimposed acute infection that was potentially reversible. She was going to die of the underlying illness in either case, but may have had some additional time left to enjoy with her mother, possibly at the cost of an ICU stay and mechanical ventilation.
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> Her response to intensive therapy would be clearer after forty-eight hours. If she had no evidence of response, it was likely that we were prolonging her death, rather than extending her life. If she did respond to therapy, then continued vigilance to her progress and frequent and regular communication with her mother would be necessary to ensure that the goals of care remained consistent with Marissa's health and her mother's values.

Be clear about ambiguous words (Greenberg et al. 1984; Levi et al. 2000). For example, parents understand "response to treatment" as "cure," while to the clinician it may only mean "10 percent tumor shrinkage" or "an expectation of two more weeks of life," at the cost of pain, discomfort, and remaining in the hospital. An alternative might be to go to Disneyland. Mention and clarify invasive procedures, pain, other unpleasant symptoms, and the time anticipated in clinic and hospital as well as the possibility of lost opportunities.

Consult with the Child

When the child is able (verbal and alert), it is incumbent on parents and practitioners to solicit his or her participation and preferences, fears, concerns, and hopes. The child's ideas should be taken seriously and addressed during the interview (Rushforth 1999, McCabe 1996, Tates and Meeuwesen 2000, AAP 1995, and King and Cross 1989).

Only the child knows the actual pain of procedures, loneliness, and fear. Particularly if the child has been through a lot of treatment, he or she knows the burdens of therapy all too well and is perhaps better able to judge the relative merits of continuing on. It may be helpful to enlist the assistance of a child life therapist or child psychologist to inform the child and solicit his or her priorities and preferences. These professionals are trained to communicate in nonverbal, nonthreatening ways that are appropriate to the child's developmental skills. Sometimes siblings have important insights to offer as well. Clinicians and parents should be clear about the questions that are on the table and must be open to new information or concerns that the child raises.

Acknowledge the Nonphysical Suffering of the Child and the Family

Acknowledge in words that the impact of the situation on all involved is tremendous. It shakes up one's world, creates crises in relationships, and challenges beliefs in a higher power. It is understandable and expected that families are angry, tired, anxious, and feeling unduly burdened. Ask about the needs of other family members and how you can help in this time of crisis (Harrison 1993).

Offer opportunities to speak to other parents who are facing or have faced similar circumstances (Krahn, Hallum, and Kime 1993). Parents recurrently ask for this assistance (Field and Behrman 2002). Affirm ongoing support and commit to minimizing the suffering for all involved. Access the strength of the interdisciplinary care team, including the social worker and chaplain, and (with the family's permission) ask their usual spiritual leader, community pediatrician, and extended family to address concerns that are beyond the skill, training, and experience of the physicians and nurses on the care team.

Realize that decisions about the goals of care are made after discussion, deliberation, and the mellowing of emotion. Parents think of questions when they are alone. Each should be answered with patience and understanding (Krahn, Hallum, and Kime 1993). Expect a process that takes time and recurring meetings.

Even in the case of a mortally wounded child, several discussions, even minutes apart, allow parents to digest information, discuss it with each other out of the intensive glare of the clinical team, and reach conclusions that are right for them. For children with more chronic conditions, expect parents to want to try all reasonable options to prolong life so if potential options are not reasonable, do not offer them.

Affirm Parents and Provide Recommendations

In the case of infants, begin by affirming that the parents bear no intentional responsibility for the prematurity, congenital defect, or inherited disorder. In the case of a chronically ill child, humbly acknowledge the difficulty of caring for the child, and the fact that they did their best. Tell parents that it is hard to imagine anyone who could have done better (even if the situation and the parents' response is not "textbook ideal"), this comfort is virtually always appropriate.

After offering clear options, follow with recommendations, based on the input of the entire care team and consultants, and augmented with the personal experience of the clinician conducting the discussion. Indicate that this decision is a joint decision with the clinical care team, not one in which the parents are abandoned to make on their own. Acknowledge that you are not sure what choice you personally would make in the same situation, if that is true. On the other hand, if, based on your values and greater experience with the situation, you see a clearer path, explain your recommendation and its underlying reasons and values.

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Affirm and support any reasonable option that parents and children select. After all, they and only they, will live with the consequences of this decision every day for the rest of their lives (Stinson and Stinson 1992). Outline the steps that follow from the decision and how care will be done. If the decision is not anticipated to be final, and a time-limited trial is appropriate, set a time to meet again and discuss the child's progress. In both cases, commitment to ongoing care of the child and family, consistency of care providers and care goals as decided, is helpful to parents and children in managing this most difficult and painful circumstance.

Life and death decisions are difficult regardless of the age of the patient. Parents face the added difficulty of deciding on behalf of another, often one who has no fully developed set of values or experience to draw from. The additional difficulty of deciding for another, based on a condition thearents have never themselves experienced, only complicates the matter further.

Parents need the partnership of a respectful care team to make the best decisions possible for themselves and their child. They appreciate how difficult it is for clinicians to witness such suffering, and appreciate a show of emotion and concern, such as tears. A strong bond often develops. Clinicians are then left to face similar tragedies with the next family. Thus to provide the kind of care that parents need, it is imperative that we also care for ourselves. Institutional changes are often necessary to create an environment that prevents the development of the callousness and impatience that parents frequently encounter in such settings.

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Examples of institutional changes include ensuring effective interdisciplinary communication through group rounds, complimenting each other on a job well done, covering for one another after a death, pausing for a breath of fresh air for a few minutes or perhaps a day off as needed. It may be helpful to have a regular time to review children's deaths and discuss feelings, or to encourage your facility to hold structured debriefings and memorial services after difficult deaths.

Conclusion

The difficult challenge of negotiating decisions about life and death for children and their families can be overcome. The physical environment, choice of language, and communication aids impact the effectiveness of communication. Small, incremental efforts are necessary to ensure the success of the conversations. It is also critical

that these decisions be viewed as a process, and that all affected parties be involved in that process, particularly the child.

More effort needs to be made to address the effect of the illness and the decision on the family, community, and the healthcare givers. Accessing the assistance of the interdisciplinary team is a good start; the use of peer support for parents and counseling, community resources, and school interventions for siblings and classmates also capitalizes on teamwork. Similarly the debriefing of healthcare workers will help ameliorate the impact of daily facing tragic situations.

In sum, it is possible to achieve good decisions that incorporate the values and experiences of the child and family and which are simultaneously medically appropriate and help control unnecessary suffering. Empathy, skill and patience are essential ingredients to achieving such success.

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