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FROM THE EDITOR

Pediatric Palliative Care: Born of Necessity

So long as we live, they too live, as we remember them.
R.B. Gittelsohn

The topic of children dying is an uncomfortable and, at times, even taboo subject in the field of medicine. Many physicians and laypeople think of it as an infrequent event that only occurs in cases of rare medical failure. Unfortunately, this is not the reality. For example, in the year 2003, more than 50,000 infants, children, and adolescents died in the United States alone [1]. Of these children, only 10 percent died in their own homes, with the remainder passing in hospitals. More specifically, 49-59 percent of these deaths occurred in the PICU, and 31-33 percent in the NICU [2]. Despite the numbers of intensive care unit deaths and the availability of potential medical interventions, Wolfe et al. surveyed the parents of children who died of cancer and found that 89 percent perceived their children as having suffered with at least one bothersome symptom in their last month of life, most commonly pain, fatigue, or dyspnea [3]. In 2005, the National Hospice and Palliative Care Organization noted that of the 4,100 hospice and palliative care programs that exist in the U.S., only 738 (18 percent) provided pediatric palliative and hospice services [4]. In addition, it was found that less than 10 percent of children who met criteria for palliative or hospice services were enrolled in these programs [5].

So what more could be done to decrease the suffering associated with these events? Palliative care has developed as our health care system's attempt to answer this question. The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [6]. It goes on to state that, in the pediatric context, it is

the active total care of the child's body, mind and spirit, and also involves giving support to the family; begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease; requires a broad multidisciplinary approach that includes the family and makes use of available community resources...[and] can be successfully implemented even if resources are limited [6].

Given the number of children who die of terminal illness each year, as well as the many children living with life-limiting conditions (in 2003, the IOM identified

400,000 such children [5]), why are so few of them receiving the benefits of palliative care? In this issue of *Virtual Mentor*, I hope to explore some of the possible answers, including—but not limited to—the widespread misunderstanding of applicable laws and standards of care; physicians' own difficulty accepting death as a natural phase of life, rather than a medical failure; lack of awareness of a child's potential capacity to anticipate his or her own death; the misbelief that shielding a family from the medical and prognostic realities is helpful; and the lack of appropriate education and research, which leaves many physicians feeling inadequate and incapable of having frank discussions with families regarding impending death. These factors, which, in my opinion, have led to the dearth of pediatric end-of-life care, will be examined through identification of the inherent, omnipresent ethical dilemmas of the field. It is my firm belief that only through open dialogue about these ethical challenges will pediatric palliative care become mainstream in medicine.

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Dedication

This edition is dedicated to Noah's Children's patients, families and staff, who are among some of the pioneers in pediatric palliative care, trailblazing the art of healing the dying. I am honored that you allowed me to join you on this uncharted and difficult journey to find meaning in this arduous path. In addition, many thanks to all of the experts in pediatric palliative care for your support and sharing and for guiding this journal to fruition.

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CLINICAL CASE

Nondisclosure and Emerging Autonomy in a Terminally Ill Teenager

Commentary by Sarah Friebert, MD

Neil was first diagnosed with acute lymphoblastic leukemia at age 3. After induction chemotherapy failed to produce a remission, his family spent the next 6 months traveling around the country trying to find the best doctors and latest chemotherapy options. When they finally decided to seek treatment for Neil at a major children's hospital hundreds of miles from their rural home, Neil and his mother moved to this city, where he spent the next 3-1/2 years in and out of eventually successful chemotherapy and a bone marrow transplant.

Years later, Neil revealed that most of his early memories involved the staff or patients of the children's hospital. He certainly remembered good experiences, like the ceremonial head-shaving parties, the local ballet company's recitals in the hospital, and his close friendships with other patients. But the reality was that Neil had lost many of those friends during his hospital stay, and he had many painful memories, too—the endless nights of nausea and pain, his mother's constant anxiety about his recovery, and the unexpectedly difficult transition back to “civilian living,” catching up in school and learning to share belongings and his parents' time with his siblings.

Neil succeeded in putting those painful memories behind him and living the life of an average kid in a small town. He'd developed an enthusiasm for football in long conversations with a football-loving nurse, and he threw himself into playing. However, when he was 14 years old, he began to notice increasing fatigue during practice and games. He didn't mention it to his mother. During his annual physical, it was noted that he had lost 15 pounds and, when questioned, he revealed his other symptoms. His mother, inconsolable, prepared for another trip to Children's Hospital.

There, Andrea, a third-year medical student, was assigned to Neil's case. She, too, shared Neil's enthusiasm for football, and they developed a rapport. But when Neil began asking Andrea about his diagnosis, she didn't know how to respond.

Neil's ALL had, in fact, returned. Because he had relapsed after transplant, only participation in a Phase I trial designed to measure toxicity and maximum dosages of new chemotherapy agents was offered as an option. But his mother had specifically asked the treatment team not to discuss Neil's diagnosis with him, believing that he couldn't cope with the news or appreciate its implications.

Meanwhile, Neil confided in Andrea that he would rather die than endure another course of chemotherapy, saying, “It was horrible. I can’t do it again. I just want to go home, but I’m scared my mom and doctors will hate me.”

Commentary

Though this all-too-common scenario raises many topics for discussion, we will focus on nondisclosure requests, assent, and emerging autonomy in pediatric health care decision making, integrating pediatric palliative care into oncology care, and caregiver moral distress. Throughout the article, the term “parent(s)” will be used generally to refer to responsible decision maker(s), and the term “child” will refer to infants, children and young adults cared for by pediatric teams.

Nondisclosure

A request for nondisclosure from the parents of a pediatric patient is unfortunately a common occurrence. Whatever the reason—specific religious or cultural injunctions and fear of causing a child to lose hope or “stop fighting” are the most common—these situations are often a cause of great distress for caregivers, especially those at the bedside, who feel like a gag order has been imposed on them. Research examining disclosure directly from the child’s perspective is lacking; nevertheless, several general themes have been elucidated. Most of the time, the feared harms from disclosure are outweighed by the benefits: children do wish to participate in their own health care decision making and cope more effectively when given honest, developmentally appropriate information [1, 2]; children who are not specifically told about their diagnosis or prognosis often do know more than adults think they do [3], and silence may perpetuate worries or fantasies that are worse than the truth; and opening the channels of communication can substantially reduce suffering [2]. In particular, research demonstrates that families who are encouraged to talk with their children about their illness and their death experience less decisional regret and have less complicated bereavement than families who maintain a position of nondisclosure [1].

Clearly, the best strategy to avoid conflict over disclosure is to prevent an impasse from the beginning. Establishing a relationship with the family that includes the child whenever possible sets the tone from the outset that “outside the door” conversations and deliberate withholding of information from patients are not encouraged. This is not to say that clinicians need to take an intolerant stance toward parental requests for “protection.” There are occasionally religious, cultural, family-centered, and even child-preference reasons not to give children full information unless and until families give permission for such information to be disclosed or do so themselves.

An approach to nondisclosure that will resolve most conflicts includes the following elements:

1. Recognize that disclosure is a process, not a binary either/or;
2. Establish a culture of openness from the start;
3. Partner with parents to preserve hope for miracles, and brainstorm solutions;

4. Inform parents that you will not directly contradict their wishes but that you also will not lie to the child;
5. Discuss with parents the known benefits of allowing children access to honest information from trusted sources and the known harms that can occur when children are “protected;”
6. Engage in a dialogue about the “process” of evolving disclosure to negotiate an approach that is family-centered but also respects the care team’s primary duty to the child-patient;
7. Explore and address family fears about clear dissemination of information;
8. Involve interdisciplinary team members and trusted family advisors in the conversations;
9. Explore what the child already knows and would prefer to know, in front of the parents and separately, if allowed; and
10. Employ nonverbal means to elicit comprehension and questions from children whose communication is not primarily verbal.

Though this strategy is appropriate in most situations, it is important to state that telling children the truth is not always the right thing to do, and each situation must be approached individually. For Neil and his mother, directed discussion will probably reveal Neil’s mature appreciation of his medical situation and allow him to assert some control over an otherwise out-of-control reality.

Assent and Concern for Emerging Autonomy

Because Neil is under 18, he is not considered to be competent (a legal term). Competence confers true autonomy, which allows one to give informed consent. Decisions about Neil’s treatment, therefore, will be made by his surrogate decision makers—in this case, his parents—who are presumed to have his best interests in mind at all times unless and until proven otherwise. Because consent is something one can only give for oneself, Neil’s parents actually provide informed *permission* for his medical treatment.

Even before they reach the age of legal competence or become emancipated minors (by marrying or establishing financial independence, for example), children often possess sufficient decisional capacity to participate in health care decision making for themselves. When treatment decisions are being considered—and especially as the likelihood of cure diminishes—most practitioners support allowing children to exercise decisional capacity to the extent that they are interested and developmentally capable, even without legal competence or emancipation. This process facilitates respect for emerging autonomy, recognizing that autonomy in practice is not a switch that gets flipped on a child’s 18th birthday.

In this scenario, Neil’s next step is enrolling in a Phase I clinical trial. This is research, not treatment, so it requires Neil’s assent. Most investigators (including the Children’s Oncology Group), practitioners, and institutional review boards agree that cognitively typical children age 7 and older possess sufficient capacity to take part in deciding whether or not they should participate in research. They are allowed, at this

age, to “dissent,” that is, to refuse. They are not allowed, however, to dissent from *treatment* until they are older; hence, their assent to treatment-related decisions also comes later.

The purpose of a Phase I clinical trial is to determine toxicity and maximum tolerated dose. Fatal toxicity rates of Phase I clinical trials have traditionally been on the order of 0.5 percent; recently, this has decreased to 0.06 percent. The possibility of direct benefit to participants—in this case, Neil—has historically been roughly 4-6 percent, but recent data indicate that response rates for individual subjects enrolled in Phase I trials are down to 2.5 percent. The research does entail some risks for Neil, which may include side effects from the treatments themselves, as well as a significant impact on his quality of life due to increased time away from home, family, and school. Nevertheless, some children do appreciate the opportunity to be altruistic and may incur personal benefits that make the risks worthwhile. It is crucial, however, that *therapeutic misconception* does not occur—in other words, families must truly understand the low chance of direct benefit from participation. To ensure that children and families receive adequate, understandable information and make truly informed choices that reflect their goals of care, some clinicians and investigators believe that enrollment in Phase I clinical trials should be a trigger for pediatric palliative care referral.

Integrating Pediatric Palliative Care into Pediatric Oncology Care

Pediatric palliative care (PPC) is most effective for all concerned— patient, family, community, treatment team, and palliative care team—when introduced as early as possible in the course of a child’s chronic, complex, or life-threatening diagnosis. Linking access to PPC with prognosis for financial or psychological reasons (such as fear of dashing hope or signaling failure) is detrimental in various ways, not the least of which is that such linking can restrict or delay access to highly beneficial and effective services. Families and patients are, in fact, capable of maintaining the dual goals of cure- or disease-directed therapy and palliative care.

Despite its documented advantages, PPC remains underused, even in situations like Neil’s. Recent national data from the American Hospital Association reveals a 58.5 percent prevalence of palliative care programs in 2517 hospitals nationwide (not pediatric); this prevalence is almost identical to the 58 percent of Children’s Oncology Group member hospitals that report that PPC services are available to their patients. Due to many barriers outlined in detail in other sources [4, 5], however, the percentage of eligible patients served is far lower.

To improve delivery of PPC along with state-of-the-art oncology care, it is helpful for health care professionals and families alike to recognize the following:

- PPC should not be described as an “either/or” choice for a family, implying that it represents a transition to second-best care; PPC is an accredited, recognized medical specialty that should be available to any child who would benefit from it;

- The goal of PPC involvement is integration with, not replacement of, the oncology team, and the family can gain access to elements of both teams as needed;
- Disease-modifying and palliative care strategies are often synergistic; for example, chemotherapy and radiation may relieve symptoms, while better sleep, nutrition, and pain control may affect tolerance of therapy;
- If a child's condition worsens, co-management prevents a disruptive transition to a new care team at the worst possible time and decreases feelings of abandonment in both directions (family and care team);
- Co-management provides an umbrella of support throughout the entire emotionally draining process, including additional support for the oncology team, which faces limited time and resources; and
- Effective integration allows the child and family self-determination about treatment options and promotes health care justice through access to high-quality care.

Neil's case includes several instances in which palliative care team involvement could be beneficial for him and his family. Nevertheless, knowing when to consult palliative care can be challenging for clinicians. In Neil's case, while it was reasonable to think (and even expect) that his initial treatment course would lead to a cure, PPC could presumably have been helpful in mitigating some of the suffering that Neil experienced even then. With his relapse, the need for integration becomes even clearer. Many PPC teams are available for any child with a life-threatening condition (which would, in fact, include almost any type of oncologic problem). Depending on the services available from the oncology team, having an additional support service to focus on symptoms, sibling adjustment, and other areas of child or family suffering is ideal. In reality, though, resource availability may preclude PPC team involvement with each new diagnosis, so some selection criteria are appropriate.

In settings where hospital- or community-based PPC is available, oncology treatment teams can use the following strategies to determine which children and families might benefit from PPC:

- Think about appropriate points at which PPC might be logically introduced, such as: family is overwhelmed at diagnosis; Phase I enrollment; time of relapse or recurrence; development of serious complications; ICU admission or transfer.
- Treat PPC as an adjunct medical specialty that comes as part of the package with an oncology diagnosis, rather than as an optional service. Families should be informed that they will be receiving a palliative care consult rather than asked if they want one, as this shifts the burden from the family to the caregivers. This is, after all, the way in which medical consultation is done in other circumstances.
- Think up front about list of diagnoses for which there is honest acknowledgment of the likelihood of cure with no burdensome treatment.

The many medical circumstances outside that small group are candidates for considering PPC.

- Forget the idea of prognosis entirely and involve PPC to enhance resource management for the complex needs of family, treatment team and community.

Compassionate Care for Ourselves as Caregivers

Finally, an important dimension of Neil's story involves our obligation to care for each other as caregivers. Support for staff, including the medical student, is of primary importance in avoiding moral distress, unacknowledged grief, and burnout. In particular, Andrea is being put in a potentially difficult situation by being asked not to disclose information to Neil, with whom she has a primary relationship. As mentioned above, it is often the direct or bedside caregivers who are the most at risk for moral distress in situations in which families have forbidden disclosure. Medical students, residents, bedside nurses, and other staff must be incorporated into the conversations about the plan of care and, specifically, the plan for handling nondisclosure.

In a true family-centered care setting, the unit of care is not just the affected child. For involved caregivers, the duty of fidelity instructs that our child patient is our primary concern and that we must make medical and other decisions in this patient's best interest. But it is the family who will live with the consequences of the decisions long after the illness episode is over, and ignoring this reality to stand on bioethical principle alone is not helpful in day-to-day care. Navigating potential or actual conflict in this arena—such as between Neil's mother and the treatment team—can be enormously stressful for those who feel caught in the middle like Andrea, who has not yet developed the skills and maturity to navigate the situation expertly. Support for all involved must be provided by the team, and outside ethics consultation can be sought if individual caregivers feel unsettled with decisions being made. At the end of the day, no clinician should be obligated to participate in a plan of care that he or she objects to on moral grounds; however, it is the duty of that clinician to recuse her- or himself rather than acting in a passive aggressive or subversive manner.

Conclusion

This article has focused on several of the more common elements that can be distressing in situations like Neil's but can also present opportunities for skillful and effective clinicians to intervene to facilitate patient, family, and staff dignity and healing. For more in-depth treatment of these and other related topics, an abbreviated list of suggested readings is included.

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CLINICAL CASE

“Please Let Me Hear My Son Cry Once”

Commentary by Wynne Morrison, MD, MBE

Norma had two goals in life: to become a parent and a gynecologist. She achieved the latter and, to boot, married a classmate, George. Her first dream seemed stymied, however, by their long hospital hours, exhaustion, and career demands. When Norma unexpectedly became pregnant at the age of 35, she and George were overjoyed, but also concerned about the risks associated with her relatively advanced age of conception—concern that turned out to be sadly justified when their unborn child was found to have trisomy 13, or Patau syndrome. George and Norma discussed options, including aborting the fetus, but decided to move forward with the pregnancy. Norma prayed every night, “Oh God, please let me hear my son cry once...that is all I want...the sound of my own child in this world.”

Norma’s prayers were answered and their son was born. Bob had a severe cleft lip and palate, but Norma and George thought their son was the most beautiful child in the world. Due to their medical competence, they were eventually able to take their child home. Because she spent so much time with her son, Norma quickly became familiar with all of his unique sounds and was quick to notice the onset of short apneic episodes. She could not tell whether Bob was experiencing pain during these attacks, but administered the morphine prescribed by Dr. Moy when she believed he was in pain. The events increased in frequency and duration, and, eventually, Dr. Moy began to advise against using morphine out of concern that this pain relief might result in respiratory failure.

When Bob was 3 months of age, conflict between Norma and Dr. Moy surfaced again when Norma requested that Bob be given his normal childhood vaccinations. Dr. Moy explained that he felt these were unnecessary and might increase morbidity. He expressed his regret at not having been trained for situations like this, and he knew there were many clinical and ethical issues at play.

When Norma called Dr. Moy to report that Bob had developed a fever, Dr. Moy told her to take him to the local emergency room immediately. There, after a taking a history and learning of the trisomy 13 diagnosis, the ED physician told Norma, “Your son is dying. There is little we can do to help him.” Dismayed, Norma pushed him to proceed with a physical examination, upon which the physician, to his surprise, found that Bob had an acute otitis media infection. He asked, “So do you want to treat his infection? Also, does your son have DNR orders?”

Commentary

Trisomy 13 syndrome is a rare genetic disorder in which the affected patient carries three copies, rather than two, of chromosome 13. Common clinical features include a cleft lip or cleft palate, cardiac anomalies, scalp defects, microcephaly, developmental delay, seizures, frequent apnea, skeletal anomalies, and other anatomic defects [1]. Life expectancy is, on average, a few months of age, although there are reports in the literature of “long-term” survival into the teenage years [2-4]. With recent advances in medical therapy and our improving ability to support children with chronic illnesses, it is likely that clinicians in many fields of practice will encounter children living with syndromes like trisomy 13 and will have to help families decide what interventions are appropriate to pursue.

In the past, most parents of children with trisomy 13 were told that the syndrome was lethal and that interventions should focus only on keeping the child comfortable. Aggressive support, such as invasive procedures like cardiac surgery or tracheostomy, was generally not offered. Koogler et al. have argued that the ubiquity of this approach made the “lethal” label something of a self-fulfilling prophecy [5]. Clinician attitudes have shifted somewhat over time, especially as it has become much more common to provide interventions like open heart surgery to children with less severe chromosomal defects, such as trisomy 21 (Down syndrome). Many physicians may still feel that it is in the best interests of children with trisomy 13 to provide comfort measures only, but the current standard is to discuss options with the parents rather than making unilateral decisions.

The physicians in this case are struggling with how to discuss these issues with parents. Dr. Moy, the primary physician, is taking a palliative approach, providing morphine for comfort to the infant, a therapy that would be contraindicated for a child with apnea whom one expected to survive. It seems that the family is comfortable with this plan and feels that the morphine is helping, but it is unclear how specific the discussions have been about goals of care. Is comfort at this point more important to them than prolonging life? If Bob stops breathing, would they want intubation or resuscitative attempts? If he is dying, would they be more comfortable having him at home or in the hospital? Having early, explicit conversations to set mutually agreed-upon goals can help ensure that all parties are working toward the same ends and increase the comfort of the primary care physician with providing interventions like morphine.

Even when such conversations have happened, however, communication across the health care spectrum can be a challenge. The treating physician in the emergency department may not be aware of the discussions the family has had with the primary care physician or may not understand the plan that is being pursued. Such lack of information can lead to unwanted interventions, or, conversely, to inaccurate assumptions that no interventions are to be provided, as appears to have happened in this case. A phone call from the primary physician to the emergency department attending physician as the family is on their way in would be extremely helpful in providing context.

Understanding Family Treatment Goals and Preferences

It would be a mistake to assume that a family's preferences will remain unchanged as a child's clinical condition changes; however, it would still put the family more at ease, and probably the emergency department physician as well, if he could say to them, "Dr. Moy tells me that you have decided to keep Bob at home if at all possible rather than rehospitalizing him. Is that still your preference?" Their wishes at this time still need to be ascertained, but the conversation does not need to begin in a vacuum.

This family's goals may also shift as they spend time with their child and bond with him. They will be more familiar than anyone on the health care team with their child's day-to-day life, particularly whether he is conscious of his surroundings and whether he is suffering. Physicians may assume that the parents are simply waiting for their child to die, but they may very well also treasure what little time they have with him. It might be a perfectly reasonable goal to try to extend his life as long as possible if the interventions required to do so do not cause too much pain or distress.

It is important for many families of children with severe disabilities that their child be accorded the same respect that a healthy child would. Bob definitely deserves a physical exam in the emergency department to attempt to diagnose a minor illness. His parents may choose to use antibiotics for an easily treatable condition like otitis media if they believe that he currently experiences more contentment than suffering. Some families may agree to a feeding tube for a child with trisomy 13 who has difficulty with oral feeding. Such decisions must be constantly reexamined as the clinical course progresses. Many families draw the line at invasive procedures, deciding not to repair congenital heart defects or undertake airway interventions such as tracheostomies. Even for such invasive procedures, however, the balance of burdens and benefits should be weighed and discussed. While some surgeons hesitate to operate on children with severe congenital anomalies due to the higher risk of complications, many centers now offer surgery to such children, particularly if the procedure in question may improve the child's quality of life.

It is wonderful that this family has identified a primary physician for their child, even though the case is a challenging one for Dr. Moy. Bob may live several months, if not more, and having a physician to provide continuity of care is vital. Routine child care, however, like immunizations, should be provided unless the family and physician together assess that Bob is imminently dying. For some children with trisomy 13 syndrome, the most life-threatening conditions, such as apnea, resolve as the child ages. The question of whether to give immunizations can be used as an opportunity to discuss goals and expectations. The family and physician alike will benefit if the health care system appropriately reimburses Dr. Moy for time spent in such discussions.

Because Dr. Moy may not have much experience talking with families about end-of-life decision making, resources in the community should be assessed. There are likely to be hospice agencies available that may be able to offer an additional layer of

support for the family at home. Hospice staff can clarify goals of care with the family so that they do not need to rehash the same conversations again and again, and they can be called to the home at any hour to avoid unnecessary emergency department visits. At the same time, hospice involvement does not preclude returning to the hospital if necessary for treatable illnesses.

Pediatric Hospice Care

There may be a hospice with pediatric experience in the area—if not, Dr. Moy may be able to partner with a local agency to provide the pediatric expertise while the hospice provides the expertise in end-of-life care. Some hospitals also have pediatric palliative care teams that work with the local hospice agencies to provide this expertise. Having a hospice staff member at the bedside to assess Bob’s degree of pain will also add to Dr. Moy’s comfort with increasing the dose of morphine if necessary. If it is being used to treat discomfort, there should be no upper limit on the dose of narcotic used, and it can be titrated to effect.

The fact that the family decided to continue the pregnancy despite a prenatal diagnosis of a severe congenital syndrome may give some insight into their values. Perhaps this decision was made because of their personal views about the morality of abortion, or perhaps it was based on a desire to see their child or give him as good a life as possible despite its likely shortened span. Many parents torture themselves over decisions such as this one after the fact, so, now that it has been made, they need to be supported and told that choosing to carry Bob to term was a very loving decision in the context of their family values. Some centers are beginning to develop programs in “fetal palliative care” as more and more severe congenital anomalies are diagnosed *in utero*. Consultation with a fetal palliative care team can help a family make decisions about termination, support them if they decide to carry a fetus to term, and help ensure that goals of care regarding delivery room interventions or resuscitation are clear and communicated to the team [6].

Although the parents in this case are both physicians, it is important that they be approached as parents rather than as dispassionate medical practitioners. They have a lot more knowledge than the typical family, but may have little experience with end-of-life care. Even if they do, discussions of orders not to attempt resuscitation (DNR) or the dying process are weighty, emotional experiences when it concerns their own child. The team should approach such conversations in the same careful manner used with any family and not assume that the physician-parents have thought everything through. Rather than asking, “Does your son have DNR orders?—which seems to imply that it might be a problem if he doesn’t—the emergency department physician might have asked what conversations the parents had had with their primary physician or with each other regarding how aggressive they wanted medical interventions to be. He could have followed by expressing the desire to assure that their wishes were honored.

The family may need a lot of help regarding the range of possible choices in this case, as well as reassurance that they are making good decisions. With calm, gentle

guidance, the family can survive this difficult process and carry away cherished memories of their son's life rather than traumatic recollections of strained encounters with the health care system.

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CLINICAL CASE

An Overwhelmed Parent

Commentary by Robert Macauley, MD

Rosa was overjoyed when she delivered her first son Alan at the hospital. He was going to be their first “true American” child, born and raised in the country she had sacrificed so much to get to. Her husband would soon be moving to the U.S. but was awaiting a work permit. On arrival home from the hospital, Alan’s older sisters were so excited that they fought over who would get to hold him first.

After his first week, however, Rosa noticed that Alan’s cry seemed to be weak and that he had trouble feeding. She reported this information to the pediatrician who quickly reassured her nothing was wrong. Rosa failed to be reassured and 2 weeks later sought consultation with another doctor when Alan’s breathing difficulty increased. The new pediatrician diagnosed respiratory syncytial virus (RSV), admitted Alan to the pediatric intensive care unit (PICU), and had him intubated. Rosa spent 4 nights in the disturbing world of beeps and flashing lights trying to understand the culture of this new environment and what the conversation she overheard meant. She was able to arrange for her daughters to stay at a neighbor’s apartment, fearing that the experience would be too much for them.

This scenario repeated itself several times over the next 3 months, and Alan was rehospitalized after unsuccessful brief stays at home. In her many efforts to understand what was wrong with her child, Rosa felt frustrated with the “doctor speak” she received. During this same time, Alan’s sisters became scared of taking care of their brother, fearing they would do something to worsen his condition. His younger sister began to quietly resent her brother for always absorbing Rosa’s attention. She made this apparent to the family one evening after Rosa refused to allow her to have a sleepover for fear that Alan would get another infection.

Rosa spent countless nights searching the Internet for explanations of what was wrong with her son. This situation came to a head one morning when Alan was in the hospital. An unfamiliar nurse arrived in his room seeking Rosa’s signature on consent forms for a tracheostomy and insertion of a gastric feeding tube. When Rosa questioned the necessity of these interventions, the nurse replied, “Oh, I thought the doctors told you your son has spinal muscular atrophy. They have to do these procedures to save him.” In a state of shock and confusion, Rosa signed the forms and cried.

Soon after the procedures, Alan was sent to a local children’s rehabilitation center on a ventilator. Initially Rosa wanted to take Alan home, but after seeing the “hole in his

throat” she thought it would be too difficult for her daughters. Her relationship with the girls had become strained. They refused to talk about Alan or even visit him in the PICU. Rosa struggled to see her son and made excuses when she could not visit.

As the months dragged on, first into a year and then into 2, Rosa stopped visiting Alan. The nursing staff grew quite fond of him and brought him toys and clothing. He even began to communicate through the use of sign language and his smile always brought happiness to the staff. They tried to contact Rosa from time to time, to provide her updates, but she never returned their calls. Many nurses felt that Rosa had abandoned her son and often accused her of being a bad mom and not caring. Even the doctors began to debate whether Rosa should be contacted regarding medical decisions about Alan.

Commentary

When people hear the term “pediatric palliative care,” they often think of kids dying of cancer. In reality, palliative care is relevant to any life-limiting condition, including those that are nonprogressive yet severe enough to render the patient vulnerable to health complications [1]. Palliative care addresses not only symptoms, but also psychological, social, and spiritual problems, as well as advance care planning. Ideally such care is “offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death” [2]. Clearly the patient in this scenario and his family would have benefited greatly from the ongoing involvement of a pediatric palliative care team.

The diagnosis of spinal muscular atrophy (SMA) is typically made either through blood testing, electromyography, or nerve conduction studies [3], yet somehow Alan’s mother was not aware of the purpose of these tests. One wonders whether a language barrier played a role in this miscommunication, highlighting the need for interpreter services even when a parent may not explicitly request them. Parents whose native language is not English may be self-conscious or may not want to seem demanding by requesting assistance.

Alan’s mother was understandably surprised when an unfamiliar nurse arrived seeking her signature on a consent form for tracheostomy and gastrostomy tube placement. The description suggests that the nurse was more concerned with obtaining a signature on a piece of paper than engaging in a thoughtful process of providing clinical information and answering questions, underscoring the importance of shared decision making in obtaining parental permission [4]. This exchange also highlights the need to explore a parent’s current perceptions of her child’s illness to determine the most effective and compassionate method of conveying information [5]. Had the nurse begun the conversation by asking Rosa what she understood about Alan’s illness, the subsequent discussion would have been far more productive.

The nurse not only informed Rosa of her son’s diagnosis in an abrupt manner, she also gave Rosa only one option: “The doctors have to do these procedures to save [Alan].” At this point the involvement of a pediatric palliative care team is crucial.

Assuming this is SMA Type I, it is likely that Alan has only months or, at most, a few years to live. Many parents would opt for tracheostomy and G-tube placement in order to have as much time with their child as possible. The goal of other parents, however, may be “to add life to the child’s years, not simply years to the child’s life” [6]. At the very least, this is an opportunity for Rosa to consider all the options and make a decision—ideally with the support and input of Alan’s father—that she feels is in her son’s best interests. This can only be accomplished in a safe and supportive environment, where the implications of her decision—as well as all relevant options—have been considered. Absent these, Rosa signs the consent form “in a state of shock and confusion.”

After initially being sent to a local rehabilitation hospital, Alan seems stable enough to return home, but his mother believes she would be unable to care for him, given her other responsibilities. Here, again, a transdisciplinary palliative care team [7] could provide support in a variety of areas, ranging from home nursing visits to care coordination to sibling support. Without these, it is easy to understand why Rosa has been so frightened of caring for her vulnerable child with a tracheostomy and G-tube in the midst of an unintelligible medical system. And clearly it is wrong to assume that her preference that Alan remain in the rehab facility signifies a lack of concern.

The same can be said for the infrequency of her visits. She has other children to tend to, and Alan seems to be receiving excellent care. On a more emotional level, Rosa may feel inadequate for not being able to provide Alan with what she believes he needs, and each visit may remind her of failed aspirations—as well as her evolving grief—as a mother. The medical staff’s protectiveness toward Alan is understandable, and certainly someone needs to be available to make decisions for him as his disease progresses. Yet for all the empathic concern and medical technology devoted to him, where is the support for his mother and sisters?

There are many points in this narrative where a pediatric palliative care team could have improved the outcome significantly: at diagnosis, at the decision point of tracheostomy and G-tube placement, and when Alan became stable enough to go home. Other questions loom: Will Alan be transferred back to the hospital when he decompensates? Will he receive aggressive resuscitation when his heart stops, and, ultimately, where, how, and in whose presence will he die?

This case highlights some of the particular challenges of *pediatric* palliative care. First, there is an understandable tendency toward a more aggressive treatment course in pediatric care than in the care of adults facing life-threatening illness. Second, the old saying “children are not little adults” highlights the critical differences—from the physiologic to the cognitive, emotional, recreational, and educational—between the age groups. Lastly, in place of the patient-physician dyad in adult medicine, pediatrics has the triad of patient-parent(s)-physician, not to mention the crucial role of siblings and classmates, and the need to coordinate care not only between home and hospital, but also school and possibly summer camp.

One of the reasons Alan did not receive the palliative care he desperately needed might have been that it was not available. Approximately 50,000 children die each year in the United States—and 10 times that many live with a chronic complex illness [1]—yet there are fewer than 100 board-certified pediatric palliative care physicians. Patients under the age of 25 make up only 0.4 percent of all hospice admissions [8], largely because the hospice benefit was designed with adults in mind and requires patients to forgo potentially curative treatment, forcing parents to choose between cure and care. The Institute of Medicine makes it clear: “We can and must reduce the number of [children] who fail to receive consistent, competent care that meets not only their physical needs but their emotional, spiritual, and cultural ones as well” [9].

Little Alan was one of those children. With palliative care from the time of diagnosis and throughout his life, he probably would have been able to go home to his mother and sisters. He would have had expert pain and symptom management, and his family would have had support from pastoral care, child life, and case management. And he would have been assured of living out his life in the company of those who cared for him most, thus achieving the ultimate goal of palliative (and, I would argue, all medical) care: “the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient” [10].

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MEDICAL EDUCATION

Microethical and Relational Insights from Pediatric Palliative Care

David M. Browning, MSW, BCD

The return to the microethical world of medicine will mean...the explicit reestablishment of the clinical relationship at the center of medicine. Ethics is what happens in every interaction between every doctor and every patient.

Paul Komesaroff [1]

I write this as a medical educator who has been immersed for the past 8 years in developing and implementing educational activities designed to improve the care of children with life-threatening conditions and their families. In response to the Institute of Medicine report *When Children Die* [2], which called for educational efforts to improve the knowledge, attitudes, and skills of clinicians who work with this population, our team from the Initiative for Pediatric Palliative Care (IPPC) developed a comprehensive, interdisciplinary curriculum [3]. In the most recent phase of the initiative, we have been conducting educational retreats in which clinicians from hospitals, hospice and home care organizations, and community coalitions come together with bereaved parents to learn from each other; to date, more than 2,000 practitioners and 200 family members have participated in these events [4]. In collaboration with colleagues at the Institute for Professionalism and Ethical Practice (IPEP) at Children's Hospital Boston, we also developed an innovative workshop for helping clinicians engage in challenging end-of-life conversations in the pediatric intensive care unit. The workshop is now part of a large portfolio of programs focused on difficult conversations in a wide range of adult and pediatric health care settings [5-7].

In this commentary, I will (1) explain our pedagogical approach, (2) describe the microethical and relational insights we have gained from our work with bereaved parents and clinicians who care for critically ill children and how these are relevant to problems in mainstream medicine, and (3) offer an example of how these insights have informed one of our current initiatives—helping health care systems address the prevalence and impact of medical errors and better respond to patients and families when mistakes occur.

As educators, our primary concern in all of these learning endeavors is the microethics of clinical and organizational practice [8]. Our pedagogical approach incorporates several strategies: creating a safe and hospitable learning environment; bringing together clinicians of different disciplines and varying levels of experience; incorporating the patient and family perspective in salient ways; emphasizing whole-person learning that integrates cognitive, emotional, and spiritual knowledge;

encouraging the expression of multiple perspectives; and leveling the hierarchy among learners [5, 9]. Our “experience-near” focus—deconstructing practice from the inside out—stands in marked contrast to more abstract and “experience-distant,” theory-based approaches that tend to shape education in medical cultures. Our outcome research thus far indicates that our pedagogical approach is making a positive difference on the levels of both clinical [6] and organizational [4] practice.

The work of the IPPC team and our initial IPEP programs focused exclusively on the education of clinicians who work with children with life-threatening conditions and their families—a particularly vulnerable and historically poorly served population. In light of this, perhaps the most intriguing aspect in the evolution of our work has been the number of requests we have received to design learning initiatives to address challenges in mainstream medicine, such as improving patient safety and quality, reducing medical errors, and addressing the fragmentation of care and communication experienced by patients and families coping with complex and chronic health conditions. Many of these challenges fall into the category of “wicked problems” [10], a term used by organizational theorists to describe problems that are especially difficult to solve because they develop in particular organizational contexts, are constantly evolving, and are held in place by the thoughts and actions of many individuals with disparate perspectives. Applying what we have learned in pediatric palliative care to mainstream medicine, I offer this working hypothesis: To effectively tackle wicked problems in contemporary health care, we will need to take a closer look at the relational and microethical aspects of everyday practice and cultivate robust organizational learning innovations that bring these challenges to light and provide collaborative frameworks for crafting solutions.

The Moral and Relational Landscape of Pediatric Palliative Care

Clinicians on the shop floor come to think of ethics in terms of prescribed tasks, such as getting consent, rather than as the ongoing work of being ethical. . . ethics becomes a set of procedures performed in accountable ways. Those procedures are often better than nothing, but their danger is that they can cut off the continuing development of a truly ethical culture of clinical practice.

Arthur W. Frank [11]

In bioethics, we can tend to forget that medicine is about the problem of human suffering, that human loss is not a failure to be managed, but a tragedy in which we are the witnesses and the community of response. We forget this concept at our own moral peril.

Laurie Zoloth [12]

In our many conversations with bereaved parents who have navigated the medical system over extended stretches of time, we have learned how essential *caring relationships* are to the process of parenting a critically ill child and to the grieving process following a child’s death. Consider the following comments made by parents

interviewed for short films we produced as part of our pediatric palliative care curriculum. Their words show how and why relationships with health care professionals *matter* so much to patients and families [13]:

Doctors should be more patient with parents. We had so many questions. They should spend more time with parents in these situations—we are going through these horrible moments in our lives.

You need nurses that care. If you want that kind of job, you got to have that kind of caring. We need them—somebody that *cares* about us.

When she died, all the health care support disappeared. All the health care relationships just stopped. I don't know how the health care system allows that to happen.

Listen, just listen and dig deep into what we're saying. *Be concerned* about what we'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*. You got to understand *me*. I know my child better than you do.

Similarly, from listening to many hundreds of clinicians who work with these parents and children, we have a better understanding of how relationships matter from *their* side of the equation. One example [14]:

Sometimes I feel pressure about “getting it right.” It's not about getting it right. It's not how “professional” I am. It's how I respond to this family as a human being, if I'm not sincere, that is what families will remember the longest. It's not really what I say, but more how I *am*, how I can *be* with them at the time.

Choosing the career of caring for critically ill children and their families can bring extraordinary rewards as well as real burdens into the lives of health care professionals. Clinicians describe experiences that have enriched their lives forever; they also share troubling accounts of the moral distress [15, 16] that ensues when, for a variety of reasons, their caring bonds with patients and families is endangered or ruptured.

In the world of clinical ethics, there is an important body of theoretical knowledge that informs professional behavior as clinicians strive to discern and respond to the complex dilemmas that emerge in practice. Thinking through and applying such important ethical principles as respect for autonomy, beneficence, nonmaleficence, and justice are important competencies. Practitioners and health care organizations alike need methods for holding themselves accountable in the carrying out of professional duties and fiduciary obligations. In busy health care settings, however,

more expedient microethics, shaped by institutional needs, also can predominate: the anesthesiologist whose workload requires her to rush through a 7-minute meeting to obtain patient or surrogate consent prior to a life-threatening operation, or the social worker hurriedly assigned by his team leader to “get the DNR” from a despairing family.

Universal human standards. Meanwhile, patients and family members, when asked to describe *their* experiences, tend to approach the topic from a different vantage point. What matters to them as laypersons are workaday human standards like being fair, treating others with respect (in the way you might wish them to treat you), being the best caregiver one can be and discerning the right thing to do in any given situation. When bereaved parents, for example, are asked about how they approached extraordinarily complex and overwhelming end-of-life decisions concerning their child [17], they often describe a kind of moral “bricolage” [18]—a heedful digging into one’s life experience and relational world for tools, resources, and moral insight, which, patched together, might allow one to figure out what to do next. These parents also tell us, almost universally, that one of their most pressing worries during their child’s illness was whether they would “measure up”—whether they could decipher how, under at times unbearable conditions, to become the best parents they could be.

Though it may not seem evident at first glance, clinicians live within the same moral universe as patients and family members. When faced with difficult decisions they, too, are moral bricoleurs of a sort, cobbling together knowledge and insight from a variety of sources in order to find a way forward. In the same way that family members measure their own moral worth as caregivers, many clinicians go home at the end of a tough day, look at themselves in the mirror, and hope to meet in their reflection the best doctor, nurse, or social worker they could be on that particular day. Sadly, such elemental matters of personal and professional integrity are rarely examined explicitly in medical settings. *These* everyday ethics of clinicians typically remain underground unless health care leaders make a conscious effort, in the interest of professional development and ongoing learning, to coax them into the light of day.

Who gets heard. Another key microethical challenge in health care settings is the question of whose voices get heard. Bereaved parents involved in our pediatric palliative care initiative frequently describe the disabling effects of having felt, at key junctures in their health care travels, that their hard-won, intimate knowledge about their child was insufficiently valued or simply ignored by health care professionals. Examples include a parent’s intuitive assessment of what a particular grimace tells them about their child’s pain, their knowledge of their child’s spiritual needs and preferences, or their suggestions as to the best way of communicating with their child. In these instances, the knowledge that most needs to be brought to the surface cannot, seemingly, be recognized. This is a sad irony, since the bringing together of parental expertise and medical expertise is, generally speaking, the *sine qua non* of optimal care for pediatric patients.

We hear parallel accounts from clinicians about *their* important knowledge that never finds the light of day: a bedside nurse who is afraid to say anything in a team meeting when a family to whom she is assigned is being talked about in a disparaging way; a young resident who consistently feels her attending physician communicates with families in a controlling and insensitive manner, but cannot say anything for fear of jeopardizing her own professional advancement; a veteran social worker who finds it disheartening when, after attending a lunchtime workshop on improving teamwork, he returns to the ward to overhear co-workers heatedly complaining about problematic dynamics with colleagues that will never be discussed openly in an interdisciplinary context.

These troubling microethical vignettes are drawn from our work in the world of pediatric palliative care. They describe problematic dynamics that are unique to the particular settings in which they happen, yet they are, at the same time, recognizable in most health care organizations. They qualify as wicked problems because they are persistent, surprisingly difficult to solve, and held in place by actors with differing perspectives. In the next section, I consider these same kinds of microethical tensions as they relate to a significant wicked problem in mainstream medicine today: how institutions deal with medical errors.

Insights for Mainstream Medicine: The Case of Patient Safety

In the current framework, health care tends to regard interactions more as a toll or price than as a goal or product. The system tends to act as if interactions were the burden it must bear so that it can deliver the care. As a result, behaviors and systems emerge to control or limit human interactions, as if they were a form of waste [19].

Donald Berwick, MD, President, Institute for Healthcare Improvement

The interactions of daily practice, as well as the moral and ethical tensions contained therein, are indisputable *empirical* realities in the everyday life of health care organizations. Yet, as Dr. Berwick asserts above, many of the systems and interventions developed to address serious health care problems tend to treat interactions as variables to be controlled or managed, rather than as living expressions of human beings that are both fundamental to optimal care and to our understanding of wicked and recalcitrant problems. As I've discussed, the interactions, interdependencies, and microethics of everyday practice are often shaped by salient but little-discussed forces in medical culture, especially dynamics involving rank, power, and authority. Generally, no one has to tell physicians in-training or beginning nurses not to contradict or disagree openly with their superiors; they just *know*.

Such taboo subjects are part of what is called the hidden curriculum, "the difference between what we say we do and what we actually do" [20]. In recent years, the explicit ideology in most medical settings is typically one of teamwork and collaboration; what matters in reality, though, is what actually *happens*. Perhaps the

thorniest barrier to overcome in addressing wicked problems in health care today is this: the voices that most need to be heard are likely to be those least likely to speak—clinicians, patients, family members, and staff who occupy the lowest rungs on the “authority gradient” ladder.

Nowhere is this more clear than in the nationwide effort to improve quality and patient safety in health care systems. Consider one of the central concerns of the patient safety movement: preventing medical errors. When a medical mistake is in the process of unfolding, its primary chance for prevention rests in the empowered voices of vigilant clinicians, staff, patients, and family members. The knowledge that can prevent the next fatal error may belong to an elderly mother sitting at the bedside of her adult child, to a newly hired nutritional aide who speaks halting English, or to a 7-year-old patient floating in and out of consciousness. These individuals will remain silent, however, if they are not shown that that they will be listened to and taken seriously and that their observations and insights are welcomed. In our work as consultants to health care systems in Boston and across the country, we are examining the evolution of medical mistakes [21] and designing educational interventions that help clinicians intervene compassionately and promptly with patients and families as soon as an error occurs in a manner that is transparent, respectful, and mindful of the need to rebuild trust in relationships that have been ruptured.

Conclusion

In Shakespeare’s *King Lear*, the protagonist’s tragic lack of insight leads him into one ill-fated encounter after another. Towards the end of the play, Lear meets Gloucester, a blind man, whom he comes to respect for his wisdom and insight into what makes people tick. He asks his new acquaintance to explain how he views the world, and Gloucester responds, “I see it feelingly” [22]. Although the king has perfect eyesight, his vision is restricted and cloudy; Gloucester, by comparison, has lost the use of his eyes, yet his vision is expansive and clear.

If we want to address the moral and ethical components of everyday health care, we will need to expand our vision beyond a narrowly constructed medical lens and adopt a wider and more lucid perspective, one that honors the mind but also encompasses the heart, the spirit, and the relational world in which we *all* live. In order to see the right things and not lose our focus, we will need to learn differently together than we have heretofore. The first step in unraveling many of our wicked “macro” problems will be to discern the “micro” ethics that will help to solve them—things like treating people respectfully, telling the truth, listening to oft-silenced voices, and valuing the knowledge of patients, family members, and health care workers who are lower on the totem pole of power.

We will need to craft educational activities that are cognitively complex, emotionally challenging, and respectful of learners—spaces for learning where, among other things, we risk talking about health care realities we’re not supposed to talk about. Like the blind man in *Lear*, we need to embrace a vision that is brave and holistic,

one that is firmly tethered to the moral and relational events unfolding every day, all around us, all the time.

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MEDICAL EDUCATION 2

Creating Training Opportunities in Pediatric Palliative Care

Laurie Lyckholm, MD, and Kathleen O’Kane Kreutzer, MEd

Pediatric palliative care is inherently challenging. Practical and ethical considerations can be complex and compounded by the denial and grief that accompany the experience of losing a child. Palliative care for children with life-limiting illnesses includes provision of expert pain and symptom assessment and management, appraisal of spiritual and emotional needs, mindful communication between the professional care givers and the child and his or her loved ones regarding advance care planning, and bereavement care for the child’s family [1].

Pediatric palliative care shares many of the concerns of adult palliative care—the principle of proportionality, i.e., the calculation of burdens and benefits of various treatments [2]; the goals of care; and surrogate decision making. In addition to these, pediatric palliative care may involve the role of the child in decision making and the concept of the child as moral agent [3]. The questions of who shares in weighing diagnostic and prognostic information, determining the child’s best interest, and consideration of experimental therapies are complicated and are influenced by social and cultural norms. Legal questions—the status of the “mature minor” and the circumstances under which child protective services should be consulted—may also come into play [4].

Hence, students and residents preparing to care for pediatric palliative care patients must receive proper training in the pertinent ethical and legal issues. The values and goals of care for the child and family must be explored continually and re-established and redefined as the child’s disease progresses or its trajectory changes. Communication about end-of-life decisions is imperative, and much of what is considered “ethical” content is based in the substance and manner of this communication [3, 5]. In this paper we discuss challenges in and approaches to providing training in ethics and communication relevant to the care of pediatric patients who need palliative care.

The Need for Training in Pediatric Palliative Care

In 2006 (the most recent data available), just over 53,000 children died between birth and age 19. (In the same year, 2,400,000 persons over the age of 19 died [6].) Among the most common causes of death in younger children (0-4) were developmental and genetic conditions present at birth, sudden infant death syndrome (SIDS), and cancer. Children over 5 were most likely to die from accidents (unintentional injuries) and cancer. After puberty, the chance of death by homicide or suicide increased [7].

According to the U.S. Department of Health and Human Services, 13 percent of children ages 0-17 (10.2 million children) have special needs [8]. While the majority of those children do not need palliative or hospice care, a sizeable portion do. To our knowledge, the number of children eligible for palliative or hospice care has not been quantified, but 24 percent of those counted as having special needs have conditions that significantly affect their activities, and, as a whole, such children have a death rate twice that of an age-matched unaffected population [9].

Children with multiple complex chronic conditions (CCC) have been shown to have a lower risk of rapid death than children with no or just one CCC, with longer hospitalization and periods of mechanical ventilation, and thus more opportunity for supportive care services [5, 10].

Pediatric Palliative Care Education

The literature about pediatric palliative care suggests that neither pediatric residents nor their program directors feel that residents are adequately trained or prepared to care for children with life-limiting illnesses. In a survey of U.S. pediatric residency program directors and residents, 78.1 percent of program directors agreed that palliative care as a whole is important, and 99 percent of residents felt that it was important to provide pain and symptom management as well as psychosocial support [11]. Yet only 38.2 percent of program directors felt that their graduating residents were competent in pediatric palliative care, and 70 percent of residents felt that training in ethical issues in pediatric end of life care was inadequate or worse.

A second survey of 80 pediatrics residents at a major university medical center indicated low rates of exposure to dying children, and less than 50 percent of respondents reported that they had been taught how to hold discussions about withdrawal or limitation of life-sustaining therapy or autopsy, how to declare death or complete a death certificate, or how to provide follow-up support to families [12].

A third study asked 77 pediatrics residents in another major university medical center to rate their training, experience, knowledge, competence, and comfort in 10 different palliative care domains [12]. No mean response in any domain achieved even a moderate level of training, education, knowledge, comfort, or competence. All mean responses were within the range of “none” to “minimal,” and there were no statistically significant improvements associated with more years spent in residency [13].

A 2008 study of nearly 200 nurses’ and physicians’ perceived barriers to pediatric palliative care found that the factors most commonly perceived as interfering with optimal pediatric end-of-life care involved uncertainties in prognosis and discrepancies in treatment goals between staff members and family members; following these factors on the list were barriers to communication [14]. In addition, a qualitative study examining interviews of an interdisciplinary group of 17 pediatric

health care professionals identified lack of formal and informal preparation in pediatric palliative care as a major problem [15].

Training Opportunities

Available data on the number of pediatric hospice and palliative care programs is not robust, but there are some indications that such programs are increasing in number. In a 2005 survey of 232 Children's Oncology Group member institutions, 58 percent of the responding institutions (including international) had a palliative care team, and 65 percent had hospice available [16].

Given those statistics, specific opportunities for pediatric residents to be involved in the care of children with life-limiting illnesses are not extensive, and those for medical students are even fewer. Despite this, physicians who will care for children at the end of life and for the families of those children must, at a minimum, learn pain and symptom management, spiritual and psychosocial assessment and care of patients and their families, interpersonal communication about goals of care, and decision making in the pediatric care context. When a medical student or resident is assigned to a patient with a life-limiting illness, thoughtful mentoring and debriefing directed toward the ethical issues that unfold in the course of caring for that patient can enhance the educational process. Designing methods that enable all students and residents to learn from every available teaching case in the environment helps maximize learning for trainees as well as for clinical teaching faculty. Because opportunities for personal experience with pediatric palliative care are limited, medical educators must not only make the most of those that *do* occur, but also provide alternative means for students and residents to consider the many aspects of care for dying children and practice the skills they need to provide expert care to the patients and their families.

Ethics Education in Pediatric Palliative Care

The principal ethical paradigms for pediatric palliative care center on the patient's role in decision making. The concept that children have moral agency was first advanced by Franco Carnevale [3], who suggested that children are moral agents themselves and not simply derivatives of their parents and other adult family members. The implications of Carnevale's now widely accepted hypothesis can evoke great distress. Consider the case of a 14-year-old boy who developed a malignant tumor in his left arm. Although he knew that his best chance at a cure would be with amputation followed by chemotherapy and radiation, the boy could not bear the thought of an amputation and refused the surgery. His parents were devastated but supported his decision, which, understandably, raised concerns about the degree to which children should be allowed to make their own medical decisions. The 14-year-old's age-appropriate moral reasoning centered on the present and what he valued most—his body image, ability to play baseball and other sports, and looking like other children. This case has been used as a teaching case with first- and second-year medical students to prompt them to consider the idea of decision making by children and the maturity-related continuum of pediatric patients'

participation in decision making from “assent” (to treatment decisions made by others) to full consent or refusal of their own.

Case studies. Ideally, medical students’ experiences during rotation through their pediatrics clerkships would include care of a child with a life-limiting illness, but not all will have that opportunity. In the real world, their learning about pediatric palliative care may be limited to discussion of case studies facilitated by residents and faculty. Examples that present and resolve ethical dilemmas can be an effective way to practice ethical decision making while, at the same time, introducing specific clinical content areas in which direct patient care experience may be difficult to come by [17, 18]. The use of the 14-year-old’s refusal of amputation, for example, asks students to consider both the clinical facts of the case with its prognosis and treatment recommendations, and moral agency, parental autonomy, contextual elements of decision making, and the concept of the “mature minor.”

Case studies are an engaging way to teach and apply principles of medical ethics in a clinical context in the first and second years. In the third and fourth years, in most curricula, students encounter real patients and their families facing ethical dilemmas, and the issues become more compelling.

Experiential learning. Encountering patients and their families in difficult situations creates a rich “relational learning” opportunity that differs greatly from the information-based learning of the early medical school years and requires students to grapple with ambiguous questions for which there may be no “right” answer [19]. Supporting students in this new and complex process is a challenging responsibility for residents and clinical teachers. Using the students’ own experiences, in their own words, as the starting point for a discussion of ethical considerations can reveal much beyond the medical knowledge they possess [20, 21]. Information about the learning environment, cultural issues, and the student’s skills related to medical professionalism and empathy may emerge and become a more explicit part of the educational interaction. The experiential education that occurs when a student or resident takes part in the care of a patient, particularly when the patient is a child with a life-limiting illness, can be transforming. As the student or resident journeys with the patient and family, navigating treatment and other decisions, he or she gains new appreciation and understanding that is invaluable to the clinical and professional development of the trainee.

Conclusion

Provision of palliative care to children with life-limiting illnesses requires the knowledge and skills for addressing the primary ethical principles of providing evidence-based, skilled medical care and shared decision making. Caregivers must also respect autonomy, deal honestly with the child and family, provide useful information, carefully and thoroughly weigh harms and benefits, and deliver care that is just, fair, and based on the needs of each child.

Ethics education in pediatric palliative care should center on the clinical aspects of care, whether it be through guided case studies or the experience of looking after a child in palliative care. Both approaches are valuable. Because there are, fortunately, a limited number of such cases, we must seize every opportunity for students and trainees to participate, when they can, in caring for these children and their families and, when they cannot, to learn from the experiences of those who have.

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THE CODE SAYS

The AMA *Code of Medical Ethics* Opinions on Seriously Ill Newborns and Do-Not-Resuscitate Orders

Opinion 2.215 Treatment Decisions for Seriously Ill Newborns

The primary consideration for decisions regarding life-sustaining treatment for seriously ill newborns should be what is best for the newborn. Factors that should be weighed are (1) the chance that therapy will succeed, (2) the risks involved with treatment and nontreatment, (3) the degree to which the therapy, if successful, will extend life, (4) the pain and discomfort associated with the therapy, and (5) the anticipated quality of life for the newborn with and without treatment.

Care must be taken to evaluate the newborn's expected quality of life from the child's perspective. Life-sustaining treatment may be withheld or withdrawn from a newborn when the pain and suffering expected to be endured by the child will overwhelm any potential for joy during his or her life. When an infant suffers extreme neurological damage, and is consequently not capable of experiencing either suffering or joy, a decision may be made to withhold or withdraw life-sustaining treatment. When life-sustaining treatment is withheld or withdrawn, comfort care must not be discontinued.

When an infant's prognosis is largely uncertain, as is often the case with extremely premature newborns, all life-sustaining and life-enhancing treatment should be initiated. Decisions about life-sustaining treatment should be made once the prognosis becomes more certain. It is not necessary to attain absolute or near absolute prognostic certainty before life-sustaining treatment is withdrawn, since this goal is often unattainable and risks unnecessarily prolonging the infant's suffering.

Physicians must provide full information to parents of seriously ill newborns regarding the nature of treatments, therapeutic options, and expected prognosis with and without therapy, so that parents can make informed decisions for their children about life-sustaining treatment. Counseling services and an opportunity to talk with persons who have had to make similar decisions should be available to parents. Ethics committees or infant review committees should also be utilized to facilitate parental decision making. These committees should help mediate resolutions of conflicts that may arise among parents, physicians, and others involved in the care of the infant. These committees should also be responsible for referring cases to the appropriate public agencies when it is concluded that the parents' decision is not a decision that could reasonably be judged to be in the best interests of the infant.

Based on the report “[Treatment Decisions for Seriously Ill Newborns](#),” adopted June 1992.

Opinion 2.22 Do-Not-Resuscitate Orders

When a patient suffers cardiac or respiratory arrest, attempts should be made to resuscitate the patient, except when cardiopulmonary resuscitation (CPR) is not in accord with the patient’s expressed desires or is clinically inappropriate.

All patients should be encouraged to express in advance their preferences regarding the extent of treatment after cardiopulmonary arrest, especially patients at substantial risk of such an event. During discussions regarding patients’ preferences, physicians should include a description of the procedures encompassed by CPR. Patients’ preferences should be documented as early as possible and should be revisited and revised as appropriate.

Advance directives stating patients’ refusals of CPR should be honored whether patients are in or out of hospital. When patients refuse CPR, physicians should not permit their personal value judgments to obstruct implementation of the refusals.

If a patient lacks the ability to make or cannot communicate a decision regarding the use of CPR, a surrogate decision maker may make a decision based upon the previously expressed preferences of the patient. If such preferences are unknown, decisions should be made in accordance with the patient’s best interests. If no surrogate decision maker is available, an attending physician contemplating a "Do Not Resuscitate" order (DNR) should consult another physician or a hospital ethics committee, if one is available.

If a patient (either directly or through an advance directive) or the patient’s surrogate requests resuscitation that the physician determines would not be medically effective, the physician should seek to resolve the conflict through a fair decision-making process, when time permits. In hospitals and other health care organizations, medical staffs or, in their absence, medical directors should adopt and disseminate policies regarding the form and function of DNR orders and a process for resolving conflicts.

DNR orders, as well as the basis for their implementation, should be entered by the attending physician in the patient’s medical record.

DNR orders and a patient’s advance refusal of CPR preclude only resuscitative efforts after cardiopulmonary arrest and should not influence other medically appropriate interventions, such as pharmacologic circulatory support and antibiotics, unless they also are specifically refused.

Based on the report “[Universal Out-of-Hospital DNR Systems](#),” adopted June 2005.

Opinion 2.225 Optimal Use of Orders-Not-to-Intervene and Advance Directives

More rigorous efforts in advance care planning are required in order to tailor end-of-life care to the preferences of patients so that they can experience a satisfactory last chapter in their lives. There is need for better availability and tracking of advance directives, and more uniform adoption of form documents that can be honored in all states of the United States. The discouraging evidence of inadequate end-of-life decision-making indicates the necessity of several improvement strategies:

- (1) Patients and physicians should make use of advisory as well as statutory documents. Advisory documents aim to accurately represent a patient's wishes and are legally binding under law. Statutory documents give physicians immunity from malpractice for following a patient's wishes. If a form is not available that combines the two, an advisory document should be appended to the state statutory form.
- (2) Advisory documents should be based on validated worksheets, thus ensuring reasonable confidence that preferences for end-of-life treatment can be fairly and effectively elicited and recorded, and that they are applicable to medical decisions.
- (3) Physicians should directly discuss the patient's preferences with the patient and the patient's proxy. These discussions should be held ahead of time wherever possible. The key steps of structuring a core discussion and of signing and recording the document in the medical record should not be delegated to a junior member of the health care team.
- (4) Central repositories should be established so that completed advisory documents, state statutory documents, identification of a proxy, and identification of the primary physician can be obtained efficiently in emergency and urgent circumstances as well as routinely.
- (5) Health care facilities should honor, and physicians use, a range of orders on the Doctor's Order Sheet to indicate patient wishes regarding avoidable treatments that might otherwise be given on an emergency basis or by a covering physician with less knowledge of the patient's wishes. Treatment avoidance orders might include, along with a Do Not Resuscitate (DNR) order, some of the following: Full Comfort Care Only (FCCO); Do Not Intubate (DNI); Do Not Defibrillate (DND); Do Not Leave Home (DNLH); Do Not Transfer (DNTransfer); No Intravenous Lines (NIL); No Blood Draws (NBD); No Feeding Tube (NFT); No Vital Signs (NVS); and so forth. One common new order, Do Not Treat (DNT), is specifically not included in this list, since it may unintentionally convey the message that no care should be given and the patient may lose the intense attention due to a dying person; FCCO serves the same purpose without the likely misinterpretation. As with DNR orders, these treatment avoidance orders should be revisited periodically to ensure their continued applicability. Active comfort care orders might include Allow Visitors Extended Hours (AVEH) and Inquire About Comfort (IAC) b.i.d. (twice daily).

Report: Issued June 1998 based on the report “Optimal Use of Orders-not-to-Intervene and Advance Directives,” adopted June 1997.

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CLINICAL PEARL

Artificial Hydration in Pediatric End-of-Life Care

Anne Keeler, RD, MEd, CSP

As recently as 100 years ago, prior to the widespread use of life-extending medical technology, death occurred at home. The dying person gradually stopped eating and drinking, coma soon followed, and death occurred from the underlying illness.

This was an accepted practice at the time, but today there is some controversy about the withholding of medical nutrition and hydration at the end of life. While the dying person admitted to an acute care setting at the end of life is likely to receive medically provided fluids, the person in palliative care generally does not [1]. Health care professionals (including pediatric specialists), caregivers, and patients differ in their views about providing or withholding medical hydration at the end of life [1, 2]. Families and caregivers often want to hydrate patients, partly because of some commonly held assumptions about its medical benefits and harm prevention.

Dehydration is uncomfortable and withholding hydration increases suffering. Palliative care professionals overwhelmingly report that dehydration at the end of life results in a peaceful, comfortable death. This seemingly counterintuitive phenomenon may be explained by the differences between the type of dehydration experienced by the person dying of an underlying illness and the other types of dehydration, as well as the beneficial physiologic sequelae of dehydration and the lack of caloric intake that often accompanies dehydration in this setting. Both hyponatremic dehydration—which can be caused when a person who has rapidly lost both sodium and water (e.g., from vomiting or endurance athletics) rehydrates only with water—and hypernatremic dehydration—which can be caused, among other things, by evaporative loss from large burn injuries—can lead to headache, abdominal cramps, nausea, and vomiting [3-7].

Most people are familiar with only with these types of dehydration. Isotonic dehydration (also called terminal dehydration), on the other hand, refers to the gradual, concomitant loss of sodium and water that occurs as the dying person decreases intake of food and fluid during the last days of life [4]. Thirst is generally mild. The most common complaint is dry mouth. Symptoms associated with the aforementioned other types of dehydration are generally not reported [8]. The patient eventually becomes dehydrated but is neither hyper- nor hyponatremic.

Isotonic dehydration actually appears to have some benefits. Patients entering terminal dehydration seem to require less pain control than those who receive hydration. Changes in metabolic state may contribute to decreased awareness.

Animal studies suggest that water deprivation results in higher levels of dynorphin, a potent opiate released by the hypothalamus [9]. At the same time, the shift from utilization of glycogen for energy to the breakdown of fatty acids as food intake diminishes results in ketone production. Rat studies suggest that an analgesic effect due to the former is experienced after 24 hours of food deprivation [10]. Observation of fasting humans suggests that ketosis provides an anorexic effect; furthermore, feelings of well-being and euphoria have also been reported by fasting adults [11, 12].

Dehydration causes biochemical abnormalities that cause discomfort. Abnormalities that develop appear to do so whether patients receive hydration or not. Patients terminally ill with abdominal cancer who did not receive hydration at the end of life rarely demonstrated hyponatremia or hyperkalemia [13]. BUN and creatinine increased as the end of life approached regardless of whether the patient received IV hydration [13].

Hydration is medically possible, so it should be provided. Medically provided hydration is viewed in law and ethics as a medical treatment, which means that, like other medical treatments, it can be withheld or withdrawn if it does not provide the desired benefit, or if the treatment creates a “disproportionate burden.” Treatments considered to be palliative, on the other hand, cannot be withdrawn. There is no ethical or legal distinction between withholding artificially provided hydration and withdrawing it after it has begun [14].

Hydration may help with symptom relief. Expectations of hydration therapy’s benefits are frequently exaggerated; though it does have some positive effects, they are very limited. Patients and caregivers (including professionals) often believe that dehydration will cause dry mouth and thirst and that hydration will prevent mental status changes. Prior personal experiences with dehydration reinforce this belief. Hydration, however, does not appear to affect fatigue [15], seems to have less effect on delirium as the end of life approaches, and has no effect on delirium resulting from organ dysfunction [16].

Dry mouth and thirst are the most common symptoms reported by dying patients who do not receive hydration, but dry mouth is not relieved with hydration [17]. Good mouth care is more beneficial in relieving dry mouth than hydration [18]. Thirst seems to be a nonspecific indicator of fluid status in the terminally ill and can be affected by other factors such as medications, sequelae of treatment, mouth breathing, and stomatitis [19].

That is not to say hydration therapy is without benefit. It was shown to reduce hallucinations, myoclonus, and sedation in a group of terminally ill cancer patients [15]. Opioid-induced neurotoxicity, a constellation of symptoms including sedation, mental status changes, and myoclonus caused by the accumulation of products of opioid metabolism, may be reversible with hydration, although data are not conclusive [20].

Burdens of Treatment

Not only is hydration often much less beneficial than assumed, but, in fact, it can bring about unwanted effects. Hydration may result in a variety of symptoms related to fluid retention, including peripheral edema, increased ascites, and pleural effusion [19]. Other reported symptoms and side effects include increased respiratory secretions, congestive heart failure, and increased gastric secretions resulting in nausea and vomiting [7, 8, 20]. Hypoalbuminemia from overhydration, which has been associated with IV hydration [13], disrupts oncotic pressure, which promotes peripheral edema. Other burdens of hydration therapy include lack of mobility, possible need for restraints, increased potential for bedwetting, need for changing or use of catheters, pain at insertion site, and barriers to physical closeness.

These unwanted effects of hydration may stem from the volume of fluid provided. Some studies have demonstrated that adequate hydration for terminally ill adult cancer patients can be achieved with lower fluid volumes than would be expected for medical or surgical patients [6]. Possible explanations include changes in body composition, weight loss, decreased insensible losses, and decreased renal function, factors which are also associated with aging and may not be applicable to children.

The Social Context

Though families may understand and respond to discussion of the benefits and drawbacks of hydration as a medical treatment, the emotional significance of withholding hydration is more difficult to overcome. The offering of food and beverages is universally experienced and recognized as a sign of love and caring. Feeding one's child is an essential part of parenthood. Ellyn Satter suggests that, in the ideal feeding relationship, the parent provides foods that are nutritious and easily managed by the child, and the child eats what he or she wants. When feeding does not go well, the parent's perception of his or her effectiveness as a parent suffers [21]. Refusal of food and fluids may be perceived as rejection of the caregiver and takes away a significant way for the caregiver to show love and support. For the parent of a dying child, this emotional distress is compounded as declining intake indicates that the disease is progressing to the end of life. Often caregivers will suggest that a child "would get better if he would just eat."

Determining Appropriate Treatment

Decision making for treatment must balance these understandable emotional responses and the child's and family's goals with the medical reality of the child's condition [22, 23]. The health care professional must weigh the risks and benefits of reasonable treatment with the comfort and interest of the child as the major consideration [23]. Consultation with the family's spiritual provider should also be sought, inasmuch as faiths differ greatly in their recommendations for the use of hydration at the end of life. But first and foremost, the child who can ask for fluids and who can safely consume them should have fluids offered. Often the small amount of fluid that is consumed by mouth is adequate to promote symptom relief.

The subjects of research regarding hydration status in the terminally ill are older cancer patients, and care must be taken when extrapolating these results to the pediatric patient. Children are at higher risk for fluid deficits due to increased total body water and insensible losses and generally have more intact renal function than older adults. The thirst mechanism in response to hydration status is more intact in the pediatric patient than in the older adult.

Current evidence suggests that hydration does not improve overall quality of life in patients within days to weeks of death, but may be some benefit for those patients with longer life expectancy [16]. Children and families should be informed that the gradual decrease in oral intake is a natural part of the dying process. If hydration is considered at the end of life, physical exam should focus on signs of fluid deficit, determination of etiology, and assessment of the effects of these symptoms on quality of life. Therapy decisions must be individualized, with patient comfort as the primary goal. Discussion with the child and family should center on realistic expectations for therapy. Health care professionals who are involved in the discussion of this topic and subsequent care of the child should come to a consensus as a team prior to presenting options to the family; open dissent among team members is distressing to patients and families.

Families should be informed that hydration may help to ameliorate some neurologic symptoms including delirium, mental status changes, and opioid-induced neurotoxicity [19]. Hydration is not likely to improve symptoms of dry mouth or thirst, however, but these symptoms can be easily managed with other measures, such as good mouth care and small sips of fluids. The burdens of hydration therapy should also be discussed.

A time-limited trial of intravenous hydration with clear definitions of the goals of treatment, length of trial including specific beginning and ending dates, and criteria for withdrawing treatment is useful to evaluate the potential benefit of initiating hydration therapy [22]. Lower volumes of hydration are associated with fewer deleterious effects; initiation at 50-75 percent of maintenance is an appropriate starting point with careful evaluation of subsequent fluid status and effect on distressing symptoms. Only if the goals of treatment have been met at the re-evaluation date should treatment continue [22].

Children and families should be informed that hydration can be withdrawn or withheld if desired, or if no benefit is observed, and be assured that the child will continue to receive appropriate care and management of symptoms whether hydration is continued or discontinued. Regardless of the decision made, families should receive support, including the suggestion of alternate ways for them to care for the child and assurance that all measures that could provide comfort have been attempted.

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HEALTH LAW

Legal Restrictions on Decision Making for Children with Life-Threatening Illnesses—CAPTA and the Ashley Treatment

Paula Tironi, JD, LLM, and Monique M. Karaganis, MD

The purpose of palliative care is to provide comfort rather than cure an illness or prolong life [1]. Palliative care can be delivered in a number of clinical circumstances. Patients with life-threatening illnesses can receive palliative care at the same time they are undergoing medical treatments intended to cure the disease. In other cases, palliative measures enhance the quality of life of patients with incurable medical conditions that may or may not be life-threatening. And in still other cases, palliative care is the only type of treatment provided to patients with life-threatening medical conditions when treating the condition is deemed futile or inhumane.

Parental preference for palliative care is often honored when the benefits of continued treatment are uncertain and the burdens of medical treatments and the illnesses themselves seem great [2]. Nevertheless, physicians, parents, and other decision makers who are considering palliative measures rather than aggressive treatment or resuscitation on behalf of pediatric patients should be aware of federal and state statutory and case law that may restrict such decision making.

Two important examples of legal restrictions on decisions involving pediatric palliative care are the federal Child Abuse Prevention and Treatment Act of 1996 (CAPTA) [3] and Constitutional and case law restrictions on sterilization surgery such as the Ashley Treatment in disabled children.

Palliative Care for Infants under CAPTA

Most states have adopted the federal government requirements for states that receive grants under CAPTA [4]. To be eligible to receive the grants, a state's child protective services must have and exercise the authority to initiate legal proceedings to prevent medical neglect—which may include withholding of medically indicated treatment from disabled infants with life-threatening conditions—and to provide medical care or treatment for a child when necessary to prevent or remedy serious harm to the child.

Under CAPTA, failing to provide appropriate nutrition, hydration, and medication to any infant with a life-threatening condition always constitutes “withholding of medically indicated treatment.” The same holds true for failing to provide such an infant with a treatment that, in the physician's reasonable medical judgment, is most

likely to ameliorate or correct the condition, *unless* at least one of the following exceptions applies:

- A. The infant is chronically and irreversibly comatose;
- B. The provision of such treatment would
 1. merely prolong dying;
 2. not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or
 3. otherwise be futile in terms of the survival of the infant; or
- C. The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. [3]

Several court cases have applied CAPTA restrictions to medical neglect.

Montalvo v. Borkovec

In the Wisconsin case of *Montalvo v. Borkovec* [5], the court held that, due to CAPTA and other legal requirements, the parents of a premature newborn were not entitled to the opportunity to give or withhold their informed consent to resuscitation of the infant.

Emanuel Vila was born prematurely by cesarean section at 23 and 3/7 weeks' gestation and weighed 679 grams. At birth, Emanuel was handed to a neonatologist who successfully performed resuscitation. The baby's parents and guardian *ad litem* sued, alleging violation of informed consent and negligence. The plaintiffs charged that the parents, rather than the physicians, should have decided whether extraordinary measures were to be taken, and that the physicians and hospital were negligent in resuscitating Emanuel without his parents' informed consent. The plaintiffs alleged further that the parents should have been given statistics regarding Emanuel's risk of developing a disability had he lived and the opportunity to withhold life-saving measures immediately after his birth.

The trial court dismissed the lawsuit, and the Wisconsin Court of Appeals affirmed the dismissal. Among other reasons for its decision, the court stated that the parents' informed consent was not sought because, under CAPTA provisions, there was no lawful alternative to resuscitation. Wisconsin receives federal CAPTA funds, so medically indicated treatment could not be withheld from this disabled infant with a life-threatening condition.

In the Matter of AMB, Minor

In the Michigan case titled *In the Matter of AMB, Minor*, [6] the court found that the decision to terminate life support and provide comfort care did not violate CAPTA because the treatment that was being provided to the patient was futile and inhumane.

AMB was born 5 weeks prematurely and had a poor prognosis for long-term survival. Her heart was missing a septum, two of her heart valves were deformed, her

aorta was very small, and the size of her heart had forced her left lung into partial collapse. She had a possible problem with her intestines, as well as hydrocephaly and other brain abnormalities suggesting corpus callosum agenesis.

Physicians administered prostaglandin intravenously to open her ductus arteriosus to help circulate oxygenated blood through her body. She was intubated and placed on a ventilator. AMB was conscious and not sedated.

The baby's mother was allegedly mentally impaired and the putative father was in jail. The child protective services agency sought temporary custody and petitioned family court for a decision regarding AMB's best interests. AMB's neonatologist testified that the baby was experiencing physical distress and that there was no hope of her surviving independent of the life support. The ventilator did not improve the baby's chances for survival because her heart lesions were not compatible with long-term survival, and without the prostaglandins and ventilator she could live for hours, days, or months.

The neonatologist recommended stopping the prostaglandins, removing the ventilator, and providing palliative care such as fluids, heat, warmth, monitoring of heart rate and vital signs, and possibly a feeding tube. The neonatologist believed that medical care was futile because there was no treatment to offer. She thought the medical care being provided was inhumane because it intensified AMB's suffering and failed to solve her health problems. The neonatologist believed further that AMB suffered from the ventilator, the tube in her throat, and the IVs, and partly because they made it difficult to hold AMB and impossible to feed her.

In proceedings that the Court of Appeals characterized as "unredeemably flawed," family court issued what appeared to be an order authorizing the hospital staff to remove life support equipment and medication and provide comfort care. Medical personnel implemented the order 6 days prior to its effective date, and AMB died soon thereafter.

AMB's appointed attorney appealed the family court decision to the Michigan Court of Appeals, which found that, although the CAPTA exception that allows withdrawal of life support had not been satisfied because AMB was not "chronically and irreversibly comatose" (she was, in fact, conscious and not sedated), AMB's case satisfied each of the other CAPTA exceptions. No available treatment would have cured or alleviated her life-threatening heart problems, and maintaining her on a ventilator and providing prostaglandin would only temporarily delay her imminent death. Thus, as the neonatologist had testified, these treatments were futile and inhumane. Therefore, because the child protective services agency's request did not constitute medical neglect as defined under CAPTA, the agency did not violate any CAPTA duty when it requested the family court to determine what would be in the baby's best interests.

The Ashley Treatment: Sterilization of a Disabled Child

At the age of 1 month, Ashley displayed symptoms of hypotonia, feeding difficulties, choreoathetoid movements, and developmental delay. She was eventually diagnosed with “static encephalopathy with marked global developmental deficits” [7]. Ashley could not sit up, walk, or use language. In the opinion of her physicians, her cognitive ability and neurologic function were unlikely to improve significantly.

Ashley’s parents wished to continue caring for her at home, but were concerned that her continued growth would make it difficult for them to attend to her needs. When Ashley was 6 years old and exhibiting early pubertal development, her parents consented to several medical interventions intended to increase her comfort and improve her quality of life: growth attenuation through high-dose estrogen, hysterectomy, and surgical removal of the breast buds [7, 8].

The treatment was widely debated in the legal and ethics communities. The Washington Protection and Advocacy System investigated all those involved in Ashley’s treatment and surgery and released a report finding that, due to a communication breakdown, the hospital had violated state law and Ashley’s constitutional and common law rights by performing the hysterectomy without a court order [8]. The hospital acknowledged that a court order was required under Washington law and entered into an agreement with WPAS to take corrective action to assure that a court order would be obtained for any future sterilization of a child with a developmental disability [8, 9].

Conclusion

While parents often have legal authority to make decisions regarding pediatric palliative care, federal and state statutory and case law imposes significant restrictions on the decision-making authority of parents and physicians. Two important examples of such law involve CAPTA restrictions on medical neglect and the requirement to obtain a court order authorizing the sterilization of a disabled minor.

States receiving CAPTA grants must restrict the withholding of medically indicated treatment from disabled infants with life-threatening conditions unless (1) the infant is chronically and irreversibly comatose; (2) the treatment would merely prolong dying, would not ameliorate or correct all of the infant's life-threatening conditions, or would otherwise be futile in terms of the survival of the infant; or (3) the treatment would be virtually futile in terms of the survival of the infant and the treatment itself would be inhumane.

Surgical sterilization of a severely disabled child as a means of palliative care may require court order to protect the child’s constitutional and common law rights.

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POLICY FORUM

Do-Not-Attempt-Resuscitation Orders in Public Schools

Kathryn L. Weise, MD, MA

Patterns of hospital and out-of-hospital medical decision making have evolved as our abilities to diagnose, treat, and palliate illness have improved. Ethical quandaries raised by these changes can impact not only those directly involved with decision making, but also the myriad people and systems indirectly affected by the individual health care choices of others. Pediatric patients receiving palliative care may still be well enough to benefit from attending school, and may at the same time have a do-not-attempt-resuscitation (DNAR) order in place. A parent's request to honor such an order in the public school setting is an example of a situation in which personal and individual parental decisions create ethically sensitive repercussions for others, including teachers, school nurses, classmates, administrators, school systems, local governments, and the legal system.

During a study published in 2005, Kimberly et al. [1] determined that, in a sample of 81 school districts in the United States, relatively few (20 percent) reported having a policy, rule, or procedure explicitly regarding the honoring of DNAR orders for students with life-shortening medical conditions. Of these districts, 63 percent prohibited school personnel from honoring DNAR orders, and in the remainder school personnel were allowed to honor the orders, but many respondents reported that they would not. The authors learned that potentially confounding discrepancies existed between state laws and school board policies and that certain states did not allow advance health care decisions for minors in spite of having legalized out-of-hospital DNAR orders for adults. The authors concluded that policies should exist to allow DNAR orders for particular children in public schools when parents and physicians have agreed that attempting resuscitation is not in the child's best interest. To give ethical support for their conclusion, they drew upon respect for autonomy, beneficence, and nonmaleficence and discussed possible safety and legal repercussions.

This was not the first study or analysis of ethical issues relating to DNAR in public schools, but it was a target article circulated by the *American Journal of Bioethics* for commentary. This format allowed immediate expansion of the discussion from a variety of viewpoints, including those of physicians, a school nurse who later entered the field of ethics, legal scholars, and philosophers. Some commentators appeared to have had direct experience in the care of children in hospital or school settings. Unfortunately, the viewpoint of a parent who had had direct experience requesting (or deciding against) withholding resuscitation in the school setting was not represented, although it is likely that several commentators had experience

discussing such issues with families in a palliative care, intensive care, or ethics consultant relationship.

Arguments against policies that support DNAR orders in public school settings mentioned the need to protect vulnerable children from discrimination based on disability [2, 3], practical issues of comprehension and implementation [4, 5], possible traumatic experiences for nonmedical school personnel and classmates who might be asked to stand by and do nothing, and the potential that policies might create legal constraints that would prevent individualization of a student's health care in the school setting [6]. Authors rightly pointed out that chronically ill children are at risk of being unfairly treated if disabling conditions that may eventually be life-shortening are conflated with imminently terminal conditions; that even medical specialists have difficulty determining when and in what forms resuscitation should be attempted, leaving nonmedical school personnel in the even more vulnerable situation of making medical decisions for which they are not trained; that in this society "doing nothing" traumatizes onlookers because it feels like abandonment of a patient; and that schools already have legal mandates to ensure best practice for providing instruction to children with special health care needs, making additional guidance less necessary and potentially constraining.

Other authors put forward a variety of arguments in support of the concept that allowing DNAR orders to stand in the public school setting is ethically defensible. Some argued that avoiding resuscitation efforts that would not be in the best interest of the child (by parents' assessment) would honor carefully considered goals of care and accord with medical or nonmedical caregivers' duties and obligations to treat a child kindly and not to harm [7-9]. These frameworks place decision making about end-of-life issues in the hands of those seen as having the most personal and accurate viewpoint from which to make plans for an individual child, rather than leaving decisions about the aggressiveness of interventions to others who not are experiencing the child's life as closely.

Some recognized that a principle-driven framework would not cover all possible ethical concerns. For instance, there was debate over which should carry more weight—respect for autonomy (whose—parents' or that of school staff present at the time of an arrest?) or best interest assessments (by whom—parents, child, or again, school staff?). One commentator pointed out that the language used to describe the issue commonly frames forgoing the act of resuscitation in absolute and negative terms ("do not" or "do nothing") rather than describing what would happen instead—providing care focused on comfort at the end of life as an alternative to aggressive interventions that carry no likelihood of achieving an agreed upon end-of-life goal [10].

Other commentators informed us that, in practice, professional societies including the National Association of School Nurses and the American Academy of Pediatrics have supported the use of DNAR orders in the school setting since publishing statements in 2000 [8, 11] recognizing that care does need to be individualized and

designed by those who know the child and the capabilities of the personnel in the school environment. In this vein, an effective plan should include role recognition, communication of goals and processes, and re-evaluation of the plan over time [8, 11, 12]. Honoring compassionately crafted goals of care at the end of an individual's life outweighed potential objections to acceptance of honoring DNAR in schools. Furthermore, it is rare for a child with a DNAR to die at school.

Since the publication of Kimberly's survey, there have been no further studies that tell us whether school policies have changed. One survey asked pediatricians whether they would respect, recommend, or request a DNAR order for a child of their own in four settings, one of which was school. When presented a scenario of a 15-year-old boy with cystic fibrosis who, with family agreement, wanted no resuscitation and wanted to stay in school as long as possible, the vast majority of pediatricians reported that they *would* respect (92 percent), recommend (85 percent), or request a DNAR order for that child [13]. One commentator on the Kimberly study stressed the need for pediatricians to understand their own roles, responsibilities, and leadership in advocating for families and children to ensure that end-of-life decisions are honored [14].

So where does this leave us? The field of palliative care has become a well-accepted and often expected element of pediatric care for children with potentially life-shortening as well as imminently life-ending conditions. Out-of-hospital school experiences can be enriching to children, even near the end of life, by helping them avoid loneliness and isolation, and by offering much-needed reminders of things shared in common with peers, even when illness creates differences. It is unlikely that parents or medical caregivers would willingly or knowingly allow a child to go to school during what is thought to be the last several days of life, and this would not even be feasible during end-of-life care of most children. We are talking about an anticipated decline or death occurring at an unanticipated time, in a school setting before the arrival of trained medical personnel.

Use of bystander out-of-hospital CPR—known to be minimally effective in the best of circumstances—could rarely be seen to be in the best interest of a child whose intimates have decided that it would not be. While there may be legitimate legal, social, and practical deterrents to a blanket statement endorsing DNAR in the public school setting, we should be able to find it in ourselves as a society to allow individual decisions that stem the tide of doing something—resuscitation—just because we can, when it is against well-considered goals of care.

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MEDICINE AND SOCIETY

Trusting Them With the Truth—Disclosure and the Good Death for Children with Terminal Illness

Hannah L. Kushnick

Discussing a child's imminent death with him or her is a terribly painful idea. Ronald Dworkin has written that there is something we feel to be particularly tragic about the "waste of life" involved in the death of a child:

The death of an adolescent girl is worse than the death of an infant girl because the adolescent's death frustrates the investments she and others have already made in her life—the ambitions and expectations she constructed, the plans and projects she made, the love and interest and emotional involvement she formed for and with others, and they for and with her [1].

This understandable feeling that a child's death is a waste naturally deters us from considering how to make it as "good" as it can be—the idea that it could be positive at all is more than distasteful.

Other emotions, desires, and circumstances give justifiable pause: the desire to spare the child pain and avoid impairing the quality of what life remain, the parents' own grief, the uncertain prognoses and mixed goals [2] that differentiate pediatric care from that of adults, and lack of knowledge about what children know and understand. Also, as Lawrence Wolfe, MD, says, "death" is "a word that, in our society, can be synonymous with evil, contamination, and darkness," and it is instinctual to want to protect one's child from these horrors [3]. In many cultures (one article describes that of China), it is highly taboo to speak openly of a patient's terminal status in his or her presence (but there are implied, customary ways of acknowledging the imminent death) [4]. A Western version of this idea manifests itself in the concern that informing the child will cause him or her to "stop fighting" for life. In America's culture of by-the-bootstraps self-determination, belief in the power of positive thinking—and its implied corollary, the infectious danger of "negativity"—is a cultural force to be reckoned with.

On the surface it may seem that young children's understanding of death is so limited that talking to them about it might only confuse, or worse, pain them, but evidence appears to suggest (Kreicbergs et al. cite two [5, 6]) that it is beneficial for the family to talk openly about the child's approaching death. It is important to do this, in a developmentally appropriate way, to allow the child the possibility of—as disturbing and even offensive as this may seem when first applied to children—a "good death."

Does Talking about Death Help?

One much-referenced study examines this idea through the experiences of the parents of children who died of cancer. Kreicbergs et al. surveyed the parents of Swedish children who had died of terminal cancer between 1992 and 1997 and found that those who discussed the child's imminent death had a much less complicated bereavement process and less regret than those who did not [7]. More specifically, 27 percent of those who did not talk about death with their child regretted that choice. Among parents who sensed their child was aware of his or her impending death and did not talk about it, nearly half regretted not having done so (a much higher incidence of regret than reported among parents who did *not* sense that awareness and did not talk about death.) None of the parents who talked with their child about death experienced regret about having done so. The authors point out that eligible parents who declined to participate in the survey may have regretted talking about death, though no evidence points in that direction. These results from parents who, we presume, have some grasp of their child's emotional "best interest" imply that if the child knows or suspects he or she is going to die it is more important to acknowledge it than it is in cases where the child does not know or suspect.

But are dying children aware of their condition? Little is known about the kids' experiences; widespread reluctance to conduct research on children in general and (understandably) children with terminal illnesses in particular has hampered further study. The limited research available indicates that in many cases, they do. It is believed that the experience of a terminal illness hastens emotional and cognitive maturation [8]. And, of course, an observant child gleans information from caregivers' and relatives' behavior, medical treatments, and other patients, but, as Barbara Sourkes puts it, the primary source "is the 'wisdom of the body': the child's irrefutable recognition of how sick he or she is" [9].

In the face of this irrefutable knowledge, attempts to protect through nondisclosure may be detectable to the child. Surveys [10] have shown that families and patients are sensitive to the trustworthiness of their caregiving team and perceive mixed messages and incongruously positive "spin" as insincere. It is not unreasonable to assume that at least some children have a similar ability to see that their parents or caregivers are sweeping something under the rug; as Kreicbergs et al. put it, telling children the truth may enable "their inner lives...and the outer world...to become congruent, thereby preventing frustration" [11]. (Of course, this doesn't necessarily prescribe a particular method or degree of explicitness. There are less overt ways of acknowledging approaching death, as in the Chinese customs discussed above, that may be effective without being unnecessarily traumatic.)

(How) Will They Understand?

How does one have such a conversation with a child? For the youngest and oldest children, of course, it is easier to determine what is developmentally appropriate, but what of the gray area in between? What do the kids know and what should they know?

In their study of the young children's knowledge of and fear of death [12], Slaughter and Griffiths conclude that talking about death with children (not particularly dying children, but children in general) in biological terms (i.e., what happens to the body) may help alleviate their fear of it [13]—though of course, there is no word on whether it will help them with grief or sadness.

The authors could not determine whether more knowledge of death tends to increase fear (as children realize that death will happen to everyone they know, including themselves) or to decrease it (by helping them understand it as an explicable and natural phenomenon) [14]. But it stands to reason that children who are dying are bound to experience this fear at some point, and informing them stands a chance of decreasing it, in addition to providing them with other benefits, which are discussed below. A low level of prior knowledge about death need not deter the parent from discussing the topic; just because children may not already fully understand the immediate biological causes of death, they are not necessarily incapable of grasping that information—and, more importantly, what they cannot or do not grasp may not be germane to their emotional processing of or coping with their *own* death.

Why Is This Important?

Of course, merely knowing what is cognitively suited to the general population of children of a given age doesn't make breaking bad news to an actual child any easier to figure out or to do. But there are truly important reasons to discuss death with dying children. One less-often discussed reason is keeping kids from being deprived of the opportunity to make their deaths meaningful. For the reasons already mentioned, the “good death” is a possibility that, in Western society, is open to adults, but is rarely extended to children. This need not be the case.

The good death is generally thought to include some combination of choice, dignity, comfort (freedom from pain), preparation for death (saying goodbye, avoiding the unwanted prolonging of life or treatment) and leaving a legacy. As Liben et al. write, the good death is about maintaining hope (not for life, but for meaning, comfort, enjoying what is left of life, and so on) during the dying process. Parents must be careful not to make the mistake of equating acknowledgment of death with robbing the child of hope—even hope for a cure, which, it is becoming known, can coexist with acknowledgment of coming death and may even be an optimal coping mechanism [15]. Loss of hope for extended life in no way impairs hope for a meaningful life and a good death [15, 16]. Children are capable of finding meaning in their deaths [3]—and that meaning tends to have a surprising amount to do with altruism.

In an area of study largely comprising interviews with parents and caregivers, Hinds et al. investigated the priorities of dying pediatric cancer patients themselves, as expressed in recently made end-of-life choices. They interviewed 20 patients between 10 and 20 years old at St. Jude's Children's Research Hospital in Memphis, Tennessee, and Sydney Children's Hospital in Sydney, Australia, who had recently made one of three end-of-life decisions: enrolling in a Phase I trial, putting in place

DNR orders, or discontinuing cure-directed therapy to focus on symptom management only. The children in question were cognizant of their terminal status and participated actively in the decision-making process. The choices were their own. The interviewers questioned the patients about their reasons for choosing as they did. Eighteen of the subjects remembered all the options given; all subjects remembered the options they had chosen and understood that the consequences of the choice were likely to include their own deaths.

Next, the interviewers inquired about what they refer to as the factors patients considered in their decisions, which is to say, what mattered to them.

By far the most reported priorities—mentioned by 19 of the 20 patients—were relational or altruistic in nature, defined by the authors as “decision making affected by caring for others (family, staff, future patients), preferences of others, and the desire to benefit others” [16]. Eleven of those patients (55 percent of the subjects) specifically mentioned wanting to help unknown others (i.e., future patients)—as the authors put it, this “was not anticipated and is not reflected in existing theories of child development” [8]. Further, “several adolescents in [the] study sample referred to their decision as their chance to do something good for someone else; one referred to his decision as his final gift to his parent” [8].

And that’s precisely the point: though a child’s legacy doesn’t generally include the kinds of things we typically think of as legacies, such as leaving behind children of one’s own, making a mark in an industry or profession, or leaving money to people or causes, the leaving of a “medical legacy” by participation in research to benefit future patients, or of a personal legacy is still eminently possible—Wolfe recounts what he calls an unexceptional (which is to say, not uncommon) story of a 9-year-old patient who carefully gave away cherished possessions to friends and family as a way of preparing for death [3]. And, as Hinds et al.’s study shows, kids are strongly motivated by those possibilities—and should be given the chance to act on that.

Conclusion

Parents and caregivers may hesitate about if, when, and how to broach this topic with dying children because of their deep care and respect for the child. But to give dying children the opportunity to have some control over, and make some meaning from, the inevitable is to afford them the utmost respect: telling them the truth and trusting them with it.

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MEDICAL NARRATIVE

Stories from Noah's Children

Kathy Leshner, LCSW, Christi Hancock, David Hancock, and Amy Spangler

Embracing Life Before and After the Death of a Child

Kathy Leshner, LCSW

Follow the stream, have faith in its course. It will go its own way, meandering here, trickling there. It will find the grooves, the cracks, the crevices. Just follow it. Never let it out of your sight. It will take you.
Sheng-yen

These words remind me to slow down and have faith that I will be shown the way. As the social worker for Noah's Children, a pediatric palliative care and hospice program in Richmond, Virginia, I am often asked the question, "How do you do it?" I can't really explain how I do what I do. I have been working with Noah's Children for the last 4-1/2 years, yet it feels like I have been doing this work for much longer. It's not like I learned how to do it in school or from a textbook. I think it's just in my being—as if it was gifted to me somehow. I love the work I do and, as long as I am able to follow the stream, I will continue to give to and receive from amazingly courageous patients and families who face challenges most people cannot conceive of. I walk with them on an arduous journey and am there with them while their child is living and after their child dies.

Another question I am asked is, "Isn't it depressing working with children who will die?" While there are times when I feel sad and times when I am overwhelmed by what I carry, I also experience a great deal of beauty and joy and learn so much from the families I work with. I can walk into a family's home and have my spirits lifted when, along with the sadness and pain, I witness hope, love, and the sense of living completely in the moment because they don't know how much time they have with their child. I meet with parents who initially struggled to come to grips with the fact that their child was born with a life-limiting condition and not expected to live beyond infancy. Now, 3 years later, their child is very much alive, and, while they are aware of the reality of the situation, they are thriving. Or I encounter parents who are incredible advocates for their children and others with special needs and their families. Or perhaps I attend a funeral or memorial service that truly honors and celebrates the life of the child. Knowing that I am able to help a family face the end of a life, while finding hope and embracing the preciousness of life, is far from depressing.

I would like to share a story about a family from Tanzania and give you a glimpse of the journey we have taken together. The language and cultural differences have been a challenge, but along with a compassionate interpreter, our interdisciplinary team has provided support to this family in numerous ways. Their beautiful baby was born with trisomy 18, a chromosome disorder, and the prognosis was poor. The parents were uncertain about bringing their baby home from the hospital and were considering having her placed in a facility; they were not sure they could handle the baby's special medical needs. Several weeks after we talked with them about our services, the parents decided to bring their baby home, and we admitted them into our program. We found out later that the parents feared they would be in legal trouble if their baby died at home. We helped them understand that the family could be together at home when their baby died and it would not be necessary to call the police. We supported them as they made the very difficult decision to sign a DDNR. We were there when their baby died, just a few weeks before she would have turned 3 months old.

Sad? Yes. Painful? Indeed. The mother was on the floor, weeping, moaning. The father kept leaving the room where their daughter's body lay. The baby's 3-year-old sister had fallen asleep, and her 5-year-old brother was running around the apartment in his usual manner, periodically stopping to look at his sister's body. The baby's two oldest sisters cried and drew pictures. They so wanted to hold their sister, but their mother would not allow it because of something that had happened when they lived in Africa: a young woman had held the body of a deceased relative and then was never able to have children. As a grief counselor, I knew that holding the baby would help the girls in their healing process, but I had to let go of that notion; I had to follow the stream.

When the parents were ready, I notified the funeral home. The priest arrived, along with family and friends; prayers were said, songs were sung; and then the mother carried her precious baby out of the apartment, leading the procession down the stairs to the funeral home's van. She laid her tiny little baby on the stretcher. I will never forget the image of the father as he stood by his baby and ever so gently fixed the blanket that covered her so it was just right. Time stood still. He seemed mesmerized as he smoothed the wrinkles in the blanket, tears rolling down his face. Amidst the anguish there was beauty and sacredness and I was honored to be present, to witness, and to quietly support.

A week or so later I received a call from the father. In his limited English, he asked me to pick up the baby's leftover formula to give to other families. When I arrived, I was greeted by the father, the mother, and their 3- and 5-year-old children. There had been concern for the mother because she had a history of postpartum depression, which can be exacerbated by the death of a child. I had always sensed a deep sadness in her and I rarely saw her smile. As we were gathering the many boxes of formula, I found a piece of bubble wrap, the kind with the big bubbles. I showed the 3-year-old how to pop the bubbles. She couldn't do it with her fingers, so I stomped on the bubbles with my foot. She was so little, she couldn't pop them that way either. My

next approach was to jump on the bubbles. This she could do. By this time, her 5-year-old brother was intrigued and came into the room to see what we were doing. The three of us held hands and, moving in a circle on the little piece of bubble wrap, we jumped and jumped and jumped, making a lot of noise and laughing. At one point I looked over at the mother, and she was laughing along with us. Our eyes met, and for the first time I saw a flicker of joy, of hope. The fact that we do not share the same culture or language did not matter at that moment; we connected in a way we had not before.

I have been wondering about the best approach to providing bereavement services to this family, in particular the mother. When I spoke with the interpreter later, she reported, with a smile, that the mother had told her about the bubble wrap. The mother told the interpreter that I was very nice. Somehow, this affirmed my idea to print the photos a volunteer photographer had taken of the family, bring the mother a scrap book and other supplies, and offer her an opportunity to move towards healing through creative expression. We won't need to talk; we can just sit together, remembering her beautiful baby and the preciousness of life. I will follow the stream and its flow...walking on sacred ground.

Kathy Lesher, LCSW, is a social worker at Noah's Children in Richmond, Virginia. She received her MSW from Virginia Commonwealth University. Her background is in the creative arts, and she integrates the arts into her work with children and families. Kathy is a member of NASW (the National Association of Social Workers), ADEC (the Association for Death Education and Counseling), and the Bereavement Coalition of Central Virginia and is on the advisory board of Full Circle Grief Center. She can be reached at Kathy_Lesher@bshsi.org.

Ella's Story **Christi Hancock and David Hancock**

During a routine ultrasound and screening when I was 12 weeks pregnant, we were devastated to find out our baby had trisomy 13. We had never heard of this chromosome disorder, and, as our perinatologist explained its physical ramifications, our hearts broke. It was a sad and scary diagnosis; most babies do not make it to birth. If they do, the life span is very short: minutes to weeks. If you are among the lucky few, your baby might live a year, rarely more. At the time we found the results of the test, we also found out our baby was a girl. It broke our hearts to know our baby girl's body would fail her. As we went through detailed ultrasounds, our perinatologist found the features associated with trisomy 13—a cleft palate and lip and possible kidney, heart, and brain abnormalities. Because few babies with trisomy 13 survive, there is limited information about them, and a precise prognosis could not be given. We prayed and hoped we would meet our baby girl, Ella.

We were blessed that Ella remained strong in utero until 35 weeks gestation, when I went into labor. Her heart rate dropped during labor, but she was a fighter. When we heard her first breath, we were elated that we could hold her and love her and she

would know us, even if just for a few moments. She was such an amazing gift. As her minutes turned into hours and then a day, the doctors and nurses in labor and delivery were impressed by her strength. Fortunately, during Ella's first day of life, our pediatrician recommended that a pediatric palliative care team, Noah's Children, come visit us in the hospital. When they came into our room that day, our lives as a thriving family seemed possible. Our pediatrician wanted us to take Ella home after that visit. The idea of taking her home to be with her big brother and sister and us, with the guidance of palliative care, brought us an indescribable feeling of comfort and hopefulness. It was a turning point; we no longer felt helpless with our precious baby. We did not know how long she would be with us on Earth, but we wanted her life to be as special and comfortable as it could possibly be. Since that first visit from Noah's Children, through Ella's life and death and into the present, we have had the gift of pediatric palliative caregivers to walk with us.

We were so fortunate to bring Ella home the day after she was born. The next day, we had a nurse and a social worker come from Noah's Children and we immediately felt a sense of peace and trust. We felt encouraged by their experience, knowledge, help, and compassion. They held Ella while the nurse, Cathy, examined her. They explained that they were on call for us 24 hours a day for both medical and emotional needs, which was an unbelievable relief. As things became more difficult for Ella, we called Cathy in the middle of the night with some questions. She answered them and encouraged us, but also came to our home to be with us. This was a huge convenience and comfort because Ella often developed breathing problems brought about by being in certain positions.

Two days after we brought her home, Dr. Bob Archuleta, the founder and medical director of Noah's Children, came into our home. In his kind and gentle manner, he educated us on trisomy 13, giving us some possible expectations for Ella's health, comfort, and typical causes of death for children with her disorder. We appreciated his honesty. He also taught us about comfort care and what options were available as problems with Ella's health arose. He guided us with information and compassion. We were always an intimate part of the process and had the final say in decisions regarding her care. Like the rest of his staff, Dr. Archuleta was always patient and made us feel like we were the only family in the program. We were also blessed that Ella's primary pediatrician completely supported the approach we were taking in her care, and he complemented the efforts of Noah's Children. The beginning of our pediatric palliative care relationship, with God's hand, allowed us to let go and live life to the fullest with Ella. We were able to appreciate and enjoy the time we had with her.

Noah's Children's interdisciplinary team meets needs in addition to the medical. Our compassionate and knowledgeable social worker, Kathy, has served as our counselor during Ella's life and after her death. She openly and consistently reached out to us and to our now 4-year-old twins, whose lives have certainly been affected by their sweet baby sister. She counseled us on how to cope with feeling at once so blessed by the amazing gift of Ella and so fearful and filled with sadness. She counseled us

on how to talk about Ella dying, especially to our twins. She gave us books to read to them, suggested art therapy (two of their drawings are below), and most importantly encouraged honest communication.

Kathy has also been an enormous resource in other ways. She arranged for a brilliant professional photographer to come to our home to take pictures of our family at no charge when Ella was 2 weeks old. These pictures completely capture Ella and our family life with her and are an irreplaceable reminder of our cherished memories. Kathy also gently encouraged us to prepare thoughts for a memorial service in an attempt to alleviate some of the distress when Ella passed away. She was completely supportive of how much we did or did not want to do, and we are grateful we had ideas ahead of time. She explained what we should do when Ella died in our home, which made that time as smooth as could possibly be expected. She also did an exceptional job filling a spiritual role as well. Another amazing gift from Noah's Children is the support they continue to provide, 2 years after Ella's death. Kathy has continued to counsel our family, which has contributed monumentally to our strength.

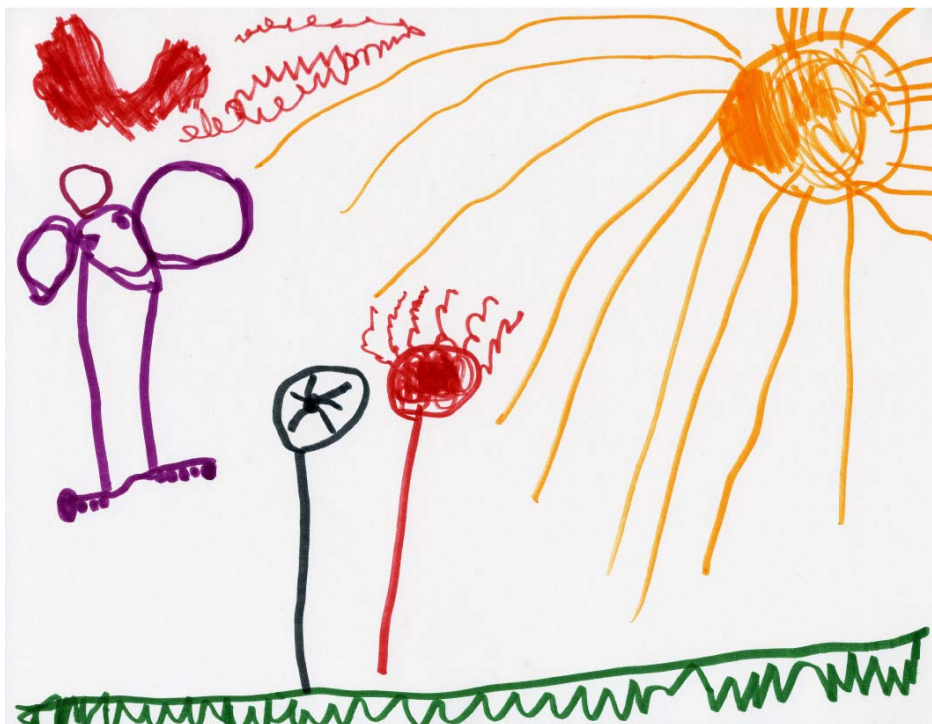
To have a physician, nurse, and social worker in our home who actually knew about trisomy 13 and understood the day-to-day life of babies with the disorder was a matchless gift. They felt, and continue to feel, like family. They have been here just the right amount: as little or as much as we wanted. We believe Ella was the most special gift, and they clearly did as well. They have taken a genuine interest in all of our children. Their emotions paralleled ours, whether it was happiness or sadness, and they were complimentary of our care for Ella, which means so much, considering the limited time we had with her.

We feel blessed that God chose us as Ella's family. We cherish the time we had with her. We could not have remained so positive if Noah's Children was not here to uplift and help us. It was so painful waiting for our child to die, but they allowed us to stay centered and focused on spending time as a family. Because of palliative support, compassion, and knowledge, we were able to just be with Ella and to truly live life with our sweet baby girl. Because of Noah's Children, we were free to develop memories—pink skies, butterflies, and the warm sun on our faces—that keep her close to us.

Christi and David Hancock, from Richmond, Virginia, are the parents of 4-year-old twins, Sierra and Dawson, and baby Ella, who would have been 2 years old this spring. The Hancocks continue to have celebrations of her life on her birthday with family and close friends. The twins continue to talk about their baby sister and draw pictures of her, happy and healthy in heaven.



First drawing, by Sierra: Ella in heaven giving flowers to God next to a rainbow, with the sun and clouds in the sky and a big yellow and green flower. Ella has wings and a halo and is wearing slippers!



Second drawing, by Dawson: Ella in heaven with a big, hot sun, 2 (red) clouds above her, with grass, a black flower, and a red tree below her. Ella has wings and a halo and toes!

Rae's Story

Amy Spangler

As parents we must make many decisions regarding our children—homecare or daycare, public school or private school. Rarely do we think about long-term medical care for our children, until a life-altering illness or accident occurs. For the past 11 years I have had to make medical choices for my son, Rae, and 3 years ago every one of them decided his fate.

Rae was diagnosed with aplastic anemia at age 6, had a stem-cell transplant and right-leg amputation at 10, and was diagnosed with dyskeratosis congenita at 14. On April 17, 2007, we were told he had 3 to 6 months to live. I'll never forget his looking at me on the way home. He said, "They just told me I'm going to die." "Yes," I said, "but we are going to live life to the fullest and take it day by day." It has now been 3 years since his diagnosis.

We entered into Noah's Children, a pediatric palliative care group, in May 2007. We were introduced to our team: Dr. Archuleta; Cathy, the nurse; and Kathy, the social worker. Unfortunately, there are no magical ways to fill your child's last days. As parents, you want to protect them from dangers and harm, especially when you know they will be leaving before you're ready. As parents and patient, you have a lot of questions and want a lot of answers, answers that won't be given. You come to rely on these team members for comfort, reason, and understanding, especially when you have other children. In our 3 years with Noah's, our team has become part of our family. They don't tell us how things should be done; instead, they help us reach our own decisions, and then they support us.

My goal was, and continues to be, for Rae to live life. We have always respected his choices and given him as much control as possible over his medical care. We know our time with him is limited and that there are things we could do to prolong his life with us, but that would be unfair to him. I have always believed that life is about quality—not quantity. We have allowed him to be as active as his body can tolerate. Last summer, he was determined to ride the roller coasters at Busch Gardens. It was all he talked about. We discouraged him, told him that he might not make it off alive. Our team talked with him, but he wasn't going to be deterred. His response was, "At least I'll die doing something I enjoy." So the team and I sat down and discussed all the possibilities and how things would be handled if, in fact, he did not survive the ride. Thankfully, we went, he rode, and he is still here.

In the past year, a lot has changed for us. Rae has started to struggle mentally and physically and has many questions that none of us can answer. Our daily lives revolve around Rae and how he feels. His heart and lungs are shutting down, and the lack of oxygen means he has a hard time processing simple tasks. As parents, we are filled with mixed emotions and sometimes feel guilty for our thoughts. Our team keeps us in check. For the most part, the feelings we experience are *normal* for what is happening in our lives.

I can't imagine where our family would be without our team. They have helped us overcome many obstacles in this journey. They have seen us at our best and worst. They have listened to our frustrations, watched many tears shed, but have always been there with caring, positive words and hugs.

Amy Spangler is the mom of three children—two sons, one who has a terminal illness, and a daughter. She returned to the workforce after 5 years of being the primary caregiver to her children. She is grateful to all those who have contributed to making Rae's life memorable and for all the memories that have been created through their generosity.

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OP-ED

What We Don't Know about How We Decide

Chris Feudtner, MD, PhD, MPH

Introduction

What ethical issues arise in the practice of pediatric palliative care that warrant empirical research? Typically questions about ethics and research involve aspects of protections for human research subjects, as codified in the United States, in the 1974 National Research Act, the 1979 publication of the Belmont Report, and the promulgation of the federal Common Rule, as first expressed in 1991 in the Code of Federal Regulations at entry 45 CFR 46 [1]. Based on these foundations, the three so-called pillars of protections have emerged to guide much of the discussion regarding ethically appropriate research practices: (1) review by a properly constituted ethics review committee or institutional review board; (2) meaningful evaluation of potential harms and potential benefits; and (3) meaningful informed consent. These protections are as important for pediatric palliative care research as they are elsewhere, and a recent article has highlighted some of the challenges that can complicate, and perhaps thwart, pediatric palliative care research in the course of safeguarding these protections [2].

My goal here, however, is to pursue a different set of ethical issues, stemming not from the act of doing pediatric palliative care research, but rather from the challenges of taking care of children with life-threatening diseases and conditions. I believe there are three areas of ethical import in which we could—and should—conduct empirical research to better understand how patients, parents, clinicians, and others grapple with the ethical challenges we confront when caring for these children. These are: how we evaluate the quality of life of others; how having a critically ill child affects others in the family and whether those effects, in turn, influence decision making for the child who is ill; and what form of decision making—shared or otherwise—parents prefer when making decisions for their children.

To make this discussion more tangible, let's imagine the following clinical scenario: a full-term baby was born 10 days ago after a placental abruption and suffered extensive brain injury. After breathing on his own for 5 days, the infant had a prolonged seizure and needed to be reintubated. Head imaging studies showed marked advanced signs of hypoxemic-ischemic encephalopathy. The neurologists are concerned that the child will have severe motor and cognitive impairments, but they still cannot be certain about his prognosis. The clinical team and the parents are questioning whether it is now ethically appropriate to consider palliative care, including the possibility of extubating the infant with a “do not resuscitate” order in

place. Within this vignette are at least three (and probably many more) ethical issues that warrant empirical research.

Whence and Whither Values?

So much depends, in the provision of pediatric palliative care, on value-based judgments regarding quality of life that we would do well to understand the factors that shape an individual's values over time. Yet despite various studies about what people value—say, for example, how individuals rate the value of different health states—we have little understanding of why we value what we value. Beyond the notion that values in general are influenced by society and culture, we do know in the realm of health that people's perception of the quality of life associated with a given set of health problems or impairments such as cerebral palsy or spinal cord injury changes as they gain more information about the day-to-day life of those who have the impairment [3, 4].

These changes in how we evaluate quality of life, which occur with the passage of time and mounting personal experience and knowledge, raise several important issues. First, how do we in health care help patients and their families gauge how their values might change, so that the decisions they make today can account for the likelihood of these changes? Second, would this “anticipatory guidance” about the likelihood of changing values be appropriate and effective—would patients and families find such guidance helpful, or presumptuous and off-putting? Third, who should be making these evaluative judgments when policy decisions about the relative merits of various medical treatments are being made? Should it be people with personal knowledge about the health condition (who have lived expertise but also unavoidable bias), or people who are more objective members of the general public (who are thus putatively less biased, but also relatively ignorant about the day-to-day realities of the condition and perhaps with general biases against disabilities or certain illnesses)? How much do these two potential sources of value-based judgments differ? Each of these questions is germane to both pediatric palliative care clinical practice and policy-making, especially in our era of comparative effectiveness with the mounting pressure to perform cost-utility analyses. In my rounds as a pediatrician, I have walked into many rooms where loving families have judged the quality of life for their child—perhaps after a recent acute event similar to that described in the vignette above, perhaps years later after providing ongoing total care for the child—to be far better than others would deem; and I have also walked into an equal number of rooms, having been told by others that the child had no meaningful quality of life, only to find that child playing gleefully with siblings.

Family Matters?

In the vignette, I did not spell out whether this was the parents' only child: would it matter if the infant were born into a family with 3 other young children? Typically, the standard of ethical decision making for pediatric cases is the child's best interest—not the family's [5]. From this point of view, whether the parents have other children is irrelevant, as is the potential impact of any medical decision on the

well-being of these possible siblings. Yet, in my experience (and as argued by others [6]), parents and many clinicians view decision making for the child patient in the broader context of the family, and do factor in—or, at the very least, worry a great deal about—the effect on siblings. We do not know the degree to which decisions are influenced by considerations of all the indirect effects of medical care on others. Nor do we know the impact upon siblings of having a sister or brother with a life-threatening condition. Data on these questions will not resolve the debate; simply knowing that a child’s illness has major collateral impact on siblings and families will not tell us that we “ought” to weigh this impact in our decision making. But it will give us some information to use in arguing whether or not we ought to do so. Suppose that the parents in the vignette had other children. Would we counsel differently if we knew of data to support the theory that these siblings are likely to feel neglected if the baby survives in a severely impaired state...or perhaps data that the siblings are more likely to pursue a career in health care or service to others? Are these considerations even relevant to the baby’s best interest?

Deciding How to Decide

As the pendulum of medical ethics has swung from the physician paternalism of early 20th century medicine to the patient-autonomy ethos that first took hold just after mid-century, we may currently be seeing a rapprochement between patients and doctors in the form of shared decision making [7]. What we may be looking at now is, in fact, a meta-decision, namely how the patient and family decide to collaborate with the health care team in making a variety of decisions about specific medical treatment options. We know from some research with adult patients that many prefer to not make medical decisions in a completely autonomous manner, but prefer instead to either share the decision or even delegate it completely to the physician [8]. What we do not know is how parents prefer to make medical decisions for children with life-threatening conditions, nor do we know the reasons or values underlying these preferences. If we had such data, we would be on a research path that would greatly deepen our understanding of the pros and cons of different modes of collaborative decision making. And while waiting for research data about parents in general, we should not be shy in clinical practice to simply ask the question: how can I best work with you and help you make the decisions that lie ahead?

Let me end by summarizing and emphasizing the main point: there is not only research ethics, but also research about ethics. Given the vastness and vagueness of the core ethical principles we have been trying to interpret and use since the 1970s—beneficence and respect for autonomy, nonmaleficence and justice—coupled with the psychological and social challenges of evaluating, judging, and enacting a plan of care for anyone confronting life-threatening conditions, let alone a child—we should not be surprised that we have a lot still left to learn, nor fail to realize our ethical obligation to do so.

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Suggested Readings and Resources

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Christi and David Hancock, from Richmond, Virginia, are the parents of 4-year-old twins, Sierra and Dawson, and baby Ella, who would have been 2 years old this spring. The Hancocks continue to have celebrations of her life on her birthday with

family and close friends. The twins continue to talk about their baby sister and draw pictures of her, happy and healthy in heaven.

Monique M. Karaganis, MD, is a board-certified pediatrician in Anchorage, Alaska. She received her BS in biology from Creighton University and her MD from the University of Illinois. Dr. Karaganis has taught at the University of Illinois and the University of Colorado as a clinical pediatric instructor for both medical students and pediatric residents and has served as a volunteer in Bolivia and at the World Health Organization in Geneva, Switzerland.

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Amy Spangler is the mom of three children—two sons, one who has a terminal illness, and a daughter. She returned to the workforce after 5 years of being the primary caregiver to her children. She is grateful to all those who have contributed to making Rae’s life memorable and for all the memories that have been created through their generosity.

Paula Tironi, JD, LLM, is a Chicago-area health attorney. She received her BA from the University of Notre Dame, her JD from the University of Michigan Law School, and an LLM in health law from the Loyola University Chicago School of Law. Ms. Tironi is the author of “The ‘Stark’ Reality: Is the Federal Physician Self-Referral Law Bad for the Health Care Industry?” and “Pharmaceutical Pricing: A Review of Proposals to Improve Access and Affordability of Prescription Drugs.” Both articles appeared in the *Annals of Health Law*.

Kathryn L. Weise, MD, MA, is a pediatric intensivist who now divides her time between bioethics and pediatrics at the Cleveland Clinic in Cleveland, Ohio. She is the program director for the Cleveland Fellowship in Advanced Bioethics and a member of the American Academy of Pediatrics Committee on Bioethics. Dr. Weise is also director of pediatric palliative medicine at the Children’s Hospital, Cleveland Clinic, and a hospitalist at the Cleveland Clinic Children’s Hospital for Rehabilitation. Her interests include professional ethics, ethics education, pediatric end-of-life care, and care of children with multiple impairments.

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