

The Ritual: Death Pronouncement

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BACKGROUND: Death pronouncement comes infrequently for the pediatrician. The place of death for most children is in the hospital. For hospitalists and pediatric intensivists in the neonatal intensive care or pediatric intensive care units, death pronouncement is not uncommon. For hospitalist physicians, the call to attend a code or to pronounce a death may come on any given shift and from almost anywhere in the hospital.

CONCLUSION: A demonstrative case is provided, followed by key concepts for practice and for educating trainees. *Journal of Hospital Medicine* 2011;6:94–97. © 2011 Society of Hospital Medicine.

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Case

The assessment of the recently arrived critically ill newborn took only seconds: a distended, discolored, and visibly painful abdomen; poor perfusion; assisted ventilation; an intravenous fentanyl drip. I asked the transport nurse practitioner, “When did she first show signs of an acute abdomen?” “Early this morning; she pooped blood,” she replied.

In less than 30 minutes, the surgeons were called, antibiotics were on board, fresh frozen plasma and packed red blood cells were being transfused, dobutamine and dopamine were infusing, and a STAT blood gas revealed marked metabolic acidemia with a base deficit of 25, a lactate of 15 mEq/L, and extreme hyperkalemia—would the anesthesiologist even want to put her to sleep for the exploratory laparoscopy?

“Where’s the family? Have they made it over yet?” I asked the team. Mother and her extended family had travelled across town from the hospital where Angel was born and spent the first 18 days of her fragile life to our facility when it became apparent that Angel would require surgery for her abdominal condition. “They are talking to the surgeon in the neonatal intensive care unit (NICU) Family Waiting Room,” a nurse replied. Organ system failure was rapidly advancing; I requested their presence.

I entered the nearby Family Quiet Room where the single teen mother was surrounded by her extended family—notably, females. “I am the neonatologist on call tonight,” I started, “and I’m afraid your little girl . . . what is her name?” “Angel.” “Angel is in a very poor and unstable condition right now. While her young life of not quite 3 weeks has always been somewhat fragile, being born at 27 weeks and less than 2.5 pounds, she is in particular trouble now with her ability to balance her body’s pH . . . her blood has too much acid in it. And I believe that this is coming from her bowels. Her bowels—intestines—are very sick and apparently tender, or painful; we have her on pain medication. The x-rays we have taken reveal a condition known as necrotizing enterocolitis: a bowel problem with circulation, infection, and inflammation. When this happens, germs from inside the bowel ‘leak’ out into the bloodstream and

they have made Angel very unstable. Her blood counts tell us she is trying very hard to fight infection, but both they and her antibiotics may not be enough. Her bowel is sick and dying, and it is releasing toxins and upsetting her balance of blood acids as well as making her potassium too high. This may result in a fatal heart rhythm problem and I don’t know that we can successfully put Angel under anesthesia and operate. She may never wake up, or she may die on the operating room table.”

Silence. A minute passes and family members express faith, hope, and retell the storied strength of this little girl. “She’s a fighter.” “She was doing fine before all this happened.” “She’ll be fine; all we need is a little faith.” Yet, mother remained more cautious, and quiet. “When will she get to surgery?” was all that she asked. “The operating room team is here and the surgeons are getting ready,” was my reply. “Let me get back to her bedside.” “Can I come see her?” she asked. “Yes, come with me.”

We returned to the bedside. Angel had terminal bradycardia, hypotension, and her perfusion was so poor it left everything but her swollen abdomen pale and mottled. Mother looked on, supported by her own mother. Quietly, efficiently, CPR was continued. An intravenous dose of epinephrine was given. Mother left the room, but some family members remained . . . to watch? To learn what one does in such a predicament? To ensure that everything possible, including CPR, was done for little Angel?

Blood from acute pulmonary hemorrhage gurgled up out of the endotracheal tube; her blood pressure dropped more, and despite epinephrine and bicarbonate, the resuscitation was for naught.

I briefly reentered the Family Quiet Room to inform mother of Angel’s progressive decline, and that it was my recommendation that we cease CPR and treat her little body with love and respect—“I would like to remove her from the life support mechanisms that are not benefiting her, and bring her to you to hold. Do you understand?” A tearful head nod affirmed the belief that no mother wants to believe.

Angel’s pupils were fixed and dilated, there was no spontaneous respiratory activity, no movement, and a pulse rate of

less than 30; I called the code after 12 minutes. I left the NICU nurses—those wonderful agents of care in the best of times and the worst of times—at the bedside to prepare for the continued transition: from life-supporting critical care toward end-of-life care and the bereavement process. I returned again to the Family Quiet Room to speak with Angel's mother.

"As you heard before we went back to see Angel, and as you saw at the bedside, her condition would not allow us to proceed toward surgery despite all that had been done for her to attempt to get her stable. I'm sorry to have to tell you this, but Angel is dying and I cannot reverse that reality. Nonetheless, even when she passes away tonight, and I cannot tell you exactly what time that will be, I want you to know that we are all concerned for you, and for your understanding of what has taken place here. I fully recommend that you consider an autopsy to examine and evaluate what Angel went through and provide some answers for us all." Again, a tearful head nod. "You don't need to sign anything right now. That can all be handled later. I will ask the nurses to bring Angel here to you."

The NICU nurse brought little Angel, lines and tubes removed, swaddled in a receiving blanket and a cap, to mother. We paused briefly, said our apologies and offered support, while allowing more extended family to stream in. Then, stating we wanted to respect their privacy, we excused ourselves to the nearby bed space and began the documentation process. I looked at my watch about 10 minutes later, knowing it really would not be long before the last remaining vital sign—a bradycardic heart beat of less than 30—would become zero. I knocked on the door, and then opened it slowly. I saw, sitting comfortably in a chair across the room, the young mother holding Angel in her arms. She was surrounded by no less than 8 others, whose eyes moved between her, Angel, and me.

I approached this young mother for the last time that evening. Silently, she opened her arms to allow me access to Angel. I knelt in front of her and slipped the stethoscope under the receiving blanket and onto Angel's chest. I listened, still, quietly, and watched the second hand on my wristwatch. A full minute without a sound; no movement or breathing; a body cool to the touch. "Angel has died. She has passed from this life. I am sorry for your loss." One final look in mother's eyes—so much more mature than her teen years should have had to allow—and I turned to leave the room. "See that," I heard from a family member who had previously spoken of Angel's strength, "she passed away in your arms. Just like she is supposed to be, in your arms."

Methods

Death pronouncement comes infrequently for the pediatrician. For intensive care specialists in the pediatric or neonatal intensive care units (ICUs), however, it is not an uncommon event.¹ For hospitalist physicians, the call to attend and direct a resuscitation, or to decide when it ceases and

pronounce a death, may come on any given shift and from almost anywhere in the hospital. How often are our trainees who may be involved in this process actually mentored or shepherded through the death pronouncement after resuscitation ends instead of being "thrown to the wolves?"² At a recent speaking engagement addressing pediatric palliative care, this author was asked by a young pediatric resident about just how one goes about death pronouncement. She was left alone to do this on call without any prior experience or instruction, and was even called to do it out of the usual pediatric care environment when she had to pronounce a newborn infant dead following a delivery in an adult ICU where the mother was emergently delivered, though critically ill.

The topic of pediatric death pronouncement is difficult to uncover in the medical literature. Most of it must be gleaned from other reports addressing communication, end-of-life care, and the emerging literature on pediatric palliative care.³ Despite efforts to address this in the past 2 decades, resident education in this area is weak by most reports.^{4–7} Even in pediatric training programs situated in children's hospitals with palliative care services, the need for continued training and enhancement of communication skills around such matters has been documented.^{6,8} As the field of pediatric palliative and hospice medicine matures, the sensitivity to this procedure warrants greater attention, and formal training in communication skills may result in improved resident competence and self-confidence.⁹

In consideration of the circumstances around an infant or child's death, it may well be appropriate to inquire about obtaining an autopsy. Although there is an established value to obtaining an autopsy, it may not always follow that every pediatric death should result in an autopsy examination.^{10,11} Nonetheless, the conduct of an autopsy, and sharing of its results with appropriate clinical staff and in a conference with family members, may provide many benefits. These include: epidemiologic data, recurrence risk calculations and input to future family planning, contributing to clinical and diagnostic education and accuracy, and assisting with the bereavement process. Autopsy information, even when the examination is limited to certain organ systems (eg, cardiovascular, gastrointestinal tract), may be invaluable to parents and of some comfort as they search for understanding and for answers.¹²

Given the fact that most children who die in American hospitals die in an intensive care environment, organ donation may not always be an option.¹³ Nevertheless, most jurisdictions require notification of organ donor or procurement services when a child has died. These are largely operative at state levels, but may have regional or institutional representatives in large medical centers. In some circumstances, family members may actually foresee imminent death and ask about organ donation before their child is removed from life support. The use of organ procurement organizations, consultants, or counselors, separate from the

TABLE 1. Steps to Consider in Death Pronouncement of a Child

1. When in the clinical situation in which you need to pronounce the death of an infant or child unknown to you, quickly gather some information:
 - a. What is the child's name?
 - b. Was this an anticipated death? (eg, following a long-standing, or known life-threatening illness) By the clinical team? By the family?
 - c. Was cardiopulmonary resuscitation desired? Performed? Effective?
 - d. Who among concerned family are present, and what is their condition? Are they quiet, in obvious grief, angry, or overwhelmed?
 - e. With whom is information most suitably to be shared?
 - f. Who has decisional responsibility for handling the body and consenting to an autopsy?
2. When entering the room, or coming to the bedside of the deceased child, remind yourself to be calm.
3. Introduce yourself (perhaps you are the 'physician on call' that evening).
4. If there are family members present, assess their reactions to the child's passing.
 - a. Are they actively grieving, or looking anxiously to you—waiting for your evaluation and pronouncement?
 - b. Do not ask family members to leave. Rather, conduct your own brief examination in front of the family: assess the pulse, respirations, and heartbeat.
 - c. Be sensitive to the body's orientation (eg, Muslim families may express a desire for the body to be facing the east, toward Mecca).
5. Clearly communicate that the child—call him/her by name—has died and offer condolences.
6. Pause for the family's immediate grief response and reaction.
 - a. Remain present and available, yet quiet.
 - b. Do not speak too much (unless you have an established relationship with the child and family).
 - c. Respond to the family's immediate reactions in a humanistic manner, and answer their questions simply, without medical jargon or long narratives on the disease.
7. Console the family as you deem appropriate—again, based on any relationship you may or may not have.
8. Allow the family time and privacy and offer your availability and that of other support staff (nursing, social work, child life, chaplain).
 - a. Ask them if there is anyone that they would like to have you contact.
 - b. Give them a time (in so many minutes or hours) when you or another staff member will return and address next steps such as disposition of the body, autopsy, organ donor services notification, and funeral home notification.
 - i. Families vary widely in the expediency with which they may want the body handled and released to a funeral home.
 - ii. Be culturally sensitive to traditions around touching the deceased; some families may choose not to hold the child.
 - iii. Be sensitive to religious stipulations regarding autopsy.
9. Ask the family if it will be all right for you, or someone from the bereavement services office in the hospital, to contact them in the near future.
 - a. Explain that this may serve multiple purposes:
 - i. To determine how they are coping (and, perhaps, make a referral for behavioral health, bereavement or grief support, and counseling).
 - ii. To schedule an autopsy review session (if an autopsy is granted).
 - iii. To schedule a general postmortem counseling session (particularly helpful after an ICU death).
10. In leaving the family, again refer to the child by name, perhaps even saying "goodbye" to the deceased, as seems appropriate to the circumstances.

clinical team's management of the patient, and even distinct from the dying process and the family's bereavement care, is generally a positive contributing factor to accomplishing family decisions supportive of organ donation.¹⁴

Borrowing from the adult experience as recounted by Hal-lenbeck,¹⁵ and in consideration of practical clinical experience, the following guidelines for pediatric death pronouncement (Table 1) are presented. Additional concepts and exemplary language are noted by Truog and colleagues in their 2006 article titled, "Sudden Traumatic Death in Children: 'We Did Everything, but Your Child Didn't Survive.'"¹⁶

Addressing a patient by name demonstrates respect. Even in the case of a dying newborn, knowing (or asking) this is a matter of demonstrating respect and developing trust. In many cultures, bereaved parents like to hear others remember and speak about their lost infant or child, although this may vary with the time, the context, and the relationship that certain caregivers had with the child. In view of this, a nurse, chaplain, or social worker may be a valuable partner to be present at this time with the family and physician. Proceeding through the initial assessment of the clinical situation in which death takes place, it is important to ascertain who is present (is a parent alone, with family, supported by friends or a member of the clergy?), who knew the child's illness and expected outcome (was death unanticipated or the result of a prolonged

illness?), and who has decisional responsibility in the circumstances now before them.

Further assessment of the situation also calls upon the clinician's sense of discerning a family's emotional response to the circumstances of resuscitation and/or death (anger, desperation, grieving, or silent?). It is important to remain calm, focused, and direct your primary attention to the patient and the parent(s)/guardian. Unless someone present is unruly, they need not leave. If someone is so anguished that they cannot hear or attend to your presence or words, quietly excuse yourself and ask for help from a social worker, a colleague, or a chaplain; then return. It is often helpful to acknowledge or validate a family member's emotions, and to show empathy.

"Anyone in this circumstance would feel devastated."

"Do you have feelings you would like to share?"

"This must seem very unfair."

For the silent family member, it may be helpful to state,

"I know we are often at a loss for words at a time like this, but I would like to express my sorrow for the loss of your [son, daughter] _____ [refer to by name]. I want you to know that we are here to answer your questions and help you in whatever manner possible when you are ready."

In order to move forward, many families need time, privacy, and support. This can be afforded them, even in a busy ICU or

Emergency Department. A follow-up visit to see how the family is doing after a period of 10-15 minutes may prove opportune in processing what has happened and addressing what happens next. If there is an identified need, or particular problem or difficulty in understanding things, additional resources (social worker, case manager, chaplain, or behavioral health professional) may be helpful. Asking if there is anyone that you can contact is often a simple way to address this.

Attending to cultural sensitivities and practices, religious rituals, and family traditions also requires some initial inquiry of the family, unless there has been a long-standing, or well-recognized, interaction pattern. It may be helpful to ask,

“How do you and your family deal with crises or difficult decisions? What is important to you at this time?”

Sometimes, it may be tempting to stumble into some explanation for the death, or failure of the resuscitation to restore relative stability. But when all of the answers may not yet be forthcoming (eg, laboratory tests may be pending or an autopsy has yet to be performed), this type of effort is potentially confusing or even harmful. It is prudent to state what is known, especially if the death follows a prolonged illness, and note that there may be more information to follow.

In sum, be present, be factual yet empathetic, and be resourceful in eliciting and addressing family member needs.

Resources:

The reader is referred to the following Fast Facts resources on-line at the end-of-life/palliative education resource center (EPERC), at the Medical College of Wisconsin:

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