

Understanding, Avoiding, and Resolving End-of-Life Conflicts in the NICU

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Abstract

Parents and health care professionals may disagree about whether to continue or discontinue life support for infants in the neonatal intensive care unit (NICU) when the infant has an extremely poor chance of survival and/or probably has profound neurological damage. Conflict usually occurs when the parents want everything possible done to keep their infant alive, while the medical team believes that continued care will only prolong suffering and consume resources needed for other patients. The argument is made that often insufficient time and effort is made to fully understand the parents' reason(s) for requesting continued life support. Instead, they are advised to stop support, the advice is rejected, and this results in conflict with the family.

A case is used to illustrate this situation, and five typical reasons families have for requesting continued life support, against the advice of the infant's physician, are presented. Each reason needs to be explored and addressed differently. Full appreciation of the reason for the family's request can often prevent conflict between the physician and the family and replace it with support and understanding. Increased emphasis on educating physicians about how to conduct end-of-life discussions, making time for repeated family conferences, and use of a palliative care consultant, should be considered as ways to improve family-physician communication and prevent unnecessary conflicts.

Key Words: End of life, premature infant, communication with families, futility, inappropriate medical care, best interests, ethics.

EIGHTY PERCENT OF THE DEATHS that occur in the neonatal intensive care unit (NICU) are preceded by decisions to limit, withhold, or withdraw life support because the prognosis for survival and/or a meaningful quality of life is extremely poor (1). Availability of powerful technologies that may save lives or only succeed in greatly prolonging dying makes it essential that families and physicians evaluate whether continuation of such therapies is in the best interest of an infant whose prognosis is extremely poor. If patients are or have been competent, their own judgments are used to determine their end-of-life care. However, the infant's interest is best served when the parents and physicians can agree about what therapeutic goal is appropriate for him, and that goal is then used to guide therapy.

Conflicts between families and medical caretakers about whether to escalate, continue, or dis-

continue life support for critically ill infants are not uncommon. Most often conflict arises in situations where the prognosis is extremely poor and continued survival depends upon therapies that may cause discomfort or suffering. In these conflicts, members of the health care team may believe that life support should be stopped, but the family disagrees and wants full support continued. The family wants to keep the infant alive at all costs, while the medical team believes that such care will only prolong discomfort for a dying or profoundly disabled infant and waste scarce medical resources. As conflict continues, both the family and members of the medical team experience significant distress or anger, which exacerbates the problem of poor communication.

Disagreement and conflict about end-of-life issues often result from inadequate understanding of the family's rationale by the medical team, and consequent disagreement between the family and medical team about the goal of treatment (2, 3). Frequently, these conflicts result from inadequate communication by the medical team (4). What follows is a case presentation that demonstrates how such miscommunication may rapidly lead to conflict and tension between the family and the medical team. Also presented are five typical reasons given by parents, in the author's experience, for

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requesting continued life support for infants when the medical team believes it is inappropriate. The article attempts to show how understanding the family's reasoning in each situation might have informed the discussion and prevented or lessened conflict. There have been recent efforts made to find legislative or judicial solutions to resolve these conflicts. Using these sorts of measures for conflict resolution may on rare occasions be necessary as a last resort, but doing so is likely to be costly, time consuming, and emotionally painful, and may not succeed in resolving the conflict. It is the thesis of this article that improved communication with families can avoid many end-of-life conflicts.

Case: A Family's Demand for "Inappropriate Care"

A 520 gm (1 pound 2 ounce) Caucasian infant was delivered vaginally at 23–24 weeks' gestation by an 18-year-old unmarried woman. The infant's mother was healthy except for being obese. She had not known she was pregnant and had not received prenatal care. She was a high school student, and lived with her mother. She was still seeing the father of the infant, but they were not "going steady." After experiencing abdominal pains she had gone to the emergency department of her local hospital, where she delivered within a few minutes of arrival. The infant was intubated after several attempts and was then placed on a ventilator. He had Apgar scores of 2, 4, and 7 at 1, 5, and 10 minutes. Soon after birth, the infant was transferred by helicopter to the regional level 3 NICU.

On arrival at the NICU the infant was hypothermic and hypotensive, and was put on high ventilator settings. Umbilical artery and vein catheters were placed, and over the first two days he was treated with two doses of surfactant for respiratory distress syndrome, given indomethacin to close a patent ductus arteriosus, and treated with pressors for hypotension.

On the third day the infant had repeated generalized seizures and was unresponsive to pain. An ultrasound study of the infant's brain showed a large right-sided "grade 4" intraventricular and parenchymal hemorrhage (venous infarct). The neonatologist discussed the infant's prognosis with other members of the clinical team, including pediatric residents, the bedside nurse, the social worker, and a second neonatologist. In light of the cerebral hemorrhagic infarct and the neurological picture, they concluded that the infant now had less than a 10% chance of survival to discharge, although death did not appear to be imminent if full

support was continued. Also, if the infant did survive, there was a 90% chance of severe-to-profound neurological damage with likely mental retardation, developmental delay, and cerebral palsy. An infant born at such an early gestational age was also likely to develop retinopathy of prematurity, with a moderate chance of reduced visual acuity or blindness.

All of these outcomes were probabilities, of course, and not certainties. While 90% of such infants die, some do survive, and while most survivors have serious disabilities, 10% do not have developmental or neurological problems. The presence of retinopathy of prematurity (and possible blindness) could not be evaluated before 6 weeks, and the earliest meaningful evaluation of the infant's developmental status would be at 6 months of age. If the medical team and the infant's mother agreed to discontinue life support at this time (i.e., day 3), the infant would soon die. But if it was decided to defer such a decision for 6 weeks until the infant's neurodevelopmental status and prognosis for vision could be better evaluated, the infant might die while receiving full life support or else he would no longer be dependant on a ventilator for survival.

The infant's poor prognosis for survival, and the likelihood of serious developmental problems if he did survive, were discussed with the infant's mother and the maternal grandmother. After several meetings it was suggested to them that discontinuation of life support be considered because further care was likely to be futile, and because in the unlikely possibility that the infant did survive, he would probably have a very poor quality of life. But the mother replied that she wanted everything possible to be done for her son.

After the family asked that full life support be continued despite the team's recommendation that it be stopped, the physicians and nurses became extremely frustrated, for several reasons. The staff didn't think that the family appreciated how burdensome continuing care was for the infant, and they believed that the infant would probably die despite continuing ventilator support. The nurses perceived that the infant was suffering, and they resented having to care for him 24 hours a day, while the family only paid occasional brief visits. Some nurses said that they felt the family was forcing them "to torture the infant" by continuing pointless care. Others questioned whether the family understood what the infant's life would be like if he survived with severe disabilities such as developmental retardation, cerebral palsy, and blindness. Subsequently, a number of nurses asked not to be assigned to the infant. The family quickly sensed the staff's disapproval and lack of support.

Rather than repeatedly face the disapproving atmosphere, critical comments, and pressure to discontinue life support, they visited less and less often, and only at night, when the attending neonatologist was not present.

In the situation described, which is not atypical, an impasse had already been reached. Communication with the family had become poor and was not likely to improve. And neither the staff's disapproval of the family's request for continued treatment nor their pressure on the family to change their mind was likely to change the situation. Staff members discussed among themselves whether to consult the hospital ethics committee, to help persuade the family to do what was "ethically correct," or to ask the courts to take custody from the family because of their "inappropriate" decision for the infant. While such discussions were understandable given the frustration felt by the staff members, there was little chance that an ethics consultation would have helped improve communication, and legal action was unlikely to resolve the conflict anytime soon. However, the impasse might have been avoided entirely if the attending neonatologist had taken time to understand the family's thinking before suggesting that life support for the infant be stopped. This could have been achieved by clearly stating the prognosis repeatedly, and then asking the family for their reaction or response without first making a recommendation to them. This process sometimes takes several meetings, since the family needs time to process the information.

Some Parents' Perspectives

Here are five reasons given to the author by different families requesting continued life support for their infant, when the medical team believed such requests were inappropriate:

1. They believed that the infant could survive and was likely to be normal or to have only mild learning problems.
2. They believed that God performs miracles, and a great many members of their church were praying for their infant to survive and be normal. They felt that if they agreed to limit or stop life support, members of their church would see them as lacking faith in God's ability to heal.
3. They knew of similar cases in which the doctors' predictions were wrong. Also they suspected that their infant might not be receiving the best possible care, because they were poor and on Medicaid.
4. The mother saw survival of her infant as the

only solution to a life crisis. One such mother had been depressed, and her boyfriend was the only person she felt close to. She believed he would remain with her if their son survived, but would leave her if their infant died.

5. The likelihood of the infant having moderate-to-severe disabilities was not important to them. They believed that the life of every child, even one with severe or profound disabilities, had great value and should be saved. They were prepared to commit themselves to raising him if he survived, regardless of his limitations.

Discussion

If the members of the health care team had taken the time to fully understand the family's reasons for asking that life support be continued, they might have done a better job in helping them deal with a tragic situation, and the conflict might have been prevented entirely. Let us look at each of the five reasons that families might give for requesting continuation of life support for their infant, when the staff felt the request was inappropriate, and consider in each instance what approach by the physician might have been helpful (Table 1).

They believed that the infant could survive and was likely to be normal or to just have mild learning problems.

In this case (the case presented in this article) the family simply misunderstood what the prognosis was for the infant. This may seem unlikely, as the neonatologist had told them clearly in several meetings that the infant would probably die, and that if he didn't, he would most likely have severe-to-profound neurologic disabilities. Yet studies have shown that it is quite common for families to misunderstand the information provided to them by physicians (4). Often this occurs because of the extreme stress and anxiety that they feel, or because they don't understand the medical terminol-

TABLE 1

Reasons That Some Families May Demand Apparently "Inappropriate Care"

Failure to comprehend prognosis.
Religious beliefs about end-of-life decisions.
Religious belief in miracles.
Lack of confidence in medical diagnosis or prognosis.
Belief that more can be done.
Secondary gain.
Disagreement about seriousness of outcome.

ogy or the concepts being presented. The infant's mother may have been "in denial," because she hadn't even known she was pregnant until the baby was born. She may also have felt tremendous guilt because she hadn't received prenatal care.

Medical terminology can also become a barrier between physicians and laypersons; it is important to use language that people understand. The terms "profound neurological disabilities" or even "brain damage" may not convey a picture of the infant's future as clearly as saying that the infant will never walk or talk, or know his family. Also, concepts such as percentage probabilities, which seem straightforward to members of the medical team, may be incomprehensible to someone who isn't familiar with them. The infant's mother may not have understood that if there was a 10% chance of the infant being neurologically normal if he survived and only a 10% chance that he would survive, then there was only one chance in one hundred of his being normal if life support were continued.

One way to assess what the family understands about the information being presented is to ask them to repeat it back in their own words. At the end of the initial family conference and at the end of each subsequent conference, the family could be asked to say what they understand the infant's condition to be. That way, misunderstandings would immediately be spotted, and could be corrected by repeating the relevant information in a way that is understood by the family—as shown by their ability to repeat the correct information in their own words. Although misunderstanding the facts seems like a trivial reason for end-of-life conflicts, it is the most common reason (4). It is also the most avoidable. Discussion of whether to limit or discontinue life support should never occur until it is clear to the physician that the family understands the prognosis. This may require repeated, calm explanations. These explanations can be accompanied by expressions of sorrow by the team members that nothing more can be done to improve things for their infant, so the family understands that everyone participating in his care wishes he could survive, and that he could be normal. In other words, that everyone has the same wishes for the infant. It is not useful to discuss limitation of life support until the family fully understands and accepts the prognosis.

They believed that God performs miracles, and a great many members of their church were praying for their infant to survive and be normal. They felt that if they agreed to limit or stop life support, members of their church would see

them as lacking faith in God's ability to heal.

Here, the family fully understands that the physician is giving them a bleak prognosis, but they believe that God can intervene and heal their infant. It isn't clear how prevalent this view is, but it certainly is not rare or limited to a geographic area or a single religious or ethnic group. Situations in which a family's religious beliefs have led to conflict with clinical recommendations near the end of life have been recognized and evaluated in several recent articles (5–7). It is beyond the scope of this article to discuss different interpretations of religious doctrine.

Discussion and evaluation of the clinical facts and what is right for the patient may, at times, be enough to lead the family to change their view. One approach that has often been successful in our NICU is to ask the family to invite their own minister or a hospital chaplain of the same faith to participate in discussions about prognosis and options for treatment. When the minister understands that the infant is suffering and will almost certainly die, he/she may counsel the family that a reasonable option is to substitute comfort care for intensive care as a way of showing compassion and love for their child. Some people have idiosyncratic ideas about the teachings of their church and don't realize that their religion considers it acceptable to discontinue life support in cases of medical futility. If their minister, rabbi, priest, or imam is present during discussions, he may help them to consider such an approach. Also, within a religious framework, the parents may come to see that discontinuing life support isn't incompatible with continuing to pray for a miracle. Whatever happens once life support is stopped, the Deity they worship would still determine the outcome. We have seen families who state that this view changed their approach and who discontinued life support when, over time, they came to appreciate their infant's suffering. However, if theirs is a deeply held belief and supported by their culture, it is quite likely that they will not modify their belief, and that efforts to convince them to do so will fail. The physician and medical team may disagree with them, but understand that it is important to avoid conflict or antagonism which will only interfere with their ability to support the family and will also decrease the chance that the family may reconsider their view in time.

They knew of similar cases in which the doctors' predictions were wrong. Also they suspected that their infant might not be receiving the best possible care, because they were poor and on Medicaid.

In this case the family mistrusts the physician.

They speak of similar cases in which the doctors' prognoses were wrong, even though the clinical situations may not have been similar to the current one. Some people question whether their infant is getting the best care, because they are poor or feel disenfranchised by society. They believe that they need to fight to get their infant the same care that a more influential person's infant would receive. Many published studies show, in fact, that minorities and Medicaid patients do get less adequate treatment than patients with the same medical condition who have private health insurance (8–10). Some evidence suggests that African-American patients are less likely to agree with a physician's recommendation to discontinue ventilator support for their infant (8, 10, 11). Mistrust by African-Americans may also be a consequence of injustices in well-known clinical studies, such as the Tuskegee syphilis study, as well as disparities in health care and health outcomes. Where trust is an issue, the proper approach is to work to gain that trust. Explanations of treatment goals, efforts taken to achieve them, and why they are unsuccessful, repeated over time, are most likely to succeed. It may also help if the doctors offers to get a second opinion. In any case, understanding the family's reasons for not agreeing to stop life support will help the physician to understand why attempts to pressure them will fail.

The mother saw survival of her infant as the only solution to a life crisis. One such mother had been depressed, and her boyfriend was the only person she felt close to. She believed he would remain with her if their son survived, but would leave her if he died.

Decisions made on behalf of an infant should focus on what course of action is best for the infant. Although it is likely, and sometimes even appropriate, that parents also take into account the consequences of their decisions on other family members and even on themselves, the reason given here to continue life support is inappropriate, albeit understandable. The mother's interest is focused on what is best for her, and the infant's life is literally held hostage for the mother's gain. One can properly question whether the mother is a competent decision maker on behalf of her child, and in extreme situations it may be appropriate to ask the court to assign another guardian for the infant.

Knowing what the issue is for the mother, however, it is clear why pressure exerted on her to discontinue the infant's life support will be met with tremendous resistance. The hope is that, over time, the infant's mother and her family can be

helped to focus on what the infant is going through, what his or her future will be like, and what the best decision would be. Psychological counseling could be offered, but may not be accepted or successful, since the young woman is facing several simultaneous life crises: the birth and impending death of her first child and the potential loss of her boyfriend, the most significant person in her life. The mother's parents or closest relatives or friends may be included in family conferences to support her during the crisis.

The likelihood of the infant having moderate-to-severe disabilities was not important to them. They believed that the life of every child, even one with severe or profound disabilities, had great value and should be saved. They were prepared to commit themselves to raising him if he survived, regardless of his limitations.

It is clear that people differ in how they view survival with severe disabilities. Some place great importance on intellectual functioning and would not, themselves, choose to survive an illness that left them with severe mental impairment and as a burden on their families. Others see the world differently. When a family cherishes a child with severe or profound disability and is prepared to sacrifice other life goals to provide loving care for that child, their view deserves great respect. The likelihood of success with the child will depend upon the goal of therapy. For if a family only views fairly intact, "normal" survival as acceptable and all other outcomes as negative, then there is only a 1% chance of a good outcome in the case described. But if the family will be happy to take home an infant even with severe or profound disability, then there is a 10% chance of success. Given that probability, it is understandable that they might ask that life-supporting care be continued.

Once the rationale behind the family's request to continue life support is understood and it is established that they truly understand what lifelong problems the infant will probably face if he survives, it may be less appropriate to try to change their minds. We should support their choice even if we would not choose the same course for our own infant. It is very important that all members of the medical team understand that people do have differing values, and that our role is to support all families whose values are reasonable and motivated by concern for their infant. The question isn't whether we would make the same choice, but whether the choice the family makes is a reasonable and acceptable one, given that ours is a di-

verse and tolerant society.

In each of the scenarios, I have tried to show that good communication can help prevent conflicts. Only by knowing what the family really understands, and what their fears, values, and beliefs are, can the physician collaborate with them in making the best decisions for the ongoing care, or end-of-life care, for their infant. In the case presented, a recommendation was made to discontinue life support because the infant had a very poor prognosis—before the physician knew what the family really understood about the infant's condition (or had much insight into their beliefs, fears, and values). They didn't accept the physician's recommendation, and this soon led to conflict about the best course of treatment for the infant. Taking time to understand the family's views first might well have avoided conflict. Not only does conflict usually fail to resolve the question of what is best for the infant, but it denies the family struggling to cope with a crisis much needed comfort and support from the medical team.

Conflicts between physicians and families concerning decisions to limit treatment for adult patients in intensive care units have been fully analyzed according to whether the conflicts originated with family, physician, or organizational and social factors (3). Presumably the same factors would exist when conflicts arise in the NICU. In what follows I discuss two factors, which I believe are barriers to optimal communication by physicians: inadequate training in end-of-life communication and time constraints.

Inadequate Training in End-of-Life Communication

Medical school curricula usually cover topics relating to death and dying (see Table 2, for instance), but rarely include practical training in the skills needed to effectively communicate with families about these issues, including how to help families deal with decisions about whether to limit or stop life support (12). Usually, physicians learn how to do this "on the job." Believing that many physicians would benefit from improved communication skills in this difficult area, the American Medical Association and several other professional societies recently published educational materials for physicians about end-of-life communication with families; but it isn't known how widely used, or useful, these written materials are (13). Physician comfort and skill levels in dealing with families about end-of-life issues vary considerably. For many, discussion of whether to discontinue life support is very difficult, and sometimes even

TABLE 2
A Checklist for Communicating Bad News

Prepare your facts.
Be sure all health care team members agree.
Invite the family to bring a few close relatives, friends, or clergy.
Include a few team members who know the patient: nurse, social worker, and chaplain.
Meet in a quiet, confidential setting.
Have all patients sit down and introduce themselves.
If the news is bad, start out by saying "I'm (we're) so sorry to have to tell you..."
Review patient's condition and treatment up to the present time.
Keep your message straightforward. Avoid medical jargon.
Discuss all realistic options.
Don't discuss alternatives that won't work.
Discuss measures that can be used to minimize pain and discomfort.
Don't discuss limiting life support until it is clear that the family fully understands and accepts the reality of the situation, usually at a subsequent meeting.
Always ask the family to explain the patient's situation in their own words.
Arrange for the next meeting time, place, and attendees.

painful. The physician is forced to deal with his or her "failure" to save the infant and thoughts about personal mortality and severe disability, and to communicate effectively with a family who may hold very different values from his or her own. The family that the physician is trying to help may also question aspects of the obstetrical or neonatal care their infant received, and as they confront the fact that their infant may die or be severely impaired, they may be in any of the stages of loss: denial, grief, withdrawal, or anger.

Time Constraints

A second major barrier is time constraints. It takes considerable time to establish a meaningful relationship and get to understand a family's level of understanding, fears, beliefs and values. Yet this is usually attempted during a series of fairly brief meetings with the family. The pressures to increase productivity, to care for more and sicker patients, and to shorten hospital stays makes it even more difficult to achieve the necessary level of communication. In academic medical centers, additional demands exist to teach and do research. Nonetheless, meaningful communication with families is so crucial for making the right decisions for their infant and to support the family, that adequate time for it must be found.

If time is scarce for the attending, it is even scarcer for the residents. Traditionally, residents have been responsible for much of the communication with the families of the patients assigned to

them. But this has become more difficult in recent years. Not only do residents now have to take care of sicker infants and deal with shorter lengths of stay, they are also required to work fewer hours. Because attending and work rounds are done in the morning, most family conferences are scheduled in the afternoon. In the past, residents were available to participate in these conferences on most afternoons, but now they are unavailable if they worked the previous night or if they are assigned to an afternoon continuity clinic. Consequently they miss many learning opportunities during family conferences that the attending physician holds with patients' families. This will greatly decrease their opportunity to communicate with "their" families and learn the important skills involved. We need to find new ways to improve resident communication skills within the constraints of the work-hour guidelines.

Conclusion

Recently there has been understandable concern about how to proceed when families make apparently "inappropriate demands" to continue life support, resulting in needless suffering by the patient and a waste of scarce and costly medical resources. This problem arises with sufficient frequency that one state, Texas, recently passed legislation that provides an extrajudicial due-process mechanism for resolving end-of-life conflicts (14). The process begins with formal committee review of the medical appropriateness of continued care, and if the care is found to be inappropriate, transfer of the patient to another hospital is the only alternative to discontinuation of that life-prolonging therapy. The legislation exempts both the physicians and hospital from civil or criminal liability if they discontinue care after diligently following the appropriate procedures. Although this sort of approach may be needed in rare situations, it is always far better, when possible, to avoid such end-of-life conflict.

I propose that such conflicts can be prevented in many or most situations if physicians become better at communicating with families about end-of-life issues (6). How can they accomplish this? For one thing, communication and understanding can be improved if a palliative care professional such as a nurse, nurse practitioner or social worker who has developed the necessary skills and has

more time available, works along with the physician to communicate with and support the family. Time constraints that have always existed in medical practice are more acute today. But adequate time must be found to understand a family's personal experience, reasoning, feelings, and religious and ethical beliefs, in order to be able to support them and to help them make the best possible decisions for their critically ill infant. Doing so can also prevent end-of-life conflicts. While this discussion focuses on end-of-life decision making in the NICU, it is equally appropriate for preventing end-of-life conflicts that may arise throughout the hospital.

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