Peer Reviewed

Clinical Pearl: A Thoughtful Approach to Neonatal End-of-life Discussions

Patricia Stevens, MS, NNP-BC

Abstract:

While an infant's death is always tragic, with a review of parents' feedback, forethought, andempathy, we can help parents through this difficult time in a better way.

Since the inception of NICU to care for critically ill neonates, death before discharge has been common. As our knowledge base grows and technology advancements are made, more and more critically ill newborns now do survive in NICU, yet there are some lives; no matter how much we try, we still cannot save. So how do we counsel parents who are resistant to this discussion and/or maintain a stance of wanting "everything done" despite being told the reality of imminent death? Do we really help the family by prolonging the inevitable, therebyprolonging pain and suffering?

Support for medical providers in this difficult situation is found in the position statement "Non-initiation or Withdrawal of Intensive Care for High-risk Neonates," which clearly states:

> *The critical role of the parents in decision-making must be respected. However, the physician's first responsibility is to the patient. The physician is not obligated to provide inappropriate treatment or to withhold beneficial treatment at the parents' request. Treatment that is harmful, of no benefit, or futile and merely prolonging dying should be considered inappropriate. In his or her best medical judgment, the physician must ensure that the chosen treatment is consistent with the best interest of the infant (1).*

The dichotomy of caring for more than one patient with conflicting needs is, at best, challenging. Following this recommendation is easier said than done. How do we have that difficult conversation with parents to facilitate end-of-life decisions when further care becomes futile? Needless suffering becomes unbearable to witness. Does death come after sometimes brutal resuscitations rather than a planned peaceful and meaningful experience surrounding family with support and closure?

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In the past few decades, we seemed to have done this better than we do now. Research had reported that most deaths in the NICU were preceded by decisions agreed upon by the medical team and family to withhold or withdraw life-sustaining medical treatment (1,2). Over the pastten years, however, it seems that these numbers have reversed. Fewer deaths are peaceful, and medical teams feel that discussing redirection of care is often met with such strong family resistance that having this discussion in these cases is often feels like a waste of time.

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This change of trend then becomes self-perpetuating, as more physicians have become more and more uncomfortable offering transition to comfort care. Several influences may contribute to this. Some physicians do not feel they have the right, either legally, ethically,or morally, to recommend withdrawal of life-sustaining medical therapy, despite support from AAP, legislation, and ethicists (1,2,3). Yet, avoidance of having this conversation can become thepath of least resistance. Some feel their training was sparse in learning communication techniques to help families make end-of-life decisions (3), and hostility from family interactionsin failed attempts reinforces further avoidance. Some erroneously contend that the burden tomake this decision falls squarely

on parents alone. If they do not request redirection of care or decide once they are given "the facts" of futility, the issue is never revisited.

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In order to provide the very best end-of-life care for our patients and their families, it is important to consider the perspective of a parent entering the foreign world of NICU for the first time. Sensory overload from monitors and staff activity. Overwhelmed by the equipment. Confusion from the foreign language of medical jargon even if English speaking, even more confusion if not English speaking. Mental and physical exhaustion after complicated pregnancyand delivery. Guilt, fear, and the list goes on. Society identifies childbearing as a natural process, yet often, without warning, natural very quickly can become unnatural.

In a meta-synthesis of predominantly empirical research, Xafis and colleagues (4) explored retrospective feedback from parents, which identifies what parents found assisted or impededthem in making end-of-life decisions for their child. The findings are not surprising. However, once identified, it becomes clear how the most needed support can be easily a neglected priority in a busy intensive care environment.

According to this research, an essential aspect of care that aided parents in this situation, having never made end-of-life decisions before, was the need for a trusting relationship with the physician, which developed with time, honesty, and continuity of care long before end-of-life discussion even begins. This alone is difficult to provide in a large academic NICU, with rotating residents, attending neonatologists, nurse practitioners, nurses, social workers.

Further, we may not have the luxury of time before mortal decline presents. Alternatively, the turn of events may occur during off-service time. Creativity in carving time for establishing relationships and very clear documentation of discussions and parents' response may help inthese situations.

Parents also felt that having the ability to speak with other parents who have experienced making end-of-life decisions for their child in the past is extremely helpful. Many NICUs are beginning to see the benefit of peer-to-peer support. Previous NICU parents can provide tremendous help to parents, either as a hospital-based or community-based program. Researchshows that the most successful programs are ones that connect with medical providers (5).

Things that hindered decision-making from the parents' perspective are important to acknowledge. Many felt bombarded with information from multiple providers that interact with parents daily. Many expressed difficulties in comprehending the information presented and retaining complex explanations, thus hampering their ability to make decisions. During this dreaded experience, they did best with very simple and consistent explanations given their state of mind. Better yet, many felt they were better able to process information in a written format that they could review after discussion.

Parents also acknowledge conflicting emotions between what is best for the infant as opposedto what they, as parents had wanted, were very difficult to endure. Maintaining some level of hope throughout the decision-making process was important to them. In fact, some parents expressed that trust for the medical team was hampered when no level of hope was expressedby the health care team. While we may feel that expression of any hope undermines our message of futility, parents felt that maintaining some level of hope, albeit slim, made the providers more credible and trustworthy.

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The truth is, there is considerable groundwork the NICU team must do long before the parent of a moribund infant is approached for this conversation. The American Academy of Pediatrics published "Guidance on Foregoing Life-Sustaining Medical Treatment" clearly identifies process guidance for further review, and it is a good place to use to evaluate how the process ofyour NICU compares. (3)

Two concepts must be openly discussed by the team in any institution to improve our care. First, there must be agreement among the medical team that the practice to forego painful resuscitations at the end of life and instead offer peaceful deaths is ethical in futile situations. The definition of futility may be subjective and should be up for discussion as well. Reaching this consensus

may be difficult in both a large academic NICU or even community level III NICU.In these cases, it may be appropriate to consult with the Palliative Care team early if available or develop a subset of multidisciplinary providers within the NICU to consult and support this practice. The subset of infants can be those with severe asphyxia requiring cooling therapy, extreme prematurity less than 24 weeks, or infants requiring ECMO. Communication and establishment of working relationships with parents should begin early, usually upon prenatal diagnosis or unexpected admission to NICU in those infants at high risk for death before discharge. Written protocols may help to improve consistency among providers.

Second, this decision must be made jointly between parent and physician within a respectful working relationship. The burden of this decision cannot be left on the shoulders of the parents alone. There will be multiple caregivers interacting with the parent, and consistency in message delivery is paramount. Trust is established by providing consistent, honest, simple information that respects maintaining some element of hope. Unless circumstances arequickly dire, redirection of care should not be broached at the first meeting. Consider the development of a peer-to-peer support program for added support for parents.

In closing, while an infant's death is always tragic, with forethought and empathy, we canhelp parents through this difficult time in a better way.

References:

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Corresponding Author

Patricia Stevens, MS, NNP-BC
Neonatal Nurse Practitioner, Consultant Comer Children's Hospital
University of Chicago Medical Center
5721 S. Maryland Avenue
Chicago, IL 60637
Email: Pstevens1@peds.bsd.uchicago.edu