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If it is a Baby, Is it a Person?

Robin Pierucci, M.D., M.A.

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Comments and information requests can be directed to:

Charlotte Lozier Institute
2800 Shirlington Rd, Suite 1200
Arlington, VA 22206
E-mail: info@lozierinstitute.org
Ph. 202-223-8073/www.lozierinstitute.org

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The CNN headline touted, “The world’s most premature baby has celebrated his first birthday after beating 0% odds of surviving.”¹ The baby is Richard Scott William Hutchinson and he was born at 21 weeks and 2 days. In the article’s accompanying picture, he still wears a nasal cannula but the device fails to obstruct his view of his birthday cake or the clear joy expressed on his happy, round face. His eager, frosting-smearing fingers anticipate the very normal mess to come. A year ago his premature body fit in the palm of his mother’s hand. Today, he continues to prove that the neonatal team who said Richard had “0% chance of survival”² was wrong.

Premature Isn’t Just Small

Richard was born at what is called the “edge of viability.” Currently, this is frequently cited as being between 22-24 weeks gestation³; however, there are now a number of infants who have been successfully resuscitated at 21 weeks and are thriving.⁴ These hopeful outcomes are a testament to modern day medical advancements. Our young, innocent patients do present doctors with unique challenges, but with innovative approaches to caring for them we can continue to improve their chances for thriving.

Why are infants born very early so fragile? The answer lies in the fact that they are not merely very small infants, the bigger issues are due to the prematurity of every organ system. Just one example of the ramifications of being born at the edge of viability is their premature skin. At the edge of viability, the skin is still more suited to deal with the fetal environment of amniotic fluid rather than the extrauterine environment of air and the variety of surfaces outside the womb. The premature baby’s skin is very smooth and soft, somewhat translucent, and continuously loses copious amounts of water to her new, non-aqueous environment. The fragile premature epithelium (skin) is also what lines their tiny blood vessels, and unfortunately, whether this epithelium is on the outside of the infant or the inside of blood vessels, it easily breaks. This can make IV access difficult at a time when the need to provide fluids to replace water losses as well as nutrition is mandatory. At

¹ Elassar, Alaa. “The World’s Most Premature Baby Has Celebrated His First Birthday after Beating 0% Odds of Surviving.” *CNN*, Cable News Network, 19 June 2021, www.cnn.com/2021/06/19/us/worlds-most-premature-baby-birthday-trnd/index.html.

² Elassar. “The World’s Most Premature Baby Has Celebrated His First Birthday.”

³ Raju, T. N. K., Mercer B.M., Burchfield D.J., Joseph G.F. 2014. “Perivable Birth: Executive Summary of a Joint Workshop by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, Society for Maternal-Fetal Medicine, American Academy of Pediatrics, and American College of Obstetricians and Gynecologists.” *Journal of Perinatology*, 34, no. 5: 333–342., doi:10.1038/jp.2014.70; Rysavy, Matthew A., et al. “Assessment of an Updated Neonatal Research Network Extremely Preterm Birth Outcome Model in the Vermont Oxford Network.” *JAMA Pediatrics*, vol. 174, no. 5, 2020, doi:10.1001/jamapediatrics.2019.6294.

⁴ Elassar, “The World’s Most Premature Baby Has Celebrated His First Birthday.”; TodayShow. “Born at 21 Weeks, This May Be the Most Premature Surviving Baby.” *TODAY.com*, 21 Nov. 2018, www.today.com/health/born-21-weeks-she-may-be-most-premature-surviving-baby-t118610.

birth, the need for IV access quickly escalates to an emergency because the premature infants have very limited blood sugar stores and they can quickly become dangerously hypoglycemic. This critical need for IV access is problematic due to immature skin and is complicated further by the physical size of these little ones and their proportionally tiny blood vessels. Look at the veins on the back of your hand. Now imagine starting an IV on the back of a hand whose palm is the size of the tip of your fingertip. While these peripheral IV's can be obtained, they often do not last long, and securing them to the fragile skin with tape adds insult to injury.

A common initial solution to the mandatory need for IV access is through use of the relatively larger vessels in the umbilicus ("belly button"). When the infant is slightly older, an IV can be placed by threading a tiny catheter through a peripheral vein in either an arm or leg into a larger more central vein where it can hopefully remain until IV access is no longer needed. Unfortunately, any successfully placed IV also means that there is a break in the skin, which risks infection at a time when there is essentially no immune system. Infection can quickly overwhelm a premature infant who literally hours before, appeared stable. An additional ripple effect of extremely premature skin is that not only do the blood vessels at the surface rupture easily, so can vessels deep within the brain. At the edge of viability, there is a significant risk of bleeding in the brain, called an intraventricular hemorrhage. The reason for this bleeding is multi-factorial, and the immature lining of the blood vessels is just one component. Skin that is developmentally appropriate for the intrauterine environment quickly has trouble in the extrauterine world. The same is true to varying degrees for every other organ system, most dramatically for tiny, premature lungs. Infants born at the edge of viability are intimidatingly small, but what makes them so tricky to care for is helping them transition out of their fetal physiology.

Despite the challenges, the practice of neonatology has dramatically and rapidly improved. In 1971, a widely used neonatology textbook stated, "The lower limit of viability is probably about 28 weeks, at which time most infants weigh two pounds, four ounces (1000g)."⁵ A seasoned neonatal intensive care unit (NICU) nurse once told me that "back in the day, if a baby was 1000 grams or needed to go on the vent, we quietly got out a death certificate." Today, in the same NICU, infants weighing 400 grams and born at 22 weeks gestation have been successfully discharged home with minimal or no respiratory support or medications. This is certainly not universally true. Not all premature infants survive, and some who do have lifelong, significant medical issues. However, patients of all ages who seek medical intervention for the underlying purpose of saving one's life have similar risks. If we refuse to resuscitate and care for our smallest patients, then the only thing we guarantee is their death. This issue of predetermined, non-transparent hospital policies for the resuscitation of premature babies led neonatologist Annie Janvier and colleagues to ask, "Which outcomes are good enough to justify intensive care treatment? Which outcome

⁵ Rysavy, Matthew A., and Danielle E. Ehret. "Extremely Preterm Birth Outcomes in Sweden." *JAMA*, vol. 321, no. 12, 2019, p. 1163., doi:10.1001/jama.2019.2020.

is worse than death? When is giving a chance not indicated?”⁶ The answers to these questions are difficult and nuanced and should be answered in the context of each individual infant’s situation. However, the answer for infants who are extremely premature or have potential disabilities should be consistent with the answers we already give to every other patient, regardless of their age, disability or illness. For example, only a limited number of hospitals perform cardiac surgery. Thus, the expectation for a patient who presents with a surgical cardiac issue (adult or pediatric) is that they will be evaluated, stabilized, and the best effort made to safely transport him or her to the most appropriate facility. Likewise, not all hospitals can or should be equipped to care for the most fragile of babies. But the impossible is not what is called for—lack of abandonment is the clarion call.

From my previous articles published in *The Linacre Quarterly* and by the American College of Pediatricians:⁷ There are multiple differences between the early 1970s and today, but some of the most recent advances have come from what we have learned *not* to do. This would include using ventilators as little as possible and instead, providing gentler, less invasive pulmonary assistance.⁸ Consistent with this medical practice change is intentionally decreasing not only obviously painful procedures, but rethinking how the entire NICU environment affects our youngest patients.⁹ Two examples of practice changes include: (1) increased use of “kangaroo care” where the premature baby is placed in skin-to-skin contact with either the mother’s or father’s chest, and (2) cue-based care times, where the staff tries not to interrupt valuable sleep and uses, within reason, the babies’ cues for checking vital signs and providing required care instead of doing this on a predetermined every-3-hour schedule. These are just two examples of the many ways in which multiple centers involved in performance improvement projects associated with the Vermont Oxford Network (an international consortium of more than 1,300 hospitals working to improve neonatal care).¹⁰ Some have intentionally decreased noxious stimuli from a variety of sources and intentionally increased parents’ presence. The infants, perhaps especially our most premature, have better outcomes when their parents are more involved. The neonatal teams are important, but the babies are neurologically better off

⁶ Janvier, Annie, et al. “Blowing the Whistle: Moral Distress and Advocacy for Preterm Infants and Their Families.” *Acta Paediatrica*, vol. 106, no. 6, 2017, pp. 853–854., doi:10.1111/apa.13852.

⁷ Paragraph from Pierucci’s works, American College of Pediatricians. 2021. “Fetal Pain: What is the Scientific Evidence.” Retrieved from <https://acpeds.org/position-statements/fetal-pain>; and Pierucci, Robin. “Fetal Pain: The Science Behind Why It Is the Medical Standard of Care.” *The Linacre Quarterly*, vol. 87, no. 3, 2020, pp. 312, doi:10.1177/0024363920924877.

⁸ Cummings, James J., and Richard A. Polin. “Noninvasive Respiratory Support.” *Pediatrics*, vol. 137, no. 1, 2015, doi:10.1542/peds.2015-3758.

⁹ Altmier, Leslie, and Raylene M. Phillips. 2013. “The Neonatal Integrative Developmental Care Model: Seven Neuroprotective Core Measures for Family-Centered Developmental Care.” *Newborn and Infant Nursing Reviews*, 13, no. 1: 9–22. doi:10.1053/j.nainr.2012.12.002; Morris, Mindy, John Patrick Cleary, Antoine Soliman. 2015. “Small Baby Unit Improves Quality and Outcomes in Extremely Low Birth Weight Infants.” *Pediatrics*, American Academy of Pediatrics, 136 (4) e1007-e1015. pediatrics.aappublications.org/content/136/4/e1007; Pierucci, Robin. “Fetal Pain: The Science Behind Why It Is the Medical Standard of Care.” *The Linacre Quarterly*, vol. 87, no. 3, 2020, pp. 311–316., doi:10.1177/0024363920924877.

¹⁰ Vermont Oxford Network. Retrieved from public.vtoxford.org.

hearing the voices they were listening to while in utero.¹¹ We have seen even our tiniest patients raise their eyebrows or entire heads in reaction to hearing their parents' voices. The neonatal staff is good, but we are not Mom and Dad and the premature babies know it. Decreasing painful stimuli and increasing parental involvement are changes encompassed in "small baby units," specialized areas within NICUs, designated for the most premature infants.¹² The evidence in support of these recent changes indicates that our most vulnerable are not only more frequently surviving, they are going home healthier.¹³

Outcomes

Hanging on the walls of many NICUs are pictures of NICU graduates holding their baby pictures. Some of the graduates are school age, some are adults, but they are all NICU survivors, and the pictures are truly moving and inspiring. We have witnessed more than one parent walk up to the pictures and say to their spouse or family member, "See, our baby has a chance." Having a chance is not a guarantee, yet evidence shows that the medical staff judge outcomes differently from parents. In a study where neonatologists and NICU families were interviewed, Adams et al. found that "in general, physicians were more concerned than families with enduring physical, mental, and cognitive impairment of children"¹⁴ and that "according to some, medicine as a profession has historically underestimated and undervalued the quality of life of persons with disabilities."¹⁵ Further substantiating the breadth of the problem, in the updated Neonatal Research Network and Vermont Oxford multi-center study that included more than 4,000 extremely premature babies, it was found that "the birth hospital contributed equally as much to prediction of survival as gestational age."¹⁶ If a hospital's policy is never to resuscitate an infant who is less than 24 weeks gestation, then no baby born there, regardless of their potential for survival, will survive.¹⁷

As immature and tiny as extremely premature infants are, they are someone's daughter, they are someone's son. The age of viability continues to move earlier, but the primary and most important diagnosis does not change—we are caring for someone's child

¹¹ Vohr, Betty R. "The Importance of Parent Presence and Involvement in the Single-Family Room and Open-Bay NICU." *Acta Paediatrica*, vol. 108, no. 6, 2019, pp. 986–988., doi:10.1111/apa.14783; Pineda, Roberta, et al. "Parent Participation in the Neonatal Intensive Care Unit: Predictors and Relationships to Neurobehavior and Developmental Outcomes." *Early Human Development*, vol. 117, 2018, pp. 32–38., doi:10.1016/j.earlhumdev.2017.12.008.

¹² Morris, Cleary, and Soliman, "Small Baby Unit Improves Quality and Outcomes."

¹³ Watkins, Patricia L., et al. "Outcomes at 18 to 22 Months of Corrected Age for Infants Born at 22 to 25 Weeks of Gestation in a Center Practicing Active Management." *The Journal of Pediatrics*, vol. 217, 2020, doi:10.1016/j.jpeds.2019.08.028.

¹⁴ Adams, Shannon Y., et al. "'Quality of Life': Parent and Neonatologist Perspectives." *Journal of Perinatology*, vol. 40, no. 12, 2020, pp. 1809–1820., doi:10.1038/s41372-020-0654-9.

¹⁵ Adams, Shannon Y., et al. "'Quality of Life': Parent and Neonatologist Perspectives."

¹⁶ Rysavy, Matthew A., et al. "Assessment of an Updated Neonatal Research Network."

¹⁷ Lantos, John D. "Ethical Issues in Treatment of Babies Born at 22 Weeks of Gestation." *Archives of Disease in Childhood*, 2021, doi:10.1136/archdischild-2020-320871.

and are privileged to do so. Importantly, we are still learning just how much better these little ones survive when their parents are intentionally included in their care. Extremely premature babies are capable of responding to their parents' love. We as a society need to consistently respond to our littlest ones too. We may not be able to medically cure every infant, but abandonment is never appropriate. We need to acknowledge that each of our smallest sons and daughters can be provided care – and with each step forward in medicine the “edge of viability” becomes a faded line in the sand. Informed by the data, the medical standard of care for providing lifesaving medicine for the most vulnerable newborns has changed. Unfortunately, the law has not. Instead of being trapped in a myriad of complexities that started in 1973, our laws need to be informed by the same research that guides medical practice. In 1973 we did not know just how far we would come in our ability to save the tiniest of human lives, and today we cannot predict how much further we will go--but we can update the law to be ethically consistent with our medical advancements and the value inherent in all human lives.

Robin Pierucci, M.D., M.A., is an Associate Scholar at the Charlotte Lozier Institute