

# Moral Distress In the NICU - Their Pain is Our Pain

Rob Graham, R.R.T./N.R.C.P.

*I dedicate this column to the late Dr. Andrew (Andy) Shennan, the founder of the perinatal program at Women's College Hospital (now at Sunnybrook Health Sciences Centre). To my teacher, my mentor and the man I owe my career as it is to, thank you. You have earned your place where there are no hospitals and no NICUs, where all the babies do is laugh and giggle and sleep.*

*“ Since the very first units specialising in the care of premature infants opened, those have questioned what is done to them. Today is no different. Constantly pushing the boundaries of viability has only exacerbated the problem.”*

Since the very first units specialising in the care of premature infants opened, those have questioned what is done to them. Today is no different. Constantly pushing the boundaries of viability has only exacerbated the problem.

At the beginning of my nearly 34-year career in the NICU, resuscitation was offered at 25 weeks postmenstrual age (PMA), discouraged at 24 weeks PMA, and was not offered at 23 weeks PMA or if weight was <500 grams. Reasons for this were the equipment limitations, the belief that the pulmonary system was incapable of supporting respiration, and the small chance of survival, making any lifesaving measures futile. In cases where resuscitation was offered below 25 weeks, PMA survival was reported to be 8% at 23, 16% at 24, and 53% at 25 weeks PMA. By 26 weeks, PMA survival increased to 63%, and 72% by 27 weeks PMA (1).

Data comparison between 1982-1985 vs. 1985-1988 showed no improvement in survival (20%) despite more aggressive treatment and technological advances. What did “improve” was the mean time to death once transferred to NICU, increasing over 10-fold (1). Perhaps this is where the seeds of caregiver moral distress were first sown.

By 1993 significant improvements in the treatment/care of these

infants are borne out by the statistics. No infants resuscitated at 22 weeks PMA survived, but at 23 weeks, survival increased to 15%. At 24 and 25 weeks, that rate was 21% and 69%, respectively, and overall survival increased to 39% (2). While the overall survival rate was significantly higher, excluding 22-week PMA infants (29 infants), survival increased to 50% in the 23 – 25-week PMA cohort.

Aside from the routine adoption of surfactant replacement, improvements in mechanical ventilation were undoubtedly a major driving force behind increased survival rates. With the introduction of microprocessors, ventilator technological improvements accelerated during the '90s. Genuine, reliable synchronisation, volume monitoring, and later volume targeting, plus greater monitoring capability, were added to the clinician's repertoire. In contrast, before the '90s, most babies were ventilated with non-synchronized intermittent mandatory ventilation (IMV), and earlier attempts to provide synchronisation (in the author's experience) were unreliable. By the late '90s, with the notable exception of the US, a new generation of ventilators could offer both conventional ventilation (CV) and high-frequency oscillatory ventilation (HFO). This facilitated the increased adoption of HFO first as a “rescue” strategy and later as a first-line mode of ventilation.

*“By the late '90s, with the notable exception of the US, a new generation of ventilators could offer both conventional ventilation (CV) and high-frequency oscillatory ventilation (HFO). This facilitated the increased adoption of HFO first as a “rescue” strategy and later as a first-line mode of ventilation.”*

Improvements in pulmonary outcomes resulted in resuscitation being routinely offered to infants below 25 weeks PMA, first at 24 weeks, then at 23 weeks. Herein lies the source of uneasiness felt by many bedside caregivers. Patient acuity and length of stay increase with declining PMA. For the caregiver, this results in more exposure to all the unpleasantness stemming from the interventions necessary for the baby's care. Follow-up analysis of survivors post-discharge revealed that acuity and length of stay notwithstanding, outcomes were very similar between 23 – 25 weeks PMA babies.

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

One analysis showed that while death at 23 weeks PMA was significantly higher than at 24 or 25 weeks PMA (44.2% vs 31.6% and 12.1%, respectively), this was not the case for minor or major morbidity nor survival without morbidity. Surprisingly, those born at 23 weeks PMA were *least* likely to suffer any morbidity and *most* likely to suffer no morbidity at all (3). Buoyed by these numbers, neonatology set its sights on the 22-week PMA infant. For better or worse, this is where we are today.

---

***“Surprisingly, those born at 23 weeks PMA were least likely to suffer any morbidity and most likely to suffer no morbidity at all (3). Buoyed by these numbers, neonatology set its sights on the 22-week PMA infant.”***

---

Survival statistics at 22 weeks PMA vary widely and are influenced by several factors. Between ≈20 and ≈70 % live to 1 year of age, with odds declining significantly with lower birth weight. Exposure to antenatal steroids improves survival, and centres that liaise with the obstetrical team have the best outcomes (4).

It is likely that when presented with this data, many bedside caregivers would be suspect; caregivers have a long history of underestimating survivability and overestimating incidence of morbidity. Two things are of note: pediatricians and neonatologists are likely to be more optimistic than bedside caregivers (RN etc.), and these perceptions were worse in 2020 than in 2010 (5).

Why would there be a discrepancy in perception between those at the bedside and physicians who typically spend very little time there? Furthermore, why would those perceptions be worse now than ten years ago? A deep dive into the complex psyche of caring for critically ill premature babies sheds some light.

---

***“Surveys of bedside nurses and residents show marked differences in feelings depending on the scenario. Moral distress is higher amongst those working in outborn facilities than inborn ones, and increases as the gestation age of the patient decreases.”***

---

Surveys of bedside nurses and residents show marked differences in feelings depending on the scenario. Moral distress is higher amongst those working in outborn facilities than inborn ones, and increases as the gestation age of the patient decreases. Tying in with the generally pessimistic attitude described above, those with less knowledge of actual outcomes are most likely to feel distressed (6). In having said that, there is more to feelings of moral distress than a lack of knowledge, and this reference indicates a reverse effect among medical residents.

Moral distress increases with acuity and decreasing PMA, as does the continuation of aggressive treatment in situations caregivers perceive as futile. It is challenging to measure feelings, but it is prudent to address their source. It is the hallmark of cognitive behavioural therapy. Let us examine some possible sources.

A bedside nurse is a witness to everything a baby goes through and the anguish of parents. They may feel powerless to alleviate it. Next to the parents, the bedside nurse is arguably the strongest advocate for the baby. Not being heard is a source of angst in and of itself. Many caregivers are female and of childbearing age if not mothers themselves. Women are known to be more empathic than men (7), and motherhood increases their capacity for empathy (8). When a mother tells you, “I feel your pain,” it may be true. This has implications in the NICU since they may be susceptible to their patient’s pain. When concerns are voiced, they are often met with “get used to it; this is the new normal” or dismissed altogether. If feelings are dismissed without acknowledgment or discussion, the person’s perceived value with those feelings is diminished, and the whole team suffers as a result.

---

***“Bearing witness to ongoing pain (real or perceived) has a cumulative effect that can result in PTSD, similar to first responders. The magnitude of this must not be ignored. Since the resuscitation of 22-week PMA infants has become routine, I have seen nurses leave or retire early or go off on stress leave.”***

---

A bedside nurse may form bonds with both patients and parents. Bearing witness to ongoing pain (real or perceived) has a cumulative effect that can result in PTSD, similar to first responders. The magnitude of this must not be ignored. Since the resuscitation of 22-week PMA infants has become routine, I have seen nurses leave or retire early or go off on stress leave. All too often, when asked why the answer is, “I cannot be part of this anymore.” With 20% survival, a bedside nurse sees only pain and suffering for 80% for the survival of 20%. “Is it worth it” is an unpopular but valid question -- one whose answer may be yes or no depending on the individual’s experience and perception.

There is no shortage of places to work for nurses seeking escape from the challenges of the NICU. The mental well-being of bedside staff must be addressed. A 15-minute de-brief just does not cut it. Increased acuity will undoubtedly lead to faster burnout for those not suffering moral distress.

For the patient in the NICU, there is no escaping a degree of pain. Some neonatologists are reluctant to provide sedation and analgesia due to uncertainty regarding long-term effects in the premature population. When they do, it may be inadequate. There is good reason to be cautious. There has been insufficient research into the drugs used for sedation to validate their use in the premature population, particularly the micro-premature. Midazolam is widely used outside the NICU, but flags have been raised regarding its

safety, namely slower growth of the hippocampus (9), and in 2017 a Cochrane review concluded there was insufficient evidence to support the use of midazolam in the premature population (10). Recently dexmedetomidine, a drug with anxiolytic, sedative, and analgesic effects but without causing respiratory depression, has been used in the NICU. To date, it appears safe, and while not established in the preterm population, there is evidence it is neuroprotective (11). Still, long-term data is lacking.

---

***“Kangaroo care (KC) has been shown to significantly reduce a baby’s stress level along with a host of other benefits (12) and is, without a doubt, the safest, most cost-effective therapy employed in the NICU. When it comes to infant comfort, KC should be a first-line therapy.”***

---

Kangaroo care (KC) has been shown to significantly reduce a baby’s stress level along with a host of other benefits (12) and is, without a doubt, the safest, most cost-effective therapy employed in the NICU. When it comes to infant comfort, KC should be a first-line therapy. I practice offering KC to any infant stable enough to do so, including babies on high-frequency jet ventilation. It is a bit of work, but it is worth it.

Many factors adversely affect the developing brain; pain has been shown to alter brain structure (13), which is also true in premature infants (14). Morphine is one of the oldest analgesics and is still widely used in the NICU. Evidence suggests it may not be the best choice as it alters the developing brain (15). Fentanyl is now being used increasingly as a first-line analgesic. Its lack of cardiovascular depressive effects is instrumental in the preterm population. Its ability to produce chest-wall rigidity if given too quickly is well known, but it also has enormous patient-to-patient variability regarding elimination half-life (317 -1266 minutes c.f. 222 in the adult). Tolerance may also develop (16). In my experience, fentanyl tolerance can develop quickly in some babies. (Perhaps this is more reflective of lower half-life than tolerance.) I recall one infant under my care whose heart rate would jump when the incubator door opened even though he received fentanyl at an **adult anesthetic** dose. In my opinion, it is crucial to assess the effect of an analgesic, not just give it.

Recent follow-up data on premature infant exposure to fentanyl is somewhat reassuring. “Higher cumulative dose was associated with lower composite motor scores on bivariate analysis... cumulative fentanyl dose was not associated with MACB-2 (17) scores on multiple linear regression” (18). Since infants experiencing more pain are likely to receive more fentanyl, it is hard to determine which is responsible for the results.

This logic brings us to the proverbial elephant in the room: cost. The cost of a day in the NICU in the US may exceed \$3500 (all figures in 2008 dollars), and bills at discharge are routinely over \$1 million. Of the 12 most costly procedures in the US, only intestinal transplantation costs more, and barely at that (19). The smallest, most premature babies spend the most time in hospital, thus cost-

ing the most for which to provide care. While the total expenditure is a tiny percentage of the US spending on healthcare, it was about \$26 billion in 2008 (20). As resuscitation of 22-week PMA infants becomes increasingly common, are insurance companies going to balk at the cost, or worse, deny coverage?

That figure does not reflect the cost of sometimes life-long post-discharge care, and caregivers are acutely aware of what life holds for these babies and their families. However, one cannot decide what quality of life is for another person, and it is impossible not to empathise with them, even if our perception of their happiness is inaccurate. In 2021 post-discharge costs were over \$25 billion annually in the US. Those costs may relegate many to a lifetime of poverty, doubly punishing since poverty in and of itself is a risk factor for preterm birth (21). Caregivers are not unaware of the burden their patients may impose on society.

---

***“While placing a price on human life is anathema to healthcare professionals, it is the de facto reality many face daily and one which insurance companies impose regularly. Whether this money could be better spent is a legitimate, even ethical, question.”***

---

While placing a price on human life is anathema to healthcare professionals, it is the de facto reality many face daily and one which insurance companies impose regularly. Whether this money could be better spent is a legitimate, even ethical, question. The US system is far too focused on catching the proverbial horses rather than keeping the barn door shut. This context is perhaps inevitable in a system focused on profit as the outcome. In countries with government-funded healthcare systems, the NICU is considered a “black hole” for money and must compete for resources with other programs.

That is not to say that money spent in NICU is not well spent; indeed, quite the opposite. A neonatologist I work with once told me that NICU provides greater value for money than anywhere else in the system. If that is true, preventing NICU admission must provide even more value.

The rate of preterm birth in the US in 2010 was 12 per 100 live births and 10.5 per 100 live births in 2021, a slight year-over-year increase. By comparison, even 10.5 is higher than the 2010 rates in the rest of the G-7 countries (21,22). Money spent reducing factors contributing to premature birth is not only a good investment but also morally imperative.

Moral distress is not going away, but we can choose to reduce it. I firmly believe that all life deserves a chance, but with one caveat: recognise the futility and stop. We once recognised the futility of resuscitating a 23-week PMA baby; we must now recognise that continuing treatment on a dying 22-week PMA infant is not care. It is cruelty.

Since nurses are the ones who spend the most time in direct con-

tact with babies and their families, this column has focused on the nursing profession. That is not to say other team members do not face the same moral dilemmas, perhaps most of all respiratory therapists.

#### References:

1. [https://www.nejm.org/doi/10.1056/NEJM198912143212405?url\\_ver=Z39.88-2003&rfr\\_id=ori:rid:crossref.org&rfr\\_dat=cr\\_pub%20%20pubmed](https://www.nejm.org/doi/10.1056/NEJM198912143212405?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%20pubmed)
2. <https://www.nejm.org/doi/full/10.1056/NEJM199311253292201>
3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4921282/>
4. <https://neonatalresearch.org/2022/01/27/active-intensive-care-at-22-weeks-gestation/>
5. <https://obgyn.onlinelibrary.wiley.com/doi/10.1111/ajo.13443>
6. [https://www.researchgate.net/publication/6501720\\_Moral\\_distress\\_in\\_the\\_neonatal\\_intensive\\_care\\_unit\\_Caregiver%27s\\_experience](https://www.researchgate.net/publication/6501720_Moral_distress_in_the_neonatal_intensive_care_unit_Caregiver%27s_experience)
7. <https://pubmed.ncbi.nlm.nih.gov/19476221/>
8. [https://www.researchgate.net/publication/352247397\\_Motherhood\\_and\\_empathy\\_increased\\_activation\\_in\\_empathy\\_areas\\_in\\_response\\_to\\_other%27s\\_in\\_pain](https://www.researchgate.net/publication/352247397_Motherhood_and_empathy_increased_activation_in_empathy_areas_in_response_to_other%27s_in_pain)
9. <https://www.contemporarypediatrics.com/view/midazolam-warning-preemies>
10. [https://www.cochrane.org/CD002052/NEONATAL\\_intravenous-midazolam-infusion-sedation-infants-neonatal-intensive-care-unit](https://www.cochrane.org/CD002052/NEONATAL_intravenous-midazolam-infusion-sedation-infants-neonatal-intensive-care-unit)
11. <https://tspace.library.utoronto.ca/handle/1807/126752>
12. <https://www.hopkinsallchildrens.org/Services/Maternal-Fetal-Neonatal-Institute/Neonatology/About-Our-NICU/Kangaroo-Care>
13. <https://www.pathways.health/chronic-pain-long-term-effects-on-the-brain-and-body-explained/#:~:text=Being%20in%20long%20term%20pain%20literally%20changes%20the,attention%2C%20memory%2C%20thought%20processes%2C%20motor%20control%20and%20coordination.>
14. <https://www.sickkids.ca/en/news/archive/2018/research-co-led-by-sickkids-shows-premature-babies-may-be-more-susceptible-to-effects-of-pain-from-lifesaving-care-harming-brain-development/>
15. <https://www.sickkids.ca/en/news/archive/2016/pain-management-in-premature-infants-linked-to-impaired-brain-development/>
16. <https://pubmed.ncbi.nlm.nih.gov/25176283/>
17. Movement Assessment Battery for Children, Second Edition
18. <https://pubmed.ncbi.nlm.nih.gov/36061415/>
19. [\[ical-procedures\]\(#\)](https://www.aoc-insurancebroker.com/most-expensive-med-</a></li></ol></div><div data-bbox=)

20. <https://journalofethics.ama-assn.org/article/cost-saving-tiniest-lives-nicus-versus-prevention/2008-10>
21. <https://www.marchofdimess.org/peristats/reports/united-states/prematurity-profile>
22. [https://data.un.org/Data.aspx?d=WHO&f=MEASURE\\_CODE%3AWHS\\_PBR](https://data.un.org/Data.aspx?d=WHO&f=MEASURE_CODE%3AWHS_PBR)

*Disclosures: The author receives compensation from Bunnell Inc for teaching and training users of the LifePulse HFJV in Canada. He is not involved in sales or marketing of the device nor does he receive more than per diem compensation. Also, while the author practices within Sunnybrook H.S.C. This paper should not be construed as Sunnybrook policy per se. This article contains elements considered "off label" as well as maneuvers, which may sometimes be very effective but come with inherent risks. As with any therapy, the risk-benefit ratio must be carefully considered before they are initiated.*

**NT**





Corresponding Author



Rob Graham, R.R.T./N.R.C.P.  
Advanced Practice Neonatal RRT  
Sunnybrook Health Science Centre  
43 Wellesley St. East  
Toronto, ON  
Canada M4Y 1H1  
Email: [rcgnrcp57@yahoo.ca](mailto:rcgnrcp57@yahoo.ca)  
Telephone: 416-967-8500



Readers can also follow  
**NEONATOLOGY TODAY**  
via our Twitter Feed  
**@NEOTODAY**