

Editorial linked to fetalneonatal-2016-312322.R1: providing active antenatal care depends on the place of birth for extremely preterm births: the EPIPAGE 2 cohort Study.

### **Variation of practice and poor outcomes for extremely low gestation births – ordained before birth?**

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Parent representatives (could this be printed in the editorial):

Jason Baardsnes is the father of Maren and Lily who were born at 25 weeks of gestational age, Lily died in the first week of life, Maren is now 7 years old.

Mikael Hébert is the father of Domenica who was born at 22 weeks of gestational age. She is now 5 years old.

Stephanie Newell is the mother of Marcus, who was born at 23 weeks of gestational age, was not offered intervention and intensive care admission, he died during birth.

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Decision-making for extremely preterm infants is ethically complex and wide variations of practice exist within and between countries. The investigators of the EPIPAGE 2 study have studied outcomes for all births between 22 and 26 weeks of gestation in France during 2011. In their current study, they explored the variation in proactive antenatal care across the country<sup>1</sup>. They demonstrate huge variation in the proportion of preterm infants who received active antepartum interventions, ranging from 22% to 61%. Alongside these data they show immense variation in the proportion of babies at different gestational weeks born alive but who subsequently died in the delivery room – 45% of livebirths at 24 weeks died before admission, and 90% at 23 weeks. Reflecting this, only 28% of liveborn babies survived at 24 weeks and there were no survivors below this.

In EPICure 2, a similar study that took place in England, there were differences in mortality between non-NICU and NICU centres across the board.<sup>2</sup> Similar large variations in mortality occurred in 2006 in the same gestational range as EPIPAGE 2; although overall non-active neonatal care only explained 32% of the variance between populations, at 23 weeks it was as high as 76%. In a recent NICHD study, interventions in the delivery room explained 78% of the variance in mortality between the constituent hospitals<sup>3</sup>.

These variations reflect a prevailing pessimistic philosophy regarding extreme prematurity. National policies often use death and adverse outcomes to justify non-intervention in preterm infants. But policies do not just reflect outcomes, they also shape them<sup>4</sup>.

How do we move past the professional negativism associated with extremely preterm birth? In our opinion, this can only happen with changes in healthcare delivery, policies, and philosophy, accompanied by transparent reporting of outcomes, and public accountability.

## **1. Healthcare delivery and policy**

It seems clear that being born in the correct place is a *sine qua non* for producing optimal outcomes, but the data suggest that this can be a lottery. It shouldn't. In 2006 only 56% of births <27 weeks of gestation occurred in centres with an NICU in England; this has steadily increased since (76% in 2015) and survival for admissions has increased in line with this, by on average 3.9% and 3.55% per annum at 23 and 24 weeks<sup>5</sup>. Within centres with an NICU, larger services have improved survival, particularly at the lower gestations<sup>2</sup>. Healthcare providers must ensure that extremely preterm births only occur in appropriately sized centres with an NICU, wherever possible, and monitor that it does. This can only happen if those managing health care and monitoring outcomes work together with providers to ensure the best outcomes.

The delivery of a baby whose mother has received antenatal steroid is more likely to result in a child in good condition at birth. Conversely, failure to administer antenatal corticosteroid during labour results in the delivery of a baby with reduced chances of intact survival, whatever decision has been made with prospective parents. Administration of steroid does not preclude a decision for comfort care, whereas non-administration increases the risk to the baby.

## **2. Philosophy, accountability and transparency**

### **Moving beyond lethal language**

It is not rare for members of the healthcare team to wince when they see the admission label on the incubator, reading “22, 23, 24 and/or 25 weeks”, but 30 years ago, “28 weeks” was an equally shocking number. Language concerning such babies and their family around these numbers may catastrophize the situation: “*we are torturing these babies*”; “*what kind of family wants this done?*”; “*what are we doing, another fetus!*”, without clear and honest discussion of the ethical arguments, and sometimes made without respect for the baby and their family. Interestingly, in front of a baby with similar outcome statistics and a different label (such as a 30-week infant in severe septic shock), healthcare professionals react quite differently. We need to be aware of our biases and get rid of this *numerophobia*. Children are more than a gestational age.<sup>4,6</sup>

Whilst death and disability are an integral part of neonatology, how the message is framed has a large impact on outcomes. For example, after the death of a baby at 24 weeks, it is not rare to hear, in centres where survival is low, that “*we did our best, they are so fragile, we should not be too hard on ourselves*”. This learned helplessness is not prevalent in centers with high survival and good outcomes, where a very different conversation exists: “*We shouldn't expect them to die. We expect them to live and do well. When they don't, we examine each chart and think long and hard at what we could have done better. We can always do better.*” We should all strive to have this commitment to our patients and their families. This is how the message is framed in other fields, where considerable advances have been made, such as oncology, heart surgery, or dialysis.

### **Creating positive encounters and listening to parental perspectives**

Neonatal professionals generally do not stay in touch with the sickest babies they cared for in the NICU. Moreover, we often remember our worst “cases”. Babies who escaped major complications and transited rapidly through the NICU are often forgotten. Drastic improvements in care can happen if we listen to parents' input both during the NICU stay and after. We suggest that when designing follow-up clinics, these be placed next to the NICU so parents can visit. We also suggest other recurrent positive events, such as yearly family picnics for clinical teams and families. Instead, we often focus on the adverse outcomes, for example we review all deaths through mortality rounds. We should also take time to celebrate our successes: many children are alive with a good quality of life because of neonatal care, and their families and society are enriched by their presence.

### **Committing to transparency and accountability**

Survival and outcome statistics should be routinely collected locally, regionally and nationally. These numbers should be transparent -with confidence intervals- and available to the public. For example, parents deserve to know that newborn babies are not

offered intensive care at 22 and 23 weeks of gestation in France, and that in some centers, babies are unlikely to survive birth at 24 weeks. An example is the UK Paediatric cardiac surgery database, where easy availability of outcome data after complex cardiac surgery led to reorganization of services and increased survival.

### **Being proud of our work**

Neonatal services are doing amazing work and have systematically described long term outcomes for years. There are always improvements to be made, but a wind of optimism is needed. As eloquently written by parents: *“Be proud of the work you do. It is so important to us. You make it possible for us to share precious time with our babies. You are the heroes for so many families. You help babies survive and we are thankful for that”*<sup>6</sup>.

### **Conclusion**

Changes in philosophy require more than hard work. With pessimism and negative language, the story can become a self-fulfilling prophecy. Parents demand (and expect) that we are critical of our results, and committed to change the way healthcare providers view and treat extremely preterm infants.

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