

Ethical issues in treatment of babies born at 22 weeks of gestation

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ABSTRACT

Many centres now report that more than half of babies born at 22 weeks survive and most survivors are neurocognitively intact. Still, many centres do not offer life-sustaining treatment to babies born this prematurely. Arguments for not offering active treatment reflect concerns about survival rates, rates of neurodevelopmental impairment and cost. In this essay, I examine each of these arguments and find them ethically problematic. I suggest that current data ought to lead to two changes. First, institutional culture should change at institutions that do not offer treatment to babies born at 22 weeks. Second, we need more research to understand best practices for these tiny babies.

In 2006, Japanese neonatologists reported that 30% of babies born at 22 weeks survived.¹ Similar reports followed from Sweden,² University of Cologne³ and University of Iowa.⁴ These reports also showed that many of the survivors had neurodevelopmental outcomes that were similar to outcomes for babies born at 23 and 24 weeks of gestation. About one-third of survivors had severe neurodevelopmental impairment.

Of note, not all studies report such good outcomes for babies born at 22 weeks. One reason for the variation in reported outcomes is that many studies report outcomes from both centres that do not attempt to treat such babies as well as from centres that do. A typical report, in this regard, is the EPICURE2 Study which reported outcomes on all babies born at 22–25 weeks in England. 152 babies were born alive at 22 weeks.⁵ Most of the mothers were not given antenatal corticosteroids. Fewer than half were delivered at a tertiary care centre. Only 13% of babies received active treatment. Not surprisingly, most died. Only 3 of 248 babies alive at the onset of labour survived. When, by contrast, pregnant women are given antenatal corticosteroids and babies are actively treated after birth, outcomes are much better. Drawing conclusions from studies in which state-of-the-art treatment is not provided gives misleading and pessimistic results about the efficacy of treatment. This, in turn, may be reflected in national policies.⁶

The ability to save babies born at 22 weeks is remarkable and replicable. One might expect that such a startling medical breakthrough would stimulate excitement, admiration, emulation and research. Oddly, it seems to have generated none of those things. Instead, key professional societies have either ignored or misrepresented the outcome data. A 2016 statement by the American College of Obstetricians and Gynecologists (ACOG) and the

Society for Maternal and Fetal Medicine (SMFM) recommended against treating babies at 22 weeks. They wrote, "(D)elivery before 23 weeks of gestation typically results in neonatal death (5%–6% survival) and among rare survivors, significant morbidity is universal (98%–100%)."⁷ Oddly, they back up that statement with a citation to a paper showing that within the National Institute of Child Health and Human Development (NICHD)-funded Neonatal Research Network (NRN), survival rate for babies born at 22 weeks who received active treatment was 25%.⁸

The response in the lay media is similarly unenthusiastic about the prospect of saving babies born at 22 weeks. In response to studies showing improved survival for babies born at 22 weeks, *Newsweek* did not report this as a remarkable medical breakthrough that could save thousands of lives. Instead, they worried that the survival of babies at 22 weeks would have implications for the legality of abortion at that gestational age.⁹

In the UK, the improved survival of babies born at 22 weeks of gestation led the British Association of Perinatal Medicine to issue updated guidelines regarding perinatal management of such babies. They recommended that decisions for such babies should not be based on gestational age alone but should reflect 'assessment of the baby's prognosis taking into account multiple factors' and follow 'multiprofessional discussion with parents'.¹⁰

Many tertiary care centres are struggling to decide whether they should build programmes to provide active treatment for babies born at 22 weeks.^{6 11} To do so requires a serious institutional commitment. That commitment must begin by having regionalised obstetrical programmes so that pregnant women who go into labour at these early gestational ages can be transported to specialised centres. Obstetricians need to consider proactive management of women in labour at 21 or 22 weeks. This should include a willingness to give antenatal steroids and to consider fetal monitoring. The role of caesarean sections (C-sections) for deliveries at this gestational age remains controversial.¹² Without such proactive management, outcomes will likely be worse than those reported in centres that have adopted a proactive approach. Those outcomes will buttress the self-fulfilling prophecies that most such babies die or survive with severe impairments.

Many bioethicists support the withholding of life-sustaining treatment from the tiniest babies.^{13 14} Some, however, argue that doing so violates the principle of justice by which patients with similar prognosis should be treated equally.¹⁵



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Three sorts of ethical concerns are generally raised about treatment of babies born so prematurely. One, reflected in the ACOG/SMFM statement, is that too many of the survivors will have severe neurocognitive impairment. Another is that parents do not want such treatment. A third is that it costs too much. Evidence suggests that none of these concerns is valid.

NEUROCOGNITIVE IMPAIRMENT AMONG SURVIVORS

All extremely premature babies are at high risk of brain damage and neurocognitive impairment. Among all babies born at less than 28 weeks of gestation, 19% of survivors have profound neurodevelopmental impairment (NDI).¹⁶ At centres that offer active treatment to most babies born at 22 weeks, the rates of severe NDI are similar to those for slightly more mature babies. They range from 19% to 35%.^{6–8 10 17} Most babies born at these low gestational ages who survive will grow up without severe NDI.

PARENTAL PREFERENCES

Treatment of these babies clearly falls within the ‘grey zone’ in which outcomes are ambiguous or uncertain. When outcomes are ambiguous or uncertain, parental preferences should guide treatment decisions.¹⁸ If parents choose comfort care, it should be provided. However, at many centres today, parents are not even offered treatment.^{11 19} At many other centres, parents who request treatment receive inadequate treatment because the centres are not prepared to care for these extremely fragile babies.

Parents generally want more treatment than doctors or nurses think is appropriate.²⁰ Parents are more tolerant than healthcare professionals of the idea that babies might survive with neurocognitive impairment.²¹ Parents also perceive that the clinicians who care for their premature babies have highly negative attitudes about treatment and about parents who want treatment.²²

Such findings about parental attitudes come with a caveat. Not all parents feel the same way. Doctors need to carefully explore with parents their values and preferences in order to arrive at a shared decision about whether or not to offer life-sustaining treatments to tiny premature babies.²³ But doctors should not assume that parents share their values or that most parents will not want treatment. Instead, it would make more sense to do what doctors do in other high-risk clinical circumstances—to be optimistic but realistic, to discuss both hopes and fears, and to tailor messages to the parents’ expressed needs for information.

Furthermore, decisions about providing neonatal intensive care are not one-and-done decisions. They evolve over time as the baby’s clinical course allows more refined prognostication. Many tiny babies die within the first few days of life in spite of efforts to save them.²⁴ Some die because treatment is withdrawn after the babies develop significant complications. Others die in spite of intensive care treatment. Decisions to initiate neonatal intensive care should always be followed by periodic discussions, based on the baby’s clinical course, about whether to continue such care.

COST AND COST-EFFECTIVENESS

The cost of neonatal intensive care unit (NICU) care has been controversial since such care was first developed in the 1960s.²⁵ As a result, NICUs have been subjected to more cost-effectiveness analyses than any comparable medical care.^{26–29} The results of these analyses show that NICU is surprisingly cost-effective, even for the most premature babies and critically ill babies.^{30 31} Cheah recently reviewed dozens of these cost-effectiveness analyses

and concluded that, even in a worst-case scenario in which most survivors had significant disabilities and died at age 30 years, NICUs were still more cost-effective than medical intensive care units (ICUs), ‘the calculated cost would be \$38 000/quality-adjusted life-year (QALY), way below the cost of adult ICU costs of more than \$100 000 per patient per QALY, and considered highly cost-effective.’³²

The reasons for this are clear. Most babies who are cared for in the NICU survive and do well. Most of those who survive with neurocognitive disabilities only have mild disabilities. Most NICU survivors go on to live a normal life span. Thus, the high initial costs of intensive care are amortised over a lifetime and the dollars/life-year (or QALY) are low.

Furthermore, most extremely premature babies who die will die in the first days of life. In the NICHD NRN, 40% of the babies born at less than 29 weeks of gestation who died did so within 12 hours of birth.³³ While these situations are sad, they are not expensive.

The result of all these unique factors related to the economics of NICU care is that the average cost of NICU care, even for the tiniest babies, is approximately \$6000/QALY.³⁴ This compares favourably with the cost-effectiveness of interventions like Pap smears (\$17 000/QALY), coronary artery bypass surgery (\$40 000/QALY) or sildenafil for erectile dysfunction (\$11 000/QALY).^{35 36}

THE MYSTERY

Treatment of babies born at 22 weeks of gestation shows very promising results. Parents seem to want such treatment. It is cost-effective. The reticence of many centres to provide such treatment seems to be a result of institutional inertia.

Institutional inertia arises because the care of these tiny and extremely fragile babies requires a deliberate and concerted team effort. Such institutional inertia has been overcome in Japan and Sweden, and in a few other centres around the world.³⁷ But it remains strong in many other places. The effort must involve collaboration between obstetricians and neonatologists. Pregnant women who are at risk of delivering at 22 weeks must be given antenatal corticosteroids and transferred to tertiary care centres. There must be discussions about the indications for C-section. Senior obstetric input is required in the management of delivery. Neonatologists must be present at the delivery. Such collaboration will also have to include NICU nurses and respiratory therapists who will need to be trained in the special techniques that seem to lead to better outcomes.³⁸

In the longer run, we will need better research on the treatment of the tiniest babies. NICHD and other funding agencies will need to fund studies to evaluate different treatment modalities. We will also need efforts to change institutional culture in order to incorporate currently available treatments that have been shown to save lives in a cost-effective manner.

CONCLUSIONS

Survival with good outcomes is clearly possible for babies born at 22 weeks of gestation. Several centres have described a number of different and equally promising approaches to the treatment of these tiny babies. Good studies comparing those treatments are urgently needed in order to determine which practices are safest and most efficacious. While waiting for those studies, centres can use existing information from centres that practise active management of babies born at 22 weeks in order to transform their own practices. This will not require new science. Instead, it will require efforts to change culture at institutions

in which the current norm is to not provide active management for such babies. Together, professionals and parents, working together, can achieve new clarity of thought, purposiveness in practice, and intentionality in national and institutional policies. These efforts will allow all babies and parents to benefit from the promise of existing perinatal interventions.

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