

Title: In Search of Consistency: Scandinavian Approaches to Resuscitation of Extremely Preterm Infants

Short title: Consistency in Resuscitation of Preterm Infants

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25 Word Summary for Table of Contents

There are differences in approaches to resuscitation decisions both within and between countries. We discuss the value of consistency in decisions.

Contributors' statement:

Dominic Wilkinson wrote the first draft, supervised and coordinated the manuscript, and is the corresponding author.

Dean Hayden contributed to the analysis, important intellectual content and helped to evaluate, revise and edit the manuscript.

ABSTRACT

Guidelines around resuscitation of extremely preterm infants have been developed, in part, to ensure consistency in decision-making between hospitals and health professionals. However, such guidelines can also highlight other forms of inconsistency – between countries, and between practice in different areas of medicine.

In this article, we highlight the ethical advantages (and disadvantages) of consistency. We argue that a uniform approach internationally to ethically complex decisions is neither likely nor desirable.

Guidelines and Consistency

The papers in this special supplement describe guidelines and practice relating to treatment of Extremely Preterm Infants (EPIs) in Sweden, Norway and Denmark.¹⁻⁵ There are differences in approach (to which we will return), but what unites these Northern European countries is a desire to have *consistent* decision-making.

Consistency is a fundamental ethical value – one that is shared by many ethical and religious traditions. The principle of treating ‘like cases alike’, is, arguably, part of the very concept of justice. In his *Politics*, Aristotle wrote “it is therefore thought by all men that justice is some sort of equality...and they hold that for persons that are equal the thing must be equal.” Aristotle, *Politics* 3.1282b⁶

If consistency is a virtue, the corresponding vice is *inconsistency* or unequal treatment. The Swedish example is relevant here. In the 1990s, the care of EPIs appeared to diverge between different regions in Sweden.⁷ The southern region accepted a 1990 guideline that restricted active obstetric management of infants prior to 25 weeks gestation, while selectively providing active neonatal resuscitation for live born infants prior to that gestation. In contrast, in northern regions of the country a more active approach to obstetric and neonatal management developed.⁷ The difference in approach between the north and the south of Sweden has provided very important epidemiological data. However, it also highlighted an ethically troubling variation in practice by geographic region – a phenomenon that is sometimes referred to as a ‘postcode lottery’.⁸ Whether an extremely preterm infant survived in Sweden in the 1990s depended on where they were born. In some parts of the country active intervention might be offered, while in other parts of the country only expectant management would be considered. A survey of Swedish neonatologists, published around the same time, demonstrated a wide range in the gestations at which resuscitation would be provided or withheld.⁹ What could explain the discrepancy between thresholds used by clinicians from within a single country? A large survey of European neonatologists has shown that physicians’ reported level of religiosity was consistently associated with differing levels of withholding or withdrawing intensive care.¹⁰ Other factors such as personality type, gender, having had children or length of professional experience has also been shown to be associated with differing attitudes to end-of-life decision making.^{11,12}

Concern to avoid this sort of variation in practice was an important motivation for the revised Swedish consensus guidelines that were published in 2016.¹³ Those guidelines recommend antenatal transfer to a level-3 setting from 22⁺⁰ weeks gestation, and consideration of antenatal steroids and resuscitation. A survey from 2016 of Swedish

neonatologists, published in this supplement, shows a much more uniform approach: most would provide resuscitation at 22⁺⁰ weeks gestation if parents desire active treatment, and most would not withhold resuscitation for an infant more than 22⁺⁶/23⁺⁰ weeks gestation.¹⁴

Guidelines and Inconsistency

While guidelines might help make practice more consistent, they also come at some ethical cost. Gestational age-based guidelines, like the ones adopted in Sweden, Norway and Denmark have come under heavy criticism in recent years. They have been accused of being overly simplistic and reductive,¹⁵⁻¹⁷ and even of representing a form of “gestational ageism”.¹⁸ (In another paper in this issue, one of us points to the disconcerting implication of such guidelines that management might change at the stroke of midnight – a phenomenon dubbed the “Cinderella effect”).¹⁴ These guidelines may also make transparent inconsistencies between approaches to care of EPIs and approaches to other patients. For example, guidelines like those in the Netherlands¹⁹ and also in Denmark²⁰ allow non-resuscitation of 24 week infants at parental request. However, as the Swedish experience makes clear, 24 week infants who receive intensive care have a greater than 70% chance of survival, while the majority of survivors (67%) are unimpaired or only mildly impaired.^{21,22} A number of authors have pointed out that it would be unacceptable to withhold life-saving treatment from an older infant or child with such a high chance of survival without disability, suggesting that this represents discrimination against preterm infants.^{15,23}

There might be ways to rationalise the difference in approach between EPIs and older children. One possibility would refer to the moral status of infants who are extremely immature.^{24,25} If the balance of benefits and burdens were evaluated differently for extremely premature infants, that might support withholding of treatment from 23 or 24 week infants. This might make decisions for EPIs more consistent with decisions about termination of pregnancy (since in Sweden, and Norway abortion is potentially permitted until 21⁺⁶ weeks). However, this would also arguably be inconsistent with national and international declarations that accord full human rights and moral status from birth.³

A different justification for the difference in treatment of EPIs relates to the burdensome nature of neonatal intensive care. Predictably, the most premature infants have a lower survival rate (and higher rate of impairment). They also will require a longer period of support and have a much higher risk of complications, needing invasive and unpleasant interventions to alleviate those complications (for example necrotising enterocolitis, severe chronic lung disease, retinopathy of prematurity, sepsis).²⁶ This double jeopardy (worse

prognosis and increased burden) is one reason why gestational age may have a closer relationship to withholding treatment than other prognostic factors. It is also one potential reason why treatment is withheld from extremely premature infants when it would be provided to other patients with similar prognosis.

International Inconsistency

One interesting feature of the papers in this issue, is the difference in approach between the Scandinavian nations. At least from afar, the Scandinavian bloc is sometimes viewed as politically, ethnically and culturally homogenous. However, despite their geographic proximity, approaches to the care of EPIs have diverged. Sweden has taken a very proactive approach to management, Denmark adopted a less invasive approach (though is increasingly providing more active treatment), while Norway appears to be somewhere in between.

But should we really expect different countries to have the same approach to ethically contentious questions? Imagine that the governments of Sweden, Norway and Denmark, after reading the debates in this issue of Pediatrics, decide that they are going to embark on a large cluster-randomised trial of different models of perinatal care for extremely preterm infants. They randomise different health services across the three countries to provide either an active Swedish-style approach, or a less intensive model, restricting obstetric and neonatal intervention to more mature infants.

We could measure a range of outcomes in such a landmark study - neonatal mortality and morbidity, but also burdens of treatment, costs of treatment, parental wellbeing, impact on families and medical teams. Whatever outcomes we are interested in, we can assume that this study will measure them and provide data at the end.

There is no doubt that this hypothetical study would generate fascinating data. It might generate important input for ethical debate (for example confirming or refuting empirical claims relevant to resuscitation decisions). But there is no guarantee whatsoever that at the end of this study that Sweden, Norway and Denmark would adopt identical policies around treatment. Indeed, it is highly likely that there would remain some differences in approach. While scientific facts are relevant to ethical questions, they do not settle ethical questions. The interpretation of outcomes will be value-laden (for example, what counts as an acceptable level of disability). What is more, any policy necessarily involves judgments about how to weigh up and trade off different values. For example, societies that place greater weight on parental interests might be expected to have a broader grey zone, with more parental discretion about decisions. Societies that are concerned to limit future health care

costs would potentially restrict active intervention at the earliest gestational ages. (Though evidence suggests that neonatal intensive care can be cost effective, even for 23 week infants).^{27,28} Divergent policies may also represent the contingencies of personalities and politics. As Berge Solberg highlights in this issue, Scandinavian approaches to prenatal testing have taken quite different paths in Norway, Sweden and Denmark for reasons that do not necessarily map onto fundamental value differences.⁴

Decisions about providing or withholding treatment from EPIs are ethically complex. Indeed, they are some of the most challenging and vexed questions in medicine. That is why they continue to be debated, and why special issues like this one continue to fill the pages of journals. An internationally uniform approach to these decisions is neither likely, nor, perhaps, even desirable. However, because these questions are so complex, none of us should rest on our laurels. We must not assume that we have all the answers or that our own approach is the right one.

For that reason, the Scandinavian experience, along with other international comparisons of approaches to treating preterm infants are extremely valuable. It is highly unlikely that a trial like the one described above will ever be attempted. Yet in effect, across Scandinavia right now infants are already randomly receiving one of several different models of perinatal care. (The randomness comes from which side of a border the infant happens to be born on rather than a computer-generated randomisation algorithm). The epidemiological data stemming from different guidelines and approaches to the care of EPI across Scandinavia provides us with some of the important information that we need to have an informed debate. Wherever we happen to live, we can all benefit from looking over the border at our neighbours, seeing what is shared and what is not, and reflecting on whether we could or should take a different approach.

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