Managing births at the limit of viability: the Danish experience

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Summary The issue of how to treat extremely premature infants has been debated several times in Denmark, and the option of withholding intensive care has received considerable support. Accordingly, a conservative, minimally invasive approach is used, with selective use of resuscitation in the delivery room, early nasal continuous positive airway pressure, and elective use of mechanical ventilation. Parents are actively involved, and the clinical process is gradual with the risks and benefits considered at each step. The risks include causing pain, suffering and loss of dignity in the short and long term for both the baby and the family. Few babies delivered before 25 completed weeks' gestation are considered to be alive at birth, and only a minority of those admitted for neonatal care do survive. Now, however, parents seem increasingly prepared to accept the suffering and uncertainty of intensive life support for the most immature babies when it becomes necessary.

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The nature of the problem

Some people assign infinite value to every human individual, from fertilization of the egg until death, but most people do not. At a very early stage of human development, systematic neglect is generally accepted in the form of contraception preventing implantation. At a later stage, abortion at the request of the pregnant woman is lawful in many countries. At an even later stage, abortion is lawful for special reasons — medical or social. Extremely preterm birth falls within this continuum.

Once there are signs of life after expulsion from the uterus, however, the result of that birth is a living human individual, and this poses a different question. Beating of the heart, pulsation of the cord or even gasping may be seen in births earlier than 20 weeks' gestation, and the radical stance of giving all possible life support is probably not taken in any society.

It has been argued that preterm babies, like other young children, do not express an essential human characteristic. They cannot enter into a full interpersonal relation, as they cannot see
other’ as an individual like themselves, an individual which is different and yet has the same rights as themselves. In this respect, these babies are unlikely to differ from animals. It is unlikely that any society would wish preterm babies to be treated like animals.

Therefore, as physicians (both obstetricians and neonatologists), we must identify those babies in whom life support is reasonable and those in whom it is not. In an open society, the reasons must be recorded and the decisions must be acceptable to parents and society at large. These decisions may have been more clearly defined in Denmark compared with other countries that are similar in most other respects.

The origin of neonatology in Denmark

In Copenhagen, a neonatal care unit with medical staff separate from obstetrics and paediatrics was established in 1965 at Rigshospitalet. In 1967, a Chair in Neonatology was established at the University of Copenhagen. The delivery and treatment of very preterm babies from most of Eastern Denmark was soon centralized to Rigshospitalet. In Western Denmark, the service developed differently; intensive care of preterm babies at the Universities of Århus and Odense was still provided in the adult intensive care unit until the mid-1990s. In spite of Denmark being a small country with a population of only 5 million and only 18 paediatric/neonatal units, treatment practices differed considerably between East and West.

Public priorities

In 1990, a consensus conference was organized by the Danish Hospital Institute and the Danish Medical Research Council. An organizing group of professionals wrote questions, a panel of experts gave evidence, and a working group of lay people wrote a report answering the questions. The group recommended that babies aged less than 26 completed weeks’ gestation should not be offered active treatment. In cases where this did happen, it was to be reported to the National Board of Health. Furthermore, it was recommended that professionals should be trained in communication skills, and that more psychosocial support should be given to families.1

The recommendation was not followed up by the National Board of Health, and when the problem of extremely preterm birth was discussed 4 years later by the Ethics Council, advisory to the Danish parliament, opinions were divided regarding the use of a fixed gestational age to limit life support.2 At the same time, a systematic research effort presented a range of questions regarding abortion and treatment of newborn babies using mailed questionnaires to about 700 individuals aged between 18 and 44 years, sampled from the Danish National Civil Registry. Case scenarios were used, and one question was whether mechanical ventilation should be offered to a 24-week, 600-g baby who was given a 40% chance of survival and a 30% risk of severe handicap if they did survive. Seventy-five percent of responders felt that mechanical ventilation should be provided in a scenario where the parents were in their forties, the mother was pregnant after in vitro fertilization, and both parents requested intervention. Only 15% of responders were against. In a scenario in which the pregnancy was unplanned, and the parents were young and undecided about the use of ventilation, 50% of responders felt that mechanical ventilation should be provided, whereas 30% were against.3

A similar study, 10 years later, confirmed that 75% of a random sample of 2000 individuals felt that intensive care of extremely preterm babies should be offered by the public health service, compared with 98% who supported ‘treatment of life-threatening illness in children’.4 These responses contrasted with those of 275 politicians in the regional governments responsible for the public hospital services in Denmark who were also surveyed; 94% supported ‘treatment of life-threatening illness in children’ as part of public health services, whereas only 36% supported intensive care in extremely preterm babies. As politicians are acutely aware of the difficulties of funding public health care from public taxes, they apparently doubt if this gives value for money.

Professional attitudes

In 1990, neonatologists expressed strong opposition to the use of a fixed gestational age limit, regardless of the region of practice. Nevertheless, over the years, the differences in practice diminished. All neonatal units in Denmark now use a conservative, minimally invasive approach to the initial management of extremely preterm babies.

The conservative, minimally invasive approach

The main element is avoidance of intubation after birth. A mask is used to deliver continuous positive
airway pressure (CPAP) with minimal fractional inspired oxygen; bagging can be used, followed by rapid transfer to an incubator and establishment of nasal CPAP and pulse oximetry. This can sometimes be done in the delivery room, which takes away the urgency of transfer and defers the need for the father to decide whether to accompany the baby or stay with the mother. Intravenous glucose is given through a peripheral line or umbilical artery and/or venous catheters. Transcutaneous partial pressure oxygen and CO$_2$ are used where there is significant respiratory distress or oxygen requirement, and surfactant is given if the arterial/alveolar oxygen tension drops below 0.36. The baby is extubated directly thereafter if possible. Apnoea and significant respiratory acidosis are treated with caffeine, and doxapram is added if respiratory failure is imminent. Feeds with human bank milk are given from a few hours after birth. Mechanical ventilation is used selectively and may be withheld or withdrawn if a comprehensive clinical evaluation finds sufficient evidence of immaturity, severe brain injury and/or multisystem failure.

Involvement of parents

A pre-delivery consultation with the parents is important, and should be tailored to the urgency of the situation as well as to the parents’ needs for information. If possible, this consultation is followed by a visit to the neonatal unit, possibly to see a baby of the same size as that expected, and occasionally for a brief conversation with the mother or father of that baby. At a minimum, the paediatrician should hear the history of the pregnancy from the parents. Although most Danish pregnant women are healthy, well educated, in a long-standing relationship with the father, and the pregnancy is planned, this is not always the case. Furthermore, as a minimum, the parents’ expectations should be clarified, and these are usually realistic. In my experience, numbers take away potential misunderstandings: ‘not so bad’ may be said to mean 70% and heard as 20%, or vice versa. The practical aspects of initial treatment are explained, including the use of a small plastic bag to reduce evaporative heat loss and to keep the baby warm, and the potential use of bagging to initiate breathing.

I always try to express that we do not wish to support the life of very ill babies to the bitter end. If the baby’s condition is poor at birth or if complications arise, the parents will be informed, and withholding or withdrawal of intensive care will be considered to avoid unnecessary suffering. Parents almost always express appreciation of this. I listen for an opening to discuss the risk of handicap. The parents may have had personal experience of handicap with family or friends. Usually, the parents agree that some forms of handicap may be worse than death, but some forms of handicap are quite acceptable.

When the baby is born, care is taken to involve and support the parents. The aim is for them to experience parenthood, to see and understand the possibilities and limitations of life support, and to join the decision process. This is sometimes difficult. Parents are usually extremely distressed, sometimes almost incapable, and the professionals involved often have to hand over to others and are often stressed by the concomitant medical complexities and responsibility. Nurses have a pivotal role, and their continuous presence and training in caring are essential. Good communication between parents, nurses and physicians is of great importance.

Legislation

The decision to institute or continue life support is medical, and according to Danish law, the physician has the final responsibility. According to the law, the parents have the right to full information and must consent to treatment. If the parents do not consent to an intervention that may be in the best interest of the child, the physician must obtain consent from the Child Welfare Board of the municipality. In urgent cases, the physician must treat. Withholding or withdrawal of treatment in children is lawful if treatment can only be ‘expected to prolong the process of dying’, whereas there is no provision in the law to withhold or withdraw treatment when the chances of survival are small or the expected quality of life in the long term is low. To my knowledge, no case has been taken to the Child Welfare Board. The main role of legislation appears to be to exert an external pressure to obtain consensus.

Mortality and long-term outcome

Between 1998 and 2002, 425 babies were admitted to the Department of Neonatology at Rigshospitalet at a gestational age of less than 28 weeks. This corresponds to 3.4 per 1000 live births in the region. Almost half were bagged on a mask after birth, 10% were intubated and 3% received cardiac
compressions and/or adrenaline. Survival ranged from 22% for babies under 24 weeks' gestation to 83% for babies at 27 completed weeks' gestation. Mechanical ventilation was used at some point during admission in 40% of survivors (115 of 294) and in 76% of non-survivors (100 of 131). The extent to which other treatments were withheld or mechanical ventilation was withdrawn before death are not known, but a previous retrospective study from Rigshospitalet showed that it is unusual for babies to die without a preceding decision to limit life support.

According to Danish law, delivery before 28 weeks' gestation is classified as a spontaneous abortion if the baby is not alive at birth. The registration of abortions has been inadequate until recently. The National Registry of Hospital Patients records diagnosis at discharge. The International Classification of Diseases (ICD10) coding has been used since 1995. For spontaneous abortions, the gestational age in completed weeks is recorded. Gestational age is determined by ultrasound in about 90% of cases in Denmark. The first report from the National Registry of Births using these criteria for 1998–2001 showed that the proportions of babies considered to be dead at birth were much higher at 22, 23 and 25 weeks' gestation compared with 26 and 27 weeks' gestation (Table 1). The cause of this difference is more likely to be social than biological.

A recent follow-up at 5 years of age of a cohort comprising all Danish babies born in 1994–1995 before 28 weeks' gestation or with a birth weight of less than 1000 g showed an incidence of cerebral palsy in 9% and an incidence of low IQ (below 2 SDs of a reference group) in 19%.

## Discussion

The most important question to our practice is how this minimally invasive approach relates to an acceptance of a reduced chance of survival of the most premature babies.

In principle, the minimally invasive approach is a policy of not treating before it is necessary, e.g. only providing mechanical ventilation for babies with manifest respiratory failure. The reasoning behind the minimally invasive approach is that a well-intended intervention to treat symptoms (e.g. oxygen for apnoea) or to prevent complications (e.g. corticosteroids for chronic lung disease) may lead to disaster. Pre-emptive use of mechanical ventilation has been associated with inadvertent hyperventilation, hypocapnic cerebral vasoconstriction, cerebral white matter ischaemia and damage, and cerebral palsy. Furthermore, the minimally invasive approach aims to minimize disturbances to reduce pain and stress.

In practice, some babies deteriorate insidiously or rapidly, and recovery following rescue intubation and mechanical ventilation is not always fast and complete. The margin of safety is narrower in these fragile babies compared with bigger, more mature babies. If the baby dies, the question remains whether this could have been avoided by more timely support of vital functions.

At present, increased mortality seems to be accepted by neonatologists as well as neonatal nurses in Denmark. The initial period of 'wait-and-see' can be viewed as a trial period, a selection of the fittest. This comes out clearly when rescue intubation and mechanical ventilation is withheld in babies at 23 or 24 weeks' gestational age, and at higher gestational ages when other clinical data or parental choice indicate a decision to withhold life support. Conversely, if a very immature baby breathes on nasal CPAP for some weeks, intensive care will usually be requested and offered if needed on account of a late complication such as sepsis or necrotizing enterocolitis. In recent years, it has become increasingly difficult to decide not to step up life support once the baby has lived for some days.

### Table 1

<table>
<thead>
<tr>
<th>Gestational age (complete weeks)</th>
<th>22</th>
<th>23</th>
<th>24</th>
<th>25</th>
<th>26</th>
<th>27</th>
<th>22–27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Births</td>
<td>155</td>
<td>142</td>
<td>131</td>
<td>150</td>
<td>185</td>
<td>248</td>
<td>1011</td>
</tr>
<tr>
<td>Per 1000 live births</td>
<td>0.60</td>
<td>0.55</td>
<td>0.50</td>
<td>0.58</td>
<td>0.71</td>
<td>0.95</td>
<td>3.89</td>
</tr>
<tr>
<td>Live births (%)</td>
<td>9</td>
<td>30</td>
<td>64</td>
<td>91</td>
<td>93</td>
<td>92</td>
<td>67</td>
</tr>
<tr>
<td>Neonatal mortality (per 1000)</td>
<td>786 a</td>
<td>857</td>
<td>578</td>
<td>272</td>
<td>186</td>
<td>101</td>
<td>277</td>
</tr>
<tr>
<td>Babies surviving to 28 days</td>
<td>3 a</td>
<td>6</td>
<td>35</td>
<td>99</td>
<td>140</td>
<td>204</td>
<td>487</td>
</tr>
</tbody>
</table>

The number of births is approximately the same across the gestational age spectrum.

a Likely to be errors of registration. These babies are not known among neonatologists.
The next question is how many winners and how many losers are created by our practice? When it allows the unfit baby to die quickly and easily without undue artificial intervention to disturb him and to separate him from his parents, it can only be seen as humane. When parents have the time to see for themselves that the baby is too small and too immature to live, his death may be easier for them to accept. When care can focus on helping the baby and his family in this process, it is seen as meaningful and professionally gratifying. Furthermore, when our practice allows the fit baby to show his capabilities, and his carers to adapt their efforts exactly to his needs, it can only be seen as appropriate and efficient care. The problem is that we cannot believe that it is always so. As already discussed, survival chances for the most immature babies are undoubtedly reduced by not providing full support of vital functions from the beginning, and three out of four extremely preterm babies who die in Rigshospitalet do so after an attempt of mechanical ventilation anyway. Furthermore, it can be difficult to dismiss the suspicion that a cerebral haemorrhage could have been avoided by intervening earlier, or that growth or development has been held back by repetitive apnoeas with bradycardia and desaturation.

Two approaches can be taken for research to diminish this uncertainty. Firstly, head-to-head trials of both types of best practice should be undertaken, and such trials are underway. The problems for participating units are to house the competencies of both practices, and to establish and maintain the necessary equipoise in the clinical team. Secondly, we should improve techniques for monitoring of well-being and for prediction of decompensation to help choose the right time for intervention for every baby.

Conclusion

In Denmark, a conservative, minimally invasive approach has served for 10–15 years in accordance with public opinion and supported by law. An advantage has been that the majority of survivors have been managed entirely without mechanical ventilation. However, recently, it has been increasingly difficult not to step up treatment for immature babies who have lived for some days.

Practice points

- Immature babies can be stabilized in the delivery room with minimal means and survive without intensive care
- Immature babies who breathe well for the first few days may need mechanical ventilation later
- The decision to withhold or withdraw care becomes increasingly difficult as the baby becomes older
- Parents can contribute to the decision process

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