

Decision-making at the limits of viability: recognising the influence of parental factors

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Advances in antenatal and neonatal care of very preterm births have significantly improved the survival of babies who were once seen as non-viable¹⁻³ highlighting the need for reconsideration of the limits of viability⁴. Recently, the American Academy of Pediatrics Neonatal Resuscitation Programme amended their recommendation to withhold resuscitation from babies born below 22 weeks of gestation rather than 23 weeks^{5,6}.

Despite these trends, the well-established high rates of severe morbidity associated with survival at 22 to 24 weeks of gestation raise difficult ethical and policy questions when determining management policy, counselling parents and deciding whether to initiate intensive care. Care at these gestations is often referred to as individualised with many doctors only initiating active care if the parents are in clear agreement that they should do so. Inevitably this can lead to significant variation in practice⁷. A recent systematic review of 34 guidelines among 23 different countries highlighted that 68% supported the use of just comfort care at 22 weeks of gestation, but there was a lack of consensus regarding care provision at 23 and 24 weeks⁸. In contrast from 25 weeks of gestation onwards, 65% supported active treatment and resuscitation⁸.

Morisaki and colleagues explored variations in the management of babies born at 22 to 24 weeks of gestation in Japan. They considered the influence of socioeconomic factors on death during delivery and up to 1 hour of life, which they labelled the peri-delivery period. Death during this period was used as a proxy for a decision to not resuscitate as most deaths where only comfort care is provided are likely to occur within an hour of birth. They hypothesised that income (measured using an area proxy), maternal age, marital status and parity may influence whether a baby was actively managed or not. All four factors were found to have a significant effect on risk of peri-delivery death. In particular they found that younger mothers (particularly teenage pregnancies), from low income areas with a previous livebirth were associated with double the rates of peri-delivery death compared to affluent older first time mothers. This contrasted with a lack of social influences on mortality for those babies that survived an hour or more. In this group just the impact of biological factors such as gender remained. This finding supports previous research which similarly found no socioeconomic influence on short term survival and management amongst very preterm babies admitted to a neonatal intensive care unit⁹.

Morisaki et al propose that in peri-delivery deaths at 22 to 24 weeks of gestation, parents' decision-making is influenced by whether their economic and social circumstances would allow them to raise a child who potentially will need sustained and perhaps life-long medical support. It will be important to explore whether similar influences exist in other high income countries as alternative factors may dominate decision making elsewhere. Japan has been at the forefront of providing active treatment for babies at 22 weeks of gestation and this is likely to be reflected in the counselling Japanese women receive. In contrast in a study of 5 countries in Europe, initiation of active treatment is consistently low at 22 weeks of gestation (between 0% and 25% of births provided with respiratory support) and varies widely between countries at 23 and 24 weeks of gestation¹⁰ (between 0% and 75% provided respiratory support). We do not fully understand the basis of this variation and whether parents' perceptions are particularly influenced by the local ethos regarding the management of these babies.

While there is much research on clinical and institutional factors related to resuscitation practices, there is a limited body of research about how parents make their decisions in these situations. Morisaki et al have identified the potentially important influence of mother's socioeconomic background on whether to pursue active support for the baby after birth. The EPIPAGE-2 study in France looked at the factors associated with withholding or withdrawing neonatal intensive care at 22 to 26 weeks of gestation¹¹. Although they looked at a range of clinical factors, they only explored

the influence of parental social factors for babies born from 24 to 26 weeks gestation and in contrast to Morisaki et al found no such association. This may reflect international variation but may also suggest socioeconomic variation is likely to be at its greatest at gestations when active treatment and resuscitation are not routinely implemented and a more individualised approach to care is taken. In contrast a UK study of women whose babies were identified as having a severe fetal anomaly found that women from more deprived areas were less likely to have a termination of pregnancy. This may reflect the different circumstances surrounding the decision-making process or societal, cultural and ethnic differences with respect to raising a child who will potentially need sustained and perhaps life-long medical support. However a better understanding of the parental contribution in all these decisions is important if we wish to be confident that such decisions are made using the best information about future risks for the baby and the support available to the family. Inevitably the factors that most influence parents and families are likely to vary country by country although there may well be some common themes. Currently there are too many unknowns and these can only be addressed by further research.

The findings of Morisaki et al also raise an important issue in relation to how population based neonatal mortality rates are interpreted. In general data from around the world has supported the concept that areas of high socioeconomic deprivation are associated with higher rates of preterm birth including, by implication, those of 22 to 24 weeks of gestation. This group of babies is of particular importance in relation to perinatal mortality as although they are relatively few in number their mortality rates are extremely high compared to more mature babies, comprising up to a third of all deaths. There is wide international variation in practice regarding whether a baby born at this gestation is registered as live born^{7,10}. This suggests that in many countries babies born at 22 to 23 weeks may be classified as a fetal death even if there were transient signs of life. In these circumstances such babies would not necessarily be included in routine statistics. When population based perinatal and neonatal mortality rates are compared for purposes of quality assurance for example comparing hospitals it has been recent practice in the UK¹² to carry out adjustment based on comparative rates of deprivation since higher levels of deprivation are associated with higher rates of preterm birth and hence mortality. The work of Morisaki et al indicates the possibility of a more complex relationship between deprivation and both perinatal and neonatal mortality. Again future research aimed at “unpicking” the interplay between deprivation and early life mortality linked to preterm birth will be essential for fair comparisons between different regions and different countries.

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