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The Neonatal Consultation with Parents Facing the Likelihood of an Extremely Preterm Birth

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It is usual practice for the neonatologist to meet with parents antenatally when there is a likelihood of extreme preterm labour and delivery. The purpose of the antenatal counselling is to inform parents and to assist them with their decision-making.

The most challenging cases are those at the threshold of viability between 23+0 and 24+6 days gestation. This is commonly referred to as the 'gray zone'. On the other hand, infants born at 22+0 weeks gestation are not offered resuscitation in most countries while for those born at 25+0 weeks gestation and over intensive care is recommended[1].

The key issues for these extremely immature infants are the survival rate and the risk of long-term neurological disability. The discussion between the doctor and parents will centre around whether or not to resuscitate the infant at birth and commence on neonatal intensive care.

The quoted survival rates are fairly similar across data series. The Irish survival rate at 23 weeks gestation is 33% and at 24 weeks gestation it is 51%. The corresponding UK figures are 4 out 10 survivors at 23 weeks, and 6 out of 10 at 24 weeks[2]. Among survivors, the rate of severe disability at 23 weeks is 25% and at 24 weeks it is 15%. The problem at the antenatal consultation, however, is that one does not know which ones will do well and which ones will have an adverse outcome. There are, however, a few pointers that may help including gender, girls have a week advantage over boys, poor intrauterine growth and multiple births on the other hand are adverse factors. Time is frequently mentioned during consultations. At 23 weeks gestation, every additional day in the womb increases survival by 3%.

Making sense of numbers in life or death situations is very challenging. The problem with risk is that it only addresses the downside of the situation. The parents may view a 25% risk of severe disability differently and consider that it indicates that the infant will have 75% chance of not developing a severe disability. David Spiegelhalter, author of the Art of Statistics 2020, states that it is better to think in terms of both harms and benefits[3].

The consultation is, by its very nature, problematic. Kaemingk et al[4] point out that uncertainty is a central theme. It is difficult to convey this uncertainty in a meaningful and positive way. One has to take into account the parents' age and life experiences, their level of understanding, and their cultural and ethnic backgrounds. An interpreter may be required. When the message is uncertain, there is the temptation for a doctor to provide the patient with ever increasing rounds of details and medical information. It can lead to a long healthcare provider monologue with limited interaction and responses from the parents. This should be avoided. It doesn't help and it only adds to the family's confusion, and sense of hopelessness.

Shared decision making is commonly recommended. It is difficult to achieve. There is an uneven balance between the doctor and the parents. The doctor has the facts and the knowledge while the parents have little. It is important to engage with the parents at an early stage. Good openers are 'what do you already know about premature babies', 'what do you most fear', 'what do you hope for'. Give the parents the time and space to express their feelings and opinions. When they are finished you can summarise by saying 'what I'm hearing you say is _____, is that correct?'. In this way it is possible to open up a dialogue that is meaningful and helpful for parents. This facilitates informed choice.

Following the preliminary interactions, some commentators believe that the best approach is to set out what can be done for the infant and then discuss whether or not it should be done. This gives the family a platform to work from. It should include a brief description of the immediate resuscitation after birth, the ventilation, the intravenous feeding, the scans, the intensive monitoring, and the prolonged length of stay. This will give them an appreciation of the complexity of care that their infant will require.

It is equally important to describe how the infant will be managed if the decision is to not commence resuscitation and intensive care.

In these circumstances the infant will be dried, wrapped in warm blankets and a hat, and handed to the parents. A single room will be allocated. The nursing and medical staff will remain in close contact and will continue to provide support. On average infants born before 24 weeks live for 60 minutes but some may survive for a few hours. A cuddle cot is available for the infant. After the infant's death a bereavement plan should be in place. A follow-up pathway should be arranged for the mother and her partner. Consistent communication is important, and conflicting information must be avoided.

The communication skill is in the ability to provide and equip the parents with the necessary information on the care pathway in order for them to make their own informed decision. They need to know that their decision is not a binary, irreversible yes or no. There will be many opportunities along the infant's intensive care journey to pause and review whether continuation of the neonatal intensive care remains the best option for the infant. The commonly mentioned review points are a poor response to initial resuscitation, development of a large intraventricular haemorrhage, or severe necrotising enterocolitis. However, it must appreciated that parents don't make decisions for their infant based on facts only. They try to work out for themselves, what a good parent would do in this set of circumstances[5]. I am struck by how often parents bring the issue of pain and pain relief even at this early stage before the birth. It is important explain that both pharmacological measures such as morphine and non-pharmacological measures such as NIDCAP with nesting, minimal noise, reduced lighting, and structured care bundles are employed. The other question frequently asked is how long the infant will be in hospital if they survive. The median length of stay for a 24 weeks gestation infant is 123 days (interquartile range being 104 – 139)[6].

It is necessary to point out the uncertainty of medical care in situations like extremely preterm births. Parents need help to cope with this high level of uncertainty. It is difficult for them to walk the tightrope between being realistic on the one hand and being hopeful on the other. The one advantage of the uncertainties is that hope remains an option as any negative outcomes have yet to become a reality.

Building a relationship with the family is beneficial if time allows before the delivery. If one can re-engage with the parents on more than one occasion, they are more likely to express their true feelings around what should be done.

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