Perinatal Ethics – where beginning and end of life issues can merge.

The perinatal time of a baby’s life (20 week’s gestation to 1 month after birth) can be 24-26 weeks long, or as short as 6 weeks for very premature babies. As with many fields of medicine, new breakthroughs in perinatal technology and treatments are racing ahead of guidelines required for their ethical use. And this perinatal period may have very complex ethical issues since, depending on the circumstances, both the beginning of life and the end of life might happen during this time. At the beginning of July 2015, the New Zealand Perinatal Society’s Bioethics Symposium was held, bringing nurses and midwives, clinicians, scientists and ethicists together to consider current challenging perinatal ethical questions for professionals and parents. Two important areas were highlighted: new next generation screening methods, and care of very premature babies at the margins of viability.

1) Next generation sequencing for antenatal, embryo and newborn screening.

At present, antenatal/prenatal screening is carried out on maternal blood at 0-14 weeks for health measures such as blood group, Rhesus factor, iron levels and diabetes. Mothers are also offered HIV testing and genetic testing for some individual genes (e.g. Down syndrome, trisomy 13, trisomy 18). If a screening test is positive, then a diagnostic test such as choriovilli sampling or amniocentesis is carried out to check the screening result. New next generation DNA sequencing methods allow for simultaneous, multiple-gene testing on maternal blood, on IVF embryos, in neonates, and in adults. These methods have the capability to screen all the genes (the genome) of a person and, not surprisingly, demand for next generation results is already high in the US. Next generation sequencing is high-throughput and quick, and cheaper than one-off gene sequencing. However, when the sequences of multiple genes or whole genome are known, several ethical dilemmas arise.

More information is produced by multi-gene sequencing than clinicians currently know what to do with. Sequences of all newly mutated and variant genes of the person will also be in the data, and the significance of some of this information is unknown (i.e. will the gene ever be expressed in the person, at what life-stage and to what extent or severity?). The meaning of informed patient/parent consent changes when the limits of what you are finding out are not known. Clinicians are faced with several decisions: what to tell parents and what not to, whether withholding information is ethical, or whether telling someone all the information without knowing its significance is ethical, and what level of information best helps parents make important decisions? Parents need to be supported to decide what testing they want, how much information to be told, and what to do with the information. Antenatal next generation screening should be backed up with subsequent diagnostic tests, but US data shows this often does not happen, instead medical actions are carried out based solely on the next generation screening. Testing of IVF embryos in NZ for single gene abnormalities is currently carried out when needed by preimplantation genetic diagnosis (PGD), but with next generation screening, again many or all genes may be screened. Questions arise such as: should all IVF embryos undergo genomic screening and what happens to the current IVF model of ‘no transfer of any affected embryo to uterus’ when effect of some sequences is not known? Parents will need non-directive genetic counselling and co-responsibility with doctors to sort through the mass of genomic results so that the onslaught of information is beneficial and not a burden. Genomic screening of newborns in Neonatal Intensive Care (NICU) first needs consideration of how this information will help critical care decisions for treatment e.g. anticipating the condition of baby, and whether to
limit treatment. The benefits of neonatal genomic screening include being cost effective compared with single gene tests and extra time in NICU, screening results are often medically actionable, and parents may feel they have a right to know all possible information about their baby. However, any secondary findings (ie. the incidentalome) could be a psychological burden to parents and later to the child, and as we don’t know the significance or impact of much of the information, a worst case scenario might be acted upon prematurely. Given the use of next generation genomic screening in the US, genomic testing in newborns is predicted to occur routinely here in NZ in the future, so robust guidelines are needed to prioritise data so that parents know what is needed to make the current decision. The role of enough skilled, knowledgeable and supportive genetic counsellors and clinical geneticists for parents cannot be overestimated.

2) Care of preterm babies at the margins of viability (22-25 weeks gestation).
The current gestational margin of viability for newborns in NZ is 23 weeks (NZ guidelines are for no resuscitation below 23 weeks, parental decision between 23-24 weeks, and resuscitation after 25 weeks). However, care decisions for neonates in the 22-25 week group vary throughout the country depending on the views of parents and clinicians. In the Netherlands, neonates are resuscitated only over 25 weeks, and France admits 22-28 weeks neonates to NICU with a lower survival rate. New Zealand 23 week neonates have a 42% survival rate, and at 24 weeks 66% survive, indicating a critical 3% daily increase in survival during this time period. Should medical effort be focussed on pushing back the 23 week margin in NZ? Gestational age is only one factor that influences a neonate’s survival, along with gender and birth weight of baby, whether the mother has had steroid treatment prior to giving birth, and if the baby is a singleton or part of a multiple birth. Gestational ageism would not be ethically accepted for any other age bracket, and neither should it be for neonates. A prognostic model incorporating each of these survival factors for the neonate could provide a more ethical platform to make care decisions. Whether to admit a neonate to NICU, to resuscitate or to withhold or withdraw treatment are all decisions which need both medical and non-medical input, and parents need preparation for the ongoing care of a surviving perivable neonate. However, the rights of a newborn are paramount, and the survival instinct of the preterm baby should never be ignored. Since 2013, a NZ perinatal palliative care group has been working to ensure support (clinical, social and spiritual) for families and neonates for a peaceful, pain-free and family-centred time for dying. Education for families about what happens before, at and after death, and support to arrange quality times to make and record memories are important, whether at home or in hospital. Societal attitudes to disabilities and genetic syndromes are changing but medical language accentuates the abnormality, rather than the uniqueness and special strengths of a child.

The Super-Power Baby Project by Rachel Callender photographically tributes children with a variety of genetic conditions as their parents see them, including Rachel’s daughter Evie – ‘while every child and family is very distinctive, there are consistent themes that emerge: unconditional love, living in the moment, empathy and compassion...these are some of humanity’s highest ideals and these children are the teachers of these values...as humans we are all different, we all have strengths and attributes that can be celebrated. There is no such thing as perfect, yet we are obsessed by it. Chasing an illusion while missing what is right in front of us.’

http://www.otago.ac.nz/bioethics/news/events/otago089135.html