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Neonatal ethics

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An extremely premature baby is born at 23 weeks of gestation, 17 weeks before term. The baby weighs just 500 grams. With full intensive care approximately 50% of these babies will survive, but many will have long-term developmental problems. Should intensive care be started or should the baby be allowed to die peacefully? The question forces us to consider the value we give to infants. After all, in UK law 23 weeks is earlier than the limit for abortion for social reasons. And who decides – the doctors, the parents, or the law courts?

Thirty years ago less than 20% of babies born before 28 weeks of gestation survived. But over the last 30 years advances in medical care at the beginning of life have transformed the prospects of survival for babies born extremely prematurely. Currently in major centres in the UK more than 80% will survive, and many babies are now surviving at 23 weeks gestation. This progress is exciting, but now there are increasing concerns about the human and financial cost of these developments in neonatal care.

Is attempting to save the life of these vulnerable babies a wise use of resources?

Up to 20% of extremely premature survivors will have an obvious disability such as cerebral palsy and many more will have evidence of educational or behavioural difficulties at school age.[1,2] This begs the question, is attempting to save the life of these vulnerable babies a wise use of resources? There is also the paradox that while society invests vast sums of money in saving the life of a premature baby after birth, it also tolerates the abortion for social reasons of fetuses a week or two earlier.

It is not only premature babies who raise ethical dilemmas. Some babies are born with serious complicated congenital malformations involving major organs such as the heart, the lungs or the central nervous system. Others have profound brain injury as a result of hypoxia at birth, or congenital infection. Should an attempt be made to treat such babies or would it be more ethical to withhold medical treatment?

Historical philosophies

Historically many societies have regarded newborn babies as having less value than adults. Infanticide and the exposure of newborn infants was a common and accepted practice in classical Greek and Roman societies.

These were societies that prized athleticism, strength and what were called 'the masculine virtues', so it was natural for babies to be despised because of their weakness, dependence and immaturity. The significance and worth that society tended to place on an individual child was in proportion to his or her future contribution to the State as an adult.[3]

There were no laws prohibiting the killing of malformed or sick infants and even healthy newborn babies were frequently unprotected by legal statute or social custom. It seems that the majority of philosophers and writers of the period supported infanticide. In Plato's *Republic* infanticide was regarded as essential to maintain the quality of the citizens: 'The offspring of the inferior and any of those of the other sort who are born defective, they will properly dispose of in secret, so that no one will know what has become of them'. For Plato (427BC-347BC), children were valued according to their approximation to the ideal adult. They must be 'malleable, disposed to virtue and physically fit'.

Aristotle (384BC-322BC) supported a law that advocated the compulsory exposure of all malformed babies: 'As to exposing or rearing the children born let there be a law that no deformed child shall be reared'. In his treatise *On Anger*, Roman playwright and philosopher Seneca (4BC-65AD) wrote, 'Mad dogs we knock on the head; the fierce and savage ox we slay; unnatural progeny we destroy; we drown even children who at birth are weakly and abnormal.

Yet it is not anger, but reason that separates the harmful from the sound'.

In the earliest known medical treatise on gynaecology, Soranus, a Roman physician of the first and second centuries AD, wrote a chapter for midwives called *How to Recognise the Newborn That is Worth Rearing*. This gives detailed clinical signs by which a healthy newborn could be distinguished from a malformed or diseased baby.[4]

In summary, the ancient Greek and Roman world regarded newborn babies as disposable and only of value in their potential contribution as future citizens. Many other ancient cultures of the East and elsewhere also practised infanticide.

Judeo-Christian difference

By contrast the Jewish community of the same period had a radically different attitude to newborn infants. This stemmed from the teaching of the Old Testament law, that every human being was made in God's image.[5] Consequently, every human being, newborn or adult, deformed or healthy, slave or free, was created with an *intrinsic* value as a unique expression of God's image.

Hence the Old Testament law taught that the deliberate destruction of any human life, including that of a newborn baby, was an affront to the dignity of God.[6] In addition the Old Testament law put a strong emphasis on the duty of the strong to protect the weak and the defenceless from abuse.

It was not surprising that the Jewish community had a reputation of being strongly opposed to infanticide, which was seen as an abhorrent pagan practice.

In the New Testament Jesus affirmed the Old Testament view of the significance of babies and young children, but took it further. In our modern child-orientated society we find it hard to appreciate just how revolutionary was Jesus' teaching that unless you become like a little child you cannot enter the kingdom of God.[7] Jesus taught that the 'welcoming' of a little child in Jesus' name was equivalent to welcoming Christ himself and the Father who sent him.[8,9] On the other hand those who caused a little child to 'stumble' would be punished severely.[10]

Unlike the Jewish religious teachers of the day, Jesus emphasised the importance of children and it is obvious that he had a special affection for them. He rebuked his disciples for preventing children from coming to be blessed by him and went out of his way to make time for them.[11,12]

Most astounding of all was the Christian claim that God had come to earth, not as an omnipotent emperor, but in the form of a weak, defenceless and dependent baby. We can deduce that because God himself became a baby then all babies were special.

The early Christians turned this theology into practice. They regarded the rescue and adoption of orphans and foundlings as an essential Christian duty, since it involved in many cases saving those babies who had been abandoned and exposed by their parents. Later on Christians set up orphanages and hospitals to care for the large numbers of babies who were rescued. Right up to the modern era, Christians set up numerous *Foundling Hospitals* in many cities in Europe to care for abandoned babies.

Facts and figures

- About 6,000 babies are born very prematurely (less than 33 weeks of gestation) each year in the UK
- About 2,400 babies die in the first four weeks of life, each year in the UK
- About 2,800 abortions a year are performed after 20 weeks of gestation
- About 100 abortions a year occur at 24 weeks and over
- The cost of providing intensive care for a newborn baby is up to £1,000 per day
- 98% of all baby deaths in the world, occur in less developed countries
- The mortality rate for babies born in sub-Saharan Africa is over 12 times that of the UK

A secular perspective

Some present-day philosophers, such as Peter Singer, base their arguments on the fact that killing unwanted infants or allowing them to die has been a normal practice in many societies throughout human history and prehistory.[13,14] He then claims that the widespread acceptance of prenatal diagnosis and abortion for fetal abnormality in our society implies that we too accept that the life of a handicapped child is not as worthwhile or valuable as the life of a healthy child.

For Singer, a person is someone who is aware of his or her own existence over time. He argues that human babies cannot be regarded as 'persons' because they are not self-aware or capable of grasping that they exist over time. The killing of a newborn baby is not equivalent to the killing of a self-aware adult.

Consequently Singer, and some other influential philosophers, argue that we should be prepared to accept the medical infanticide of unwanted or deformed newborns.[15] As in the world of ancient Greece and the Roman Empire they regard the newborn baby as a being of potential value for the future but of little intrinsic worth.

Modern practice of neonatology

The development of neonatal care is founded on a philosophical perspective that is much closer to the Judaeo-Christian understanding than that of the Graeco-Roman world. A founding principle of neonatology is that every baby deserves the very best care, medical treatment and protection from harm. Behind this is the belief that every baby, however small or sick, has intrinsic value as a unique human person.

The Old Testament principle of defending the defenceless has been

translated into a duty of care and respect for the weakest and most vulnerable members of our society. If we are to take this Christian duty seriously we should be advocates on behalf of those who cannot speak up for themselves, and defend newborn babies and other vulnerable patient groups from those who might abuse or maltreat them.

Most neonatal health professionals regard the deliberate killing of newborn babies as not only illegal but unethical, because it is incompatible with respect for the intrinsic value of human life.

However treating babies with respect and care does not mean that we are compelled to provide intensive treatment in every situation that arises. Despite spectacular advances in medical technology, there are some babies who cannot benefit from medical treatment and death is inevitable. In such cases it seems clear that withdrawing or withholding intensive care is an ethical and appropriate option. Our moral duty to attempt to prolong life is not absolute; it does not apply when there is no prospect of recovery. It's worth remembering that the purpose of intensive care is not to prolong life, but to support someone while they return to health.

In practice there may be professional or personal pressures that make it difficult for healthcare staff to withdraw intensive care once it has been started. Some babies may receive weeks or months of treatment even when the outlook is hopeless. On these occasions intensive care can change from being a source of healing and restoration and can become a source of harm, even a technological form of child abuse.[16]

Treating babies with respect means that we must protect them from potentially abusive medical care. We must learn to recognise the point where medical treatment becomes futile and abusive, where the burdens of treatment exceed the benefits.

The problem then is weighing up the burdens and benefits of intensive medical treatment. If there is no hope of long-term survival and intensive support is merely prolonging the process of dying, withdrawal of medical treatment, following full discussion and with the agreement of the parents, is most consistent with a genuine respect for the dignity of the individual.

Techniques such as ultrasound scanning or magnetic resonance imaging of the brain can give vital information about the presence of brain injury in the critical first hours and days after delivery. Although it will never be possible to foresee the long-term outlook with complete reliability, it is increasingly possible to use brain scans to give a moderately accurate prediction of the likely long-term development for an individual baby.

Of course techniques like brain scans, which allow the extent of brain injury to be assessed, do not solve the painful ethical dilemmas concerning the appropriateness of intensive care for a malformed or critically sick newborn. However scans and other diagnostic tests provide objective information which can be discussed in detail with the parents and with other concerned individuals, and on which ethical decisions about intensive care can be based. In this way respect for the dignity and worth of the individual baby, and concern for their best interests, can be translated into practical decisions about medical care.[17]

Value or benefit?

This does not mean that Christians would join Singer in regarding the life of a baby with severe brain injury as of less value than that of a healthy baby. Nor does it mean that the presence of disability reduces the value of life.

In historic Christian theology each baby is of unique significance as a person made in God's image. But severe brain injury or abnormality does reduce or abolish the benefit that intensive care can bring. Advanced medical technology may prolong existence, but in the most severe cases there can never be independent existence or the capacity for forming relationships.

So as healthcare professionals, it is not our place to make *value of life* decisions, deciding which life is worthwhile and which life is futile. But it is our place to make *treatment* decisions, deciding which treatment is worthwhile and which is futile.

Christians are sometimes accused of vitalism, that is the belief that every life should be prolonged by technology to the maximum extent possible. But this is a false perspective. In fact respect for the dignity of each individual made in God's image, will help us to discern the point when enough is enough and when medical treatment should be withdrawn because the burdens of treatment outweigh its benefits.

Making treatment decisions

The aim of all treatment decisions is to act in the baby's best interests. However in some of the agonising clinical decisions concerning an extremely premature or brain-damaged baby, it is often not clear which course of action is in the baby's best interests. This is when a policy of open communication and discussion between the healthcare staff and the parents is of vital importance. The aim is for professionals and parents to come to a consensus through a process of open and honest explanation and discussion. These discussions are often emotionally charged, time-consuming and difficult, but with patience and persistence a consensus can usually be reached.

On occasions, however, there is a major disagreement between professionals and parents. A second opinion from an independent specialist may be valuable, and emotional support from religious leaders or a counsellor is often helpful. On the rare occasions that there is complete deadlock, it may be necessary to involve the Family Courts for a legal adjudication.

Caring for the dying baby

When health professionals and parents recognise that intensive treatment should be withdrawn or withheld, it is important to realise that although medical treatment may stop, caring must

never stop. We must provide the highest quality of terminal care for dying babies, just as we should provide terminal or palliative care for every dying adult.

Basic care includes adequate pain relief. It also includes controlling distressing symptoms such as breathlessness and convulsions. Secondly, except in extreme cases where there is no gastrointestinal function, milk and fluids should be given via a nasogastric tube, as sick babies are unable to take milk by mouth. Allowing babies to die from starvation and dehydration is not treating them with respect.

Providing compassionate and skilled care so that a terminally ill baby may die at peace, in dignity and pain-free, can be seen as a triumph of neonatal care

Finally, and equally important, each dying baby deserves tender loving care. Loving cuddles, where possible from mother, father or other close relative, are a physical demonstration of the tender care and respect that we owe to each baby. Many parents look back with sadness but also with fond memories to a special time they spent cuddling their dying baby. Caring for dying babies and their families is costly and difficult but it is an important and rewarding part of modern neonatal care.

The death of a newborn baby is one of the most devastating psychological traumas a parent can sustain, often with lifelong consequences. Siblings can also be profoundly affected by the death of a long-expected brother or sister. Health professionals need to ensure that emotional and practical support is provided for parents and for siblings, before, during and after the death. Many professionals too can suffer from the emotional costs of providing this level of care and it is important that support mechanisms are in place for them.[18,19]

Conclusion

The status and value of newborn babies has been a controversial issue for more than 2000 years and the controversy continues. Some secular philosophers argue that babies are disposable at the parents' wishes. However in historic Christian theology every baby, however weak or malformed, is seen as a unique person known and loved by God, and our duty as a society and as health professionals is to respect, care and protect each baby from harm or abuse.

We do not have an absolute moral duty to use every treatment for every baby and sometimes the burden of intensive care may outweigh its benefits. Providing compassionate and skilled care so that a terminally ill baby may die at peace, in dignity and pain-free, can be seen as a triumph of neonatal care.

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