

After a controversial BBC documentary, **John Wyatt** defends the resuscitation of extremely pre-term babies

23 WEEK BABIES - THE PRICE OF LIFE

key points

Responding to a recent BBC documentary the author makes a clear and well argued defence for the treatment of extremely pre-term neonates. He explains that resuscitation rules based on gestational age alone are inadequate as they fail to take account of the likelihood of each individual baby's survival.

The assertion that preterm survivors would be highly likely to experience significant disability was badly overstated. Furthermore an attitude that undermines the value of a disabled survivor's life is highly insulting and survivors generally rate their quality of life at a similar level to those who are born at term without medical problems.

Each extremely pre-term baby deserves the chance to be considered for treatment. In cases where there is a good chance of survival it should be standard practice to start provisional intensive care especially in a rich nation such as the UK.

The recent BBC documentary **23 week babies - the price of life** represented six months of filming on the neonatal intensive care unit at Birmingham Women's Hospital. Brilliantly filmed and produced, the programme powerfully illustrated the conflicting emotions of parents confronted with a baby struggling for life at 23 weeks. Four words came to mind: pain, hope, love, despair. As a mother cuddled the tiny form of her bruised and dying baby she whispered, 'Little princess - you are so beautiful...'

But although the programme showed the heart-breaking reality of neonatal death - 'when hello means goodbye...', the underlying theme was expressed in stark form by Adam Wishart, the presenter, 'Is it worth trying to keep these babies alive?' The opinion of many of the professionals interviewed was clearly 'No'.

The clinical decision about whether to commence resuscitation in a baby born at 23 weeks' gestation is complex and multifaceted. These are not easy decisions and they are too important to be discussed by professionals alone. It is right that all of us should discuss and debate the implications. But in addition to the obvious and difficult moral and personal dimensions there are a number of technical and clinical factors, which were not raised in the programme.

Inaccuracy in gestational age

The programme gave the impression that gestational

age can be measured with complete accuracy. The only situation in which this is possible is in the rare case of an IVF pregnancy when fertilisation occurs in the laboratory. In all other pregnancies the gestational age is obtained by a combination of the menstrual dates and antenatal ultrasound scanning. Even with early ultrasound scanning, gestational age may be out by four to seven days. If there is no early ultrasound it is possible for the gestational age to be out by plus or minus ten to fourteen days or even more. If the baby who is thought to be 23 weeks of gestation is in reality 25 weeks of gestation this makes a big difference to the chances of survival. Hence in each case of delivery at a stated age of 23 weeks, clinicians need to assess the likelihood that the gestational age is in error when making a decision whether to resuscitate. It is a well-recognised principle of medicine that if there is genuine uncertainty about whether life-saving treatment is appropriate or not, it is better to initiate treatment rather than fail to commence treatment.

Outcome studies have shown that other clinical variables besides gestational age are crucially important in determining the likelihood of survival and the risks of disability. These include birth weight (the higher the better), gender (girls do better than boys), multiple pregnancies (singletons do better than twins and triplets), and whether antenatal steroids were given prior to delivery (antenatal steroids improve survival and reduce brain injury).

Based on data from a large number of neonatal intensive care units in the USA, a web-based calculator¹ has been developed which allows the chances of survival to be estimated, based on an individual baby's gestational age, weight, gender, birth order and steroid treatment.

Based on the USA data, a 23 week gestation singleton female baby of 600 gms weight with antenatal steroids has a 40% chance of survival and a 17% chance of survival without moderate or severe disability. In other words if she survives she has over 40% chance of surviving without disability. In contrast a 24 week gestation twin baby of 500 grams weight without steroids has a 17% chance of survival and only a 4% chance of survival without moderate or severe disability.

So making blanket resuscitation rules based on gestational age alone is scientifically and medically indefensible. It is a basic principle of medicine that we should individualise treatment to the specific patient we are caring for. In this regard neonatology should be no different from any other branch of medicine.

Outcome figures vary between different neonatal units

A statistic repeated in the programme was that nine out of 100 babies born at 23 weeks will survive and only one will reach adulthood without disability. It is not at all clear where this figure came from but it is highly contestable. The EPICure study looked at all extremely premature babies born in the whole of UK and Ireland in 1995.² It gave overall survival rates of 11% of all live births at 23 weeks. However other published studies have shown much higher survival rates for babies at 23 weeks of gestation. A study based at University College London Hospitals, found an overall survival rate of 46% as a proportion of all live births at 23 weeks for the period 1996 to 2000³ and other published studies have reported survival rates of 66% from USA⁴ and 41% in Australia.⁵

Most extremely preterm survivors rate their own quality of life highly

The BBC programme gave the strong implication that the majority of extremely preterm survivors were significantly handicapped. In the EPICure study, at 11 years of age 52% of children born at 22 and 23 weeks had mild or no disability.⁶ This seems very different from the impression given by the BBC programme. It is one of the paradoxes of neonatology that the long-term outcome after extreme prematurity is better than the outcome following severe birth asphyxia or congenital brain abnormalities. It is very unusual for ex-preterm survivors to be so severely disabled that they are unable to interact with others and engage actively in life.

Studies of health related quality of life in adolescents and adults have shown that ex-preterm survivors give similar self-ratings to those who were

born at term without medical problems.⁷ In my experience disabled ex-preterm survivors regard any paternalistic suggestion that their life was not worth saving as outrageous and offensive.

UK and European law is quite clear that every baby born alive has the full human rights of a citizen, including 'the right to life'. This is also confirmed in the UN Declaration on the Rights of the Child. From the moment of birth health professionals have a legal duty of care to act in each baby's best interests. In other words the primary responsibility we have is to do the best we can for each individual baby. In each case we should try to balance the burdens and risks of intensive care against the likely benefits for a particular child. The law makes birth the transition point at which full human rights are acquired, irrespective of gestation, and to act in a way which is not in a baby's best interests would be a serious breach of those rights. We cannot treat these babies as disposable – they are as much citizens as we are.

Conclusion - Is it worth trying to keep these babies alive?

Each baby deserves the best possible care. Yet the decision as to whether to commence resuscitation or not is complex. In some cases it is clearly right that doctors say 'enough is enough'. Just because a treatment is available does not mean that it should be used. But if there is a realistic chance that a particular baby can survive without overwhelming and catastrophic injury, then surely as a rich country we owe it to each child to give them a chance of life. In this situation it is best to start 'provisional intensive care'. We start intensive treatment in order to give each baby the very best chance of survival but we recognise that if it is clear that the baby cannot survive, or if there are catastrophic complications, then we may withdraw intensive support.

These decisions are painful and difficult. But there is no reason for doom and gloom about premature babies. We should celebrate the successes that have been achieved, value the lives of those who have survived against all the odds, whether disabled or not, and look forward to future advances in the care of these vulnerable citizens.

John Wyatt is Emeritus Professor of Neonatal Paediatrics at UCLH. The opinions expressed are his own and do not reflect those of any body or organisation.

A longer version of this article is available on the CMF blog. See bit.ly/iqwqjW

Photos kindly provided by Bliss, the special care baby charity, who provides vital support and care to premature and sick babies and parents across the UK. www.bliss.org.uk



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