

Ethics & Medicine

A Christian Perspective

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**Rutherford House
Medical Ethics Project**

Aims: The aim of the Project is to develop a Christian mind on the complex and fundamental challenges posed to society by technological advance in medical science. Rutherford House is a research centre whose theological position is Protestant and conservative, but the Project is intended to draw together those with a common concern for a distinctively Christian approach to medical ethics.

The Project is currently engaged in publishing and in organising conferences, and hopes to be able to expand these and other areas as support allows.

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The Handicapped Child

We are grateful to Professor O. Peter Gray of the Department of Child Health, University of Wales College of Medicine for writing this Guest Editorial.

There is considerable debate in both lay and professional spheres about the management of children who are known to be handicapped at birth. The matter was recently crystallised for the Down's Syndrome child by the Dr Arthur trial. It now seems that the fate of a newborn baby found to be suffering from Down's syndrome can be determined by the paediatrician in charge and the parents. If there is agreement between these two parties that the infant should not be treated then its fate is sealed. Treatment - or the lack of it - can include, under these circumstances, withholding feeding. Limited treatment has already been practised although it must be pointed out that the infant concerned weighed only 1.2 kg and had a lethal congenital malformation which nevertheless was amenable to surgical treatment. How wide this practice is remains unknown; on the other hand the deliberate taking of the life of any person young or old remains a criminal offence. The fine line - if there be one - between acts of commission and omission can apparently be drawn in the British legal system.

One of the frequent causes of difficulty in the debate about the treatment of handicapped newborns relates to the term handicap itself. Children born with diseases of internal organs who may in later life be subject to difficulty with their movements because of breathlessness or have problems with their bowels or kidneys which may cause stunting of growth could be regarded as being handicapped in that they have a disability. There are very few who would wish to give them anything other than full medical, surgical and any other form of treatment needed. The main area of concern is about those babies who have a defect of either their brain or their senses - especially of the eyes or the ears. The debate in this group can be divided into two areas, namely those of *thinking* and *doing*. The Lorber criteria referred to *doing*. Children who have paralysis of the lower half of the body with all its vital components are thought by followers of this line of thinking to receive the kindest form of treatment by withholding surgery. On matters like this the debate can be quite clearly crystallised. The fundamental tenets are apparent to both sides. The child cannot move the lower half of the body and never will. Should such a child, or should he not, be given the operative means of life-extension? - that's the debate. On the other hand the fundamental tenets are not so clear when the matter of the *thinking* capacity of the child is limited. Some of the problems relate to the degree of reduced thinking capacity needed before treatment should be withheld. There must be very few who would advocate that a child with no brain - anencephaly - should receive full ventilatory and every other technical life-support system needed. It could only be advocated by those who have no knowledge of this condition, for those born without a brain will never be able to undertake any meaningful life. Can such a body have a soul? Where there is no thought or feeling can the soul find a resting place? Well, that is the one extreme

and about such a child there must be little debate. The other extreme is normality. In between there are children with every degree of mental impairment. The debate centres on the area of the cut-off point, the criteria which are adopted to determine the cut-off point and the alternative treatments to be instituted. That is where the debate starts and that is where some of the biblical principles should be brought to bear.

Does the possession of the means of survival mean that these should be applied every time? These are very real dilemmas for parents and staff.

The debate about the lengths to which treatments must go and the depths to which they are pursued is a frequent cause of discussion in the neonatal nursery. Problems arise like this. Modern technology enables quite a sizeable percentage of babies to be kept alive who are born weighing about 0.75 kg. or so in weight. For those weighing 1.5 kg at birth the outlook is fairly good, at least in terms of immediate survival. The babies can be fed through their veins and their lungs and heart made to work effectively. The technology is here and it may well be asked why is it not always applied. One good reason is that the babies may not be born in an institution which can provide this highly sophisticated type of care and the transfer becomes too hazardous. But the big dilemma for the doctors, nurses and parents is, should it always be provided when the baby is known to be at great risk of serious handicap. The modern technology which provided the means of keeping babies alive under the highly skilled care of the nurses and doctors, has also provided ways of finding out a lot about the babies' internal organs, their structure and function, and the state in which they have or have not survived the birth process. Every organ is important but the one which has the most profound significance for the child to lead an effective and rewarding life is of course the brain. It is not difficult, using ultrasound scanning, sometimes combined with sophisticated modifications, to learn a lot about the intactness or otherwise of the baby's brain. Has the baby had brain damage or has he not? It is not difficult, for instance, to find out if the baby has had a bleed into his brain and the degree of it, nor is it too difficult to find out if parts of the brain have been damaged during the birth process or immediately after. Possession of this information places a tremendous dilemma in the laps of the nursing and medical staff as well as the parents. The dilemma is compounded because although the outlook can be given with a fair degree of probability even in the early days of life, it is still a probability. Put simply, if it is known in the early days of life that a particular child is likely never to be able to walk, may well have fits and not be able to talk or see, should that baby be given every modern facility to live, or 'should nature be allowed to take its course'. Before the days of modern technology, these babies would not live. Does the possession of the means of survival mean that these should be applied every time? These are very real dilemmas for parents and staff.

Paediatric surgeons have had to live with this dilemma for a considerable time. If a child with Down's Syndrome has a lethal malformation of the gastrointestinal tract or heart which could be corrected by surgery thus permitting the child to live, should the surgeon's scalpel be used? The answer is usually, but not invariably 'Yes'. The child who is born with spina bifida presents another major problem. If the defect in the spine is small and there are no, or but minor, complications, there is no reason to refuse an operation, but if the child has paralysis of the legs, bladder and bowels, as often as not in Great Britain, the child is not given the benefit of the operation. There has been great debate about this but the majority of paediatricians have been swayed by Lorber's criteria. A newborn baby with spina bifida is examined and if found to be suffering from major paralysis he is not given the benefit of surgery. It is interesting to ponder on the reasons why Lorber's views have had such a profound effect upon the death of small babies with spina bifida. If an adult developed the same degrees of paralysis after, say, a road accident or an infection, would the same line of argument be held if he required surgery for one reason or another? I very much doubt it, because for one thing the adult would be highly likely to make his views known in no uncertain way, and it would be most unlikely that he would want his life terminated by non-intervention. The 'adult' surgeons take different attitudes to the paediatric staff, apparently. One of the factors which has swayed paediatricians and paediatrics surgeons is the likelihood of operations being many for the child and the possibility of life extending into the third decade being small. However, many children of the 1950's and 1960's who were operated on have survived and proved to be a source of inspiration to many. They can and do have the same opportunities of being Christians as non-handicapped and lead lives which can be of greater importance to the Kingdom of Heaven than vast numbers of non handicapped people.

For many years there has been a tradition that all life is a gift of God and sacred. The debates which have been outlined above, would not have arisen in a preceding era but times have changed. The permissive generation has arrived. Abortions are conducted throughout most of the world with little compunction. For the Christian, however, life is still sacred. The Christian recognises that the Lord gave, the Lord has taken away; blessed be the name of the Lord. Death is inevitable. God in his mercy however, has given man certain tools of healing to lengthen his days. Without these tools the lives of people with certain illnesses would go. An appendicitis untreated may well give rise to a peritonitis and death. Meningitis and septicaemia are equally potent in shortening life but given treatment can be rendered innocuous. It seems that man has been given the tools to counter some of the diseases which came with the fall of man. The question arises as to whether these gifts of healing should be employed on every occasion. Is there an analogy with the life of the Lord Jesus Christ who went about doing good, healing the sick, giving strength to the lame, sight to the blind and hearing to the deaf. He healed multitudes but even so not all. Those who were not privileged to come within his orbit, did not receive his healing mercies. Those who went to the Lord Jesus requesting help received. Those who didn't remained the same. Should the same logic be applied to those born with obvious handicap? Can the simile be stretched to indicate that those parents who wish their

child to be treated should be given modern benefits whereas those who don't so desire be allowed their wishes? The fault in that argument is that the child cannot be consulted and were his opinion to be sought doubtless he would not ask for an early grave.

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The granting of life, however, can be at the expense of much suffering. The processes required for survival of the very small and handicapped can be painful and prolonged and it must be confessed that sometimes one who is utterly committed to the sanctity of life can look at a little child receiving frequent therapeutic procedures and just wonder if it is right to inflict further suffering. The feeling sometimes creeps over one of 'enough is enough'. That impression comes from the very practice of Christianity. The Word commands us to have compassion on one another. Should compassion include stopping further active procedures and allowing the child the dignity of an honourable death? There are times for instance when it is obvious to the parents as well as the practitioners that the infant's soul has left his body. The baby technically may be still alive in the sense that the heart is beating, but there is no sign of brain activity and the child does not have the basic ability to breathe independently. Separation of the baby from the life support system and restoring him to the bosom of the family can be a sublime moment. The parents receive the child, no longer attached to machinery, needles and the like, but dressed in clothes his own and placed on the mother's or father's lap for such time as the heart continues to beat. Calm reigns where turmoil beat. For the Christian, suffering can be mixed with gratitude. Many a non-Christian too has spoken of what a child of even a few days' total life can both teach and give. Decisions such as these as to when enough is enough require much prayer. They do arise from time to time, not only when the infant's brain damage is to so great a degree that the only evidence of life of any sort is the heart beating - but also when, in addition, there is evidence that there is no possibility, humanly speaking, of life if it is maintained being more than that of a body with no effective thought processes. Decisions about maintaining life through mechanical means in bodies which are not even a pale reflection of their Maker's design require a clear conscience before the Judge of all the earth before they can be delivered with conviction, compassion and hope. The burden for the Christian is not only lightened by prayer but also eased because the may well believe - as I do - that the Lord who made the child will accept his soul.

Professor O. Peter Gray

Life and Death and the Handicapped Newborn

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The death of handicapped newborn infants whether by withholding beneficial treatment, hydration, or nutrition, or by some direct act is extraordinarily important to those of us who are interested in the sanctity of human life because this practice could never have come about had it not been for abortion. I shall refer to this for brevity as infanticide although I realise that on this side of the Atlantic infanticide does not have exactly the same definition that we use.

By infanticide I will mean the deliberate killing, - because that is what it is, - of a newborn whether by an act of omission or a deliberate procedure that deprives the child of life.

When the Supreme Court of the United States in 1973 made abortion on demand the law of the land, it chilled some of us to read that the justice who wrote the majority opinion said that he considered the Hippocratic oath which forbid abortion to be irrelevant. He further stated that he spurned whatever morality might be gleaned from the Judaeo-Christian heritage of our country but instead turned to the pagan religions of Rome, Greece and Persia. Although those countries practised abortion, it was infanticide and euthanasia which were more important inhumanities in their culture.

It is important to remember that infanticide is euthanasia in a specific age group. Because infanticide gained such a foothold in our country in the 1960s and 1970s, I am afraid it will come back to haunt us some day when the forces of euthanasia have their way. I can almost hear their reasoning now: 'Why are you concerned about euthanasia? You've been practising it on newborns now for several decades.'

A third important thing about infanticide is that it is being practised by a segment of our population from which we should expect more and being ignored by others who should have more integrity. It is being practised by that segment of the medical profession which, in days gone by, we could always count upon to stand in the role of advocate for children.

Finally, infanticide is being ignored by the law. Infanticide is homicide. The law makes believe it does not happen.

It was really infanticide and all of its implications that brought me into the Pro Life Movement. For more than 34 years I devoted the major part of my professional life to the management of children who were born with congenital defects, many of them incompatible with life, but usually amenable to surgical correction.

Because I was the sixth person in our country to devote his surgical skills to children alone, then because I eventually became the Surgeon-in-chief of the oldest children's hospital in America, I probably did more newborn surgery than anyone in the country until the time that I was called by President Reagan to assume my present post.

Therefore, I know what can be accomplished in the way of rehabilitation of the child. I know what can be done with his family. I know these youngsters become loved and loving, that they are creative, and that their entrance into a family is frequently looked upon in subsequent years as an extraordinarily positive experience.

"Because the start of life was a little abnormal, it does not mean you are going to finish that way. I am a normal functioning human being, capable of doing anything anybody else can."

You might be interested in an anecdote from the early 1970s. My colleagues and I had spent an entire Saturday operating on three newborns with congenital defects lethal without surgical correction. We had successfully corrected the defects and at the end of the day sat down and with a great feeling of satisfaction said that we had given about 70 years of life to each of three children but in toto they weighed about ten pounds, all three of them together.

Then one of us said do you realise that while we have spent the day doing this, right next door they have killed babies of the same size who were perfect, just because their mothers didn't want them.

I went home that night, tired as I was, and began to write a book, *The Right to Live, the Right to Die*, which I finished by Monday morning.

The argument is frequently made by people who have never had the privilege of working with handicapped children who are being rehabilitated into our society after correction of a congenital defect, that such infants should be allowed to die or even encouraged to die because their lives could obviously be nothing but unhappy and miserable.

Yet, it has been my constant experience that disability and unhappiness do not go hand in hand. Some of the most

unhappy children I have known have been completely normal. On the other hand there is a remarkable joy and happiness in the lives of most handicapped children. Some have borne burdens cheerfully which I would have found difficult to face, indeed.

With the affluence of our society, we are really seeing only the beginning of what can be done for handicapped youngsters, both technically and medically, as well as in their pursuit of leisure activity. Who knows what happiness is for another person? What about rewards and satisfaction in life for those who work with and succeed in their rehabilitation of handicapped children? Stronger character, compassion, deeper understanding of another's burdens, creativity and deeper family bonds - I'm convinced that all of these attributes result from this so called social burden of raising a child that is less than perfect.

"I really think that all my operations and all the things I had wrong with me were worth it, because I really enjoy life and I don't let the things that are wrong with me bother me."

There is also no doubt in my mind that the value placed upon the patient by his associates, as one who is respected, honoured and loved is a source of inspiration to all who see it.

The first film in our country on the subject of infanticide was produced by Johns Hopkins Hospital and Medical School in Baltimore and was entitled, 'Who shall survive?'

This was not a motion picture scenario. It was filmed in real life and real time. It depicted a mother who had just given birth to a child who had a simple intestinal obstruction that could have been corrected with a 45 minute procedure and a 99 per cent success rate. Unfortunately, the youngster also had Down's Syndrome and the mother did not want a retarded child. After discussion by the medical staff, the nursing staff, the social service workers, a psychiatrist and a chaplain, it was decided by all of these that the child should die. A sign was hung on the foot of the bed which said 'Nothing by mouth', and the crib was put in a corner. Fifteen days later a parched, emaciated, too weak to cry, little infant died.

The Foundation which provided the money for that film had as its intent to show the horror of infanticide. Instead, that film has been used in medical schools in the United States to teach young medical students and physicians how to handle the problems of a child who is not deemed worthy of life.

The first medical article along these lines appeared in the prestigious *New England Journal of Medicine* under the title, 'Dilemmas of the Newborn Intensive Care Nursery,' and was authored by Professor Raymond Duff and Professor A. J. M. Campbell both of Yale University. They acknowledged that over a two-year period 14 per cent

of the deaths in that unit were deaths that they permitted to happen because it was their considered judgment after discussion with the family that these children had lives not worth living.

Here are several statements they make in support of their position: 'Survivors of these neonatal intensive care units may be healthy and their parents grateful, but in some instances continue to suffer from such conditions as chronic pulmonary disease, short bowel syndrome, or various manifestations of brain damage.'

Duff and Campbell also said: 'Often too, parents' and siblings' rights to relief to seemingly crushing burdens were important consideration in our decision.'

It's odd that Duff and Campbell talk about these parents who have entered into a conspiracy to kill their child, have deeper meaning in their lives after this experience. Could it not be that if they were seeking deeper meaning in their lives they might have better found it in taking care of the child that had been given to them?

Although Duff originally just withheld feeding from these patients, toward the end of that awful era he was giving parents morphine to administer to their own children after he had discharged them to home care.

Another voice at the same time came from Arthur Dyck of Boston, Professor of Population Ethics at Harvard School of Public Health, who said: 'The moral question for us is not whether the suffering and dying are persons, but whether we are the kind of persons who will care for them without doubting their worth.'

Professor Dyck believes in the equality of life rather than the quality of life ethic. I agree with him. So did Hippocrates.

I would not have you believe that everyone in our country feels that way. Even two physicians who worked right in the same unit with Duff and Campbell wrote a letter to the journal that published their paper and said the following: 'As consultants to the Newborn Special Care Unit, we wish to disassociate ourselves from the opinions expressed by the authors. The growing tendency to seek early death as a management option that the authors referred to has been repeatedly called to the attention of those involved and has caused us deep concern. It is troubling to us to hear young paediatric interns ask first, 'Should we treat?' rather than 'How do we treat?'. We are fearful that this feeling of nihilism may not remain restricted to the Newborn Special Care Unit. To suggest that the financial and psychological stress imposed upon a family with the birth of a handicapped child constitutes sufficient justification for such a therapy of nihilism is untenable and allows us to escape what perhaps after all are the real issues - the obligation of an affluent society to provide financial support and opportunity for a gainful life to its less fortunate citizens.'

I don't know what partition of health professionals in the United States feel as I do about the withholding of beneficial treatment from handicapped newborns, but I do know that the vocal ones, or at least those that are reported in the Press, are not on my side.

One of the best words of wisdom on this subject was given by Professor John A. Robertson, then of the University of Wisconsin Law School, who said this: 'One must decide for whose benefit is the decision to withhold treatment from a child with severe birth defects. Is no life better than one of low quality? The person to ask is an individual who has a disabling birth defect.'

I did just that with some of my patients. The patients at the time ranged in age from eleven to thirty years. One patient had been born with a number of major congenital defects down the midline of his body requiring thirty-seven operative procedures for correction. Another was born without an oesophagus, requiring transplantation of the colon to replace that absent organ. Still another was born with a tumour of the tongue necessitating almost total amputation of that structure in a series of operations. The final youngster with congenital defects was born with major defects of the oesophagus, no rectum, and no innervation of the bladder.

The other four children all had tumours. One was a benign tumour of the bones of the face, which had required a number of operations for correction and we still had not achieved perfection. The other three had cancers of the adrenal gland, of the parotid gland, and of the uterus. There can be no doubt about how such young people feel about the joy of living, despite the time-consuming and usually painful medical and surgical procedures they have endured to correct birth defects or those discovered in early childhood. Here is a sampling of their comments:

Because the start of life was a little abnormal, it does not mean you are going to finish that way. I am a normal functioning human being, capable of doing anything anybody else can.

At times it got very hard, but life is certainly worth living. I married a wonderful guy and I am just so happy.

At the beginning it was a little difficult going back to school after surgery but then things started looking up with a little perseverance and support. I am an anaesthetist and I am happily married. Things are going great for me.

I really think that all my operations and all the things I had wrong with me were worth it, because I really enjoy life and I don't let the things that are wrong with me bother me.

If anything, I think I have had an added quality to my life - an appreciation of life. I look forward to every single morning.

Most of the problems are what my parents went through with the surgery. I have now been teaching high school for eight years and it is a great joy.

They spend millions of dollars to send men to the moon. I think they can spend any amount necessary to save someone's life. The human life is so important because it is a gift - not something you can give so you really don't have the right to take it either.

I really don't consider myself handicapped. Life is just worth living. What else can I say?

Two Nobel laureates have voiced opinions concerning this subject of infanticide although they did not include that word in their statements. James Watson of DNA Double Helix fame said:

If a child were not declared alive until three days after birth, then all parents could be allowed the choice only a few are given under the present system. The doctor could allow the child to die if the parents so choose and save a lot of misery and suffering. I believe this view is the only rational, compassionate attitude to have.

That was in May 1973. In January 1978 Francis Crick, was quoted in the *Pacific News Service* as saying:

No newborn infant should be declared human until it has passed certain tests regarding its genetic endowment and that if it fails these tests, it forfeits the right to live.

Before, during and after the activities just described in America, the same thing was going on here.

In Sheffield Mr Robert Zachary and Dr John Lorber were a team making great strides in the treatment of spina bifida. Suddenly Lorber changed his mind and became the chief exponent of infanticide in Great Britain. He was a very convincing spokesman. He travelled throughout the United States and Canada urging paediatricians not to operate upon patients with spina bifida.

Dr Lorber began his presentation with a dissertation on the beneficial advances in recent medical history that are allowing many people to live in an integrated society who formerly would have died or suffered severely. He then distinguishes this from the indiscriminate use of medicine which keeps alive many people who have by his definition no hope of becoming independent functioning members of society.

When I read British statistics that 100 per cent of the patients not treated by surgery in the first few days of life died, I know that they did not die from natural causes. They were either sedated so they could not drink or eat or they actually were given increasing doses of morphine to prevent the pain which almost all neurologists agree does not exist in these youngsters.

Listen to Dr Lorber's explanation:

This is where medical science has led us in the seventies. I show you these children not to horrify you or to make you faint but to make you understand why it is that I prefer the policy of selected treatment rather than creating this immense misery for such an immense number of individuals. We had to restore the balance.

Those who are severely affected from birth get worse and worse. Humanity demands that such badly affected infants should not be put through such constant severe punishment. Criteria had to be found, preferably on the first day of life which could reliably separate those infants who may die early but even more importantly those who would live but would suffer from severe multisystem handicaps and would be unable to live an independent and dignified existence in spite of the best possible treatment. Such a selection is easily possible.

Hear how Dr Lorber sets the death sentence: 'It is essential that those who are not treated should not live long. It is imperative, therefore, that non-treatment should really be non-treatment, not just no operation. Nothing should be done to prolong life.'

There was another side. One of your eminent surgeons, Robert B. Zachary, in the Forshall Lecture given before

the British Association of Paediatric Surgeons in 1976 said this:

I believe that our patients, no matter how young or small they are, should receive the same consideration and expert help that would be considered normal in an adult. Just because he is small, just because he cannot speak for himself, this is no excuse to regard him as expendable, any more than we would do so on account of race or creed or colour or poverty. Nor do I think we ought to be swayed by an argument that the parents have less to lose because he is small and newborn, and has not yet established a close relationship with them, or indeed because the infant himself does not know what he is losing, by missing out on life.

Professor Rickham of Liverpool addressed the issue in an address on the 100th anniversary of the Sheffield Children's Hospital entitled, 'The Swing of the Pendulum.' He said:

How many normal newborn infants will live happily every after, especially in our present time? It may be argued that by not selecting, we artificially increase the number of people with an unhappy future, but can we be sure of this in any given case? After all, doctors deal with single, individual patients and not with statistical possibilities. It has also been pointed out that even a child with a grave physical and mental handicap can experience emotions such as happiness, fright, gratitude and love and that it may be therefore, in fact, a rewarding task to look after him. It has been further argued that, strictly speaking, selection implies a limitation of resources, because with an optimum of resources and care a great deal can be done for these children and their families. In underdeveloped countries these resources do not exist, but in developed countries, where such enormous sums are spent by governments on purposes which are of a very doubtful benefit to humanity at large, the distribution of resources is a debatable subject. Finally, it can be argued that if selection is practised, it may not be necessarily the fittest on whom the greatest effort should be expended.'

On one occasion when Dr Lorber presented his material at a neurosurgical meeting in 1977, Dr John Freeman of Johns Hopkins spoke in response to Dr Lorber. Among his comments were these:

I don't know where he gets those slides of all those deformed human beings and indeed if the outcome were anything like what he presents, I would be standing beside him rather than opposite him. Selection takes many forms and I agree with selection, but I select a very small number, not 75 per cent. Selection takes many forms. But watch the terms. We are talking about selection for death, not university or college, a perversion, I think, of the term. We both believe strongly in discussing the prognosis with the parents. Yet, Dr Lorber's parents make diametrically opposite decisions to mine. Dr Lorber treats 25 per cent of the children brought to him: I treat 95 per cent. When a severely affected child with spina bifida is born, the question asked is, 'Should we do everything possible to maintain that child's life and make it the best life possible or is it best for that child to die? And that is the problem stripped of all the rhetoric.'

Withholding Treatment from Handicapped Newborns

In 1984, in the third year of his first term, President Ronald Reagan did something unusual for a President - He wrote a book entitled *Abortion and the Conscience of the Nation*. There were two additional chapters to that book entitled 'Afterwords.' One was by Malcolm Muggeridge. The other I wrote some years earlier in 1977 entitled *The*

Slide to Auschwitz. My essay had to do with the then growing practice of not feeding handicapped newborns because in the eye of some beholders they did not have lives worthy to be lived. It is not surprising then that the President was incensed over the death of a child known only as 'Baby Doe'.

Baby Doe was born at 8:19 p.m. on the 9th April 1982 which was Good Friday. He was cyanotic, that is his blood was not properly oxygenated: he had an oesophageal atresia, that is an obstruction in the oesophagus incompatible with life but amenable to surgical correction: and he had Down's Syndrome, a form of mental retardation.

His obstetrician said he would be severely retarded, something no one could possibly have known at that stage of the child's development. He referred to the newborn as a blob and he said that the mortality for the surgical procedure to correct the oesophagus was fifty per cent. To indicate how wrong that prediction was, I have repaired 475 such defects and in the last eight years of my practice I never lost a full term baby and my survival for prematures was 88 per cent.

There was also a paediatrician and a family practitioner both of whom thought the child should be referred to the nearest University Children's Hospital for surgical relief of the obstruction. But the obstetrician advised the family to refuse consent for surgery and told the family that the youngster would die in a few days from pneumonia.

At 9.30 a.m. on the same day the family took time out to think it over and at 10 .00 a.m. decided: 'We do not want the baby treated.' The paediatrician asked if they realised what they were doing to which they replied 'Yes'. The obstetrician commented that the family had made a wise and courageous decision.

"The human life is so important because it is a gift - not something you can give so you really don't have the right to take it either."

On April 10th, the following day, the obstetrician ordered the baby to be fed but told the nurses that this would result in choking and death. He forbade the use of IVs and ordered the child kept comfortable with sedation. The hospital administrator, fearing litigation asked the family to take the baby home. They refused. The hospital attorney asked for a judicial hearing and the superior court judge said in view of the fact that there were two medical opinions, the parents could decide to take either one and inasmuch as they had already made that decision he would permit the child to die.

On Sunday 11th April the intensive care unit nurses revolted. The baby was transferred to a private room with private nurses and was given phenobarbital and morphine.

On Monday April 12th three attorneys sought to declare

the child 'neglected' under the Child Abuse Statutes of the State of Indiana. The baby was now weak, parched, and spitting blood. At 11.00 p.m. on that date one of the lawyers sought a court order for intravenous feedings which was refused.

On Tuesday 13th several childless couples petitioned the court for adoption of the child which was denied. The interesting reason given was that it would look as if the family were abandoning the child rather than wanting it to die instead of living with its defects. Meanwhile the lawyers appealed to the Indiana Supreme Court, which without explanation refused to hear the case. On April 15th one of the lawyers was en route to Washington to file and appeal with the United States Supreme Court.

The hospital staff was in an uproar. The chief of staff ordered the paediatrician to start an IV and the altercation he would have had with the obstetrician who barred him from entering the patient's room was prevented by the death of Baby Doe at 10.01 p.m.

In spite of the tremendous things that have happened in the past half decade with organ transplantation, aids, new methods of health care financing and so on, there has been no area of public health policy that has stimulated such widespread discussion, such conflict - including law suits against the Government - and such profound change as this area labelled 'Baby Doe'.

The federal response to what happened to Baby Doe took two forms: first the Federal Government relied upon civil rights legislation first enacted in 1973 which prevented discrimination in the denial of medical treatment and nourishment to handicapped infants with life threatening conditions. After the Government was successfully sued and regulations written to control the care of handicapped newborns were invalidated, Congress stepped in and enacted amendments to child abuse legislation that protected Baby Does under State Child Abuse Statutes.

There were non-binding interpretive guidelines accompanying the regulations which clarified the standard of 'medically beneficial treatment'. Treatments which 'are futile' or 'will do no more than temporarily prolong the act of dying of a terminally ill infant' were not required. Moreover, it was legitimate to withhold treatment if it was 'too unlikely of success given complications' or because it created 'risks' of potential harm to the infant.

If there were more than one reasonable course of treatment which would be medically beneficial, then medical judgement in selecting among treatments would be respected. In spite of the apparent deference to reasonable medical judgement there was underlined in the regulations a presumption in favour of treatment.

These guidelines were incorporated into the suggestion that hospitals with newborn intensive care nurseries set up patient care review committees and the response among medical institutions in the States was gratifying. In about a year and a half more than three-quarters of the hospitals with such units had patient care review committees, and most of the other hospitals either had combined one with another to have one committee for several hospitals or were in the process of forming a committee.

Having monitored the care of handicapped newborns probably as closely as anybody in the United States for the past twenty years, I would say in retrospect that probably the practice of withholding treatment and nutrition from handicapped newborns peaked out *before* Baby Doe was born and the practice had started to decline. With the adverse publicity about Baby Doe, especially in reference to the decision made by the physicians in charge, and with the subsequent regulations under Civil Rights Authority, paediatricians began to rethink their position. What formally was considered to be a broad grey area of dilemma in reference to decision-making was sharpened to a very narrow zone with black and white on either side.

Pro-Life organisations, the advocacy groups representing the handicapped, and the prestigious American Academy of Paediatrics joined together with me and Madeline Will, the Assistant Secretary for Education, and the compassionate care of handicapped newborns took a definite up-swing.

"If anything, I think I have had an added quality to my life - an appreciation of life. I look forward to every single morning."

This improvement in care continued in spite of the regulations in reference to Civil Rights Authority being found invalid by the United States Supreme Court and continued during the time of Congressional debate over protecting handicapped newborns under child abuse legislation. The situation was such that in late 1985 I said publicly that I thought handicapped newborns were better protected and better cared for than they had been in the previous decade and a half.

Now in spite of all the debates, public and private, despite the litigation which sharpened decision-making, both medically and legally, there isn't very much left in the way of statutory authority that can be enforced.

The child abuse amendments protecting handicapped newborns certainly represent a strong statement of national policy. This is particularly significant because the legislation was drawn up by a coalition of senators of Conservative and Liberal persuasion as well as Republican and Democratic affiliation. The house version of the same legislation was equally well represented.

The difficulty is that with fifty States with diverse child abuse regulatory procedures, the standard is probably not legally effective. Congress did stop short of demanding that the States conform with each other in statute and in regulatory action, as well as enforcement procedures.

You could say it in another way and that is that the legislation has imposed a standard of actions on hospitals and State child protective service agencies which is essentially unenforceable against individuals.

There are two options open and that is the law can develop on its own at the State level and perhaps a standard which is uniform will be adopted, but that really requires

cancellation of the federal standard. The other alternative is for Congress to strengthen its previous resolve and enact new legislation demanding a federal standard. Meanwhile, in the foreseeable future but not for too long, handicapped children are protected by personal reassessment of ethical positions by physicians, by general consensus that where we were in the years before Baby Doe was wrong, and of course in our country, unlike your own, there is the constant fear of litigation. The greatest protection that handicapped newborns have in the States today is the concern on the part of physicians and surgeons who care for newborns that someone is watching.

**"I really don't consider myself
handicapped. Life is just worth living.
What else can I say?"**

When the Baby Doe case first hit the newspapers, a number of people said the Government 'had no right' to interfere in a manner that was the responsibility only of the parents and of the attending physicians. Yet everyone knows that there are truancy laws and child abuse laws and immunisation laws and so on where the State's right to interfere is never seriously challenged. Those laws seem to be mainly accepted because for the most part they concern children who are no longer infants.

If the Baby Does of this world were thirty-five years old, they would have a national advocacy organisation and a strong Congressional lobby. Unfortunately they are too small, too weak, and too poor.

There is no constitutional definition of how old someone has to be in order to receive the protection of the State. There is no minimum age requirement for native born citizenship. For example, an American born child does not have to remain in the United States for a week . . . or two weeks . . . or even for an hour in order to qualify - thirty five years later - to run for President. The child merely has to be born an American. I don't find that difficult to understand. I never did. And following that same logic, I believe that a newborn infant whose life is put at risk by a parent, a guardian, a physician, or by whomever - I believe that child is a citizen and deserves to be accorded the full protection of the State.

Back in 1977, a journal, *Pediatrics*, published a survey made of two groups: one, the 400-member surgery section of the American Academy of Pediatrics; the other, a group

of 300 persons who chaired departments or divisions of Paediatrics, Neonatology, and Genetics. They were asked a series of questions and it read almost like a friend of the court brief on Baby Doe but of course this was five years earlier.

For example, they were asked, 'Would you acquiesce in the parents' decision to refuse consent for surgery in a newborn with intestinal obstruction if the infant also had Down's Syndrome alone?' Among the surgeons, 77 per cent would have acquiesced, 19 per cent would not. But the paediatric groups split on the question. Half said they would and half said they wouldn't. What if the parents decided that they did not want any corrective surgery done? Sixty-three per cent of the surgeons said they would then stop all supportive treatment; 31 per cent said they would continue to at least give oral feedings. However, only 43 per cent of the paediatric group would stop all supporting treatment . . . but they were generally unsure about what they would do instead. Only 18 per cent would give oral feedings.

But by far the largest number of responses to this and similar questions fell in the 'No answer' column.

I just don't believe that we can accept 'No answer' as an answer. Not from paediatricians - not from surgeons - not from the Government - and not from the public. If confronted by a newborn infant with one or more disabling conditions, each one of us must be prepared to respond - not take off and walk away. And that is the ethical issue we have got to deal with.

Baby Doe asks us to confess how we really feel about our fellow human beings. Baby Doe prods us into revealing whether we *are* - or *are not* - the friends of the helpless, the weak, the hurt, the injured, and the troubled.

The lives of health professionals as well as the lives of the parents and the disabled are remarkably shaped by the care we give the handicapped. I think that in my forty years of hands on experience has convinced me that all aspects of medical ethics are dwarfed by the question: 'How are we to care for those who cannot - in one way or in every way - care for themselves?'

When we have settled that question, then we can turn to the others such as finances, resources, committees and so on. No one said it would be easy. I am not even saying it can be objective. What I am saying is that the quality of life we talk so much about is nowhere as important as in the reflection these decisions make in the quality of our own lives.

Life, Death and the Handicapped Newborn: A Review of the Ethical Issues

RICHARD HIGGINSON

In this article my aim is to survey a range of opinion among Christian ethicists on the issue of how the handicapped new-born should be treated. I shall focus upon the views of three Christian ethicists. In one sense my choice of thinkers is arbitrary; but in a number of ways it is highly significant. The three thinkers I have selected, Joseph Fletcher, Richard McCormick, and Paul Ramsey, are widely recognised as important and influential figures in the field of Christian ethics. The opinions which they hold differ considerably, and this is representative of a wide range of opinion in the Western Christian community on the subject of how severely handicapped infants should be treated. They are all Americans: this is symptomatic of the fact that on this issue the most detailed and carefully thought out work which has gone on among Christian ethicists has happened in the United States; comparatively little of note has emerged in this country. They belong to different churches: Fletcher (who died recently) was an Episcopalian, McCormick is a Roman Catholic, and Ramsey a Methodist. Ethicists from a wide range of denominations have taken part in these discussions, but it would be misleading to see any of the three as spokesman for a particular denominational 'line'. Finally, the views which they hold reflects their different philosophical presuppositions, or one might say their different ethical methodologies; and here their approaches overlap with many in the secular world, so that the views of Fletcher, McCormick and Ramsey find their counterparts both among non-Christian paediatricians and philosophers.

In order to help pinpoint the differences in view between these three men, I shall try to show what the implications of their views might be for the way in which one would treat three infants with different types of handicap. The three conditions which I have chosen are reasonably common. The first child, whom I shall call Angela, is a Downs Syndrome baby who has been born suffering from duodenal atresia (a blockage of the intestine). If an operation is not performed on Angela to remove the obstruction, she is sure to die. But if an operation is successful (as it almost always is), then Angela can expect to live a normal life - as normal, that is, as a Downs Syndrome child can ever experience. The second child, whom I shall call Benjamin, is a spina bifida baby. His is a fairly severe case of spina bifida. He is suffering from kyphosis (a pronounced curvature of the spine), an open wound on the back, very limited movement of the hips and legs and some enlargement of the head (indicating that he has the associated handicap of hydrocephalus, water on the brain, a condition likely to grow worse). If operations are performed on Ben to close the wound on his back, to increase the movement in the lower part of his body and to divert the fluid in his brain, then the balance of probability is that he will live longer than if he is just given basic nursing care. The third child whom I shall call Charlotte, is suffering from intracranial cancer

(cancer affecting the bones enclosing the brain). No operation can do anything significant to help Charlotte; but it is possible that through the use of tubes and respirators her existence can be prolonged longer than would be the case if no artificial aids were given.

Fletcher, McCormick and Ramsey do not each consider all three cases of this type. Nevertheless, I think it is possible to infer from what they do say what their likely attitudes would be.

Fletcher

Two considerations dominate Fletcher's approach to the treatment of the handicapped new-born. One is that he is blatantly and unashamedly consequentialist and Utilitarian in his attitude to moral decision-making. A principle such as 'sanctity of life' or a rule such as 'do not kill innocent people' does not hold any decisive weight for Fletcher. What is decisive is the likely consequences of any action, evaluated in terms of whether they make for human well-being or not. Well-being is measured in terms of quantity of happiness. Fletcher believes that Christian *agape* or love points in this highly situational, Utilitarian direction.¹ The other important consideration is that Fletcher has a highly specific and circumscribed idea of what a human person is. He has laid down 15 criteria for, as he puts it, indicating humanhood.² These are: minimal intelligence (a minimum IQ of 40), self-awareness, a capacity for self-control, a sense of time, a sense of the future, a sense of the past, a capacity to relate to others, a capacity for a concern for others, the ability to communicate, control of one's existence, curiosity, a capacity to adapt to and initiate change in one's life, a balance of reason and emotion in one's life, idiosyncrasy or distinctiveness, and a functioning neocortex. It is a demanding set of criteria, and one may well be forgiven for wondering at the end of it whether anyone is fully human. For instance, if I am a fairly boring, not particularly inquisitive sort of person who fails to stand out in a crowd, am I in danger of being struck off Fletcher's list of human beings?

What is the connection between Fletcher's love-motivated Utilitarianism and his demanding criteria for personhood (a word I prefer to his own highly idiosyncratic 'humanhood')? Fletcher believes that someone who is not a person cannot claim any right to life. And from his other perspective, he does not believe it loving to keep someone who is not a person alive. On the other hand, he believes it is loving to spare such creatures unnecessary suffering. The loving thing to do is to put non-persons out of their misery, i.e. to kill them. There is no doubt that Fletcher would recommend this procedure with each of Angela, Benjamin and Charlotte. He would not operate to save or improve the condition of any of them. Downs children do not meet his criteria of personhood; he thinks it right and

loving to abort fetuses known to be suffering from the syndrome, and 'if through ignorance or neglect or sheer chance (like the 47th chromosome) the damage has not been ended prenatally, why should it not be ended neonatally?'³ Fletcher considers a case comparable to that of Angela which occurred at the Johns Hopkins Hospital in Baltimore in 1971. A Downs child suffering from duodenal atresia was not operated on (the parents having refused consent to the corrective surgery) and was wheeled off into a corner where it lay dying of dehydration and starvation for 15 days. Fletcher argues that it would have been much kinder to kill the child quickly and directly rather than expose it to a slow, lingering, painful death.

Fletcher's approach sounds brutal, and it is one which very few medical practitioners would like to see put into practice, yet it is arguable that he takes to its logical extreme a viewpoint which is much more widespread and fashionable. Firstly, Fletcher follows the assumptions underlying liberal abortion through to a logical conclusion justifying infanticide. If it is acceptable to kill fetuses suffering from Downs Syndrome or spina bifida, why is it unacceptable to kill infants? Such a distinction can only be based on positing a major gulf between the status of the (well developed) fetus and that of the newly born child. Yet if one assesses the characteristics of the fetus and infant respectively, there is not that much difference. Both lack most of Fletcher's criteria for personhood, assuming (a major assumption) that personhood should be defined in this way. Why then does the one (the fetus) warrant so little protection and the other (the baby) so much? Secondly, Fletcher rightly discerns that not to take action which would almost certainly save a life is to be as responsible for that individual's death as to take life directly. If Angela is allowed to die, it is because certain people (the doctor and/or the parents) desire and intend her to die. They are as responsible for Angela's death as they would be if a father who desired the death of his son discovered him drowning in the bath and neglected to pull his head out of the water.

Before moving on from Fletcher's position, it is worth noting one aspect which underlines the thoroughgoing nature of his Utilitarianism. It is often observed that Downs children are happy and easily contented; they actually seem to be spared some of life's anguish which accompanies the possession of greater intelligence. If they are to be eliminated in infancy, this can hardly be on the grounds that they are likely to suffer extreme unhappiness in later life. The Utilitarian arguments which are used to justify their elimination will almost certainly revolve around the suffering and burden experienced by the Down's child's family and by society in caring for him or her. In other words, the happiness likely to be experienced by the actual patient counts for little beside the suffering which is predicted for those *affected* by the patient. The one is sacrificed for the well-being of the many. The philosophy of 'the greatest happiness of the greatest number' wins, at the expense of the individual who is *most directly* affected by whatever action is taken.

McCormick

McCormick is a difficult thinker to categorise. He is not a thoroughgoing Utilitarian like Fletcher. But he also believes in very few absolute rules. What he looks for on this and other issues are 'broad guidelines' and 'substantive

standards' which illuminate the doctor's decision making, but do not unduly restrict it. Perhaps he is best described as a proportionalist, one who identifies the morally right choice as the one which will bring about a better proportion of benefits to harms than any other available choice. He seeks to be true to a balanced middle path which he describes as characteristic of the Judaeo-Christian tradition, avoiding both medical *vitalism* (which preserves life at any cost) and medical *pessimism* (which kills when life seems burdensome or 'useless'). He argues that life is indeed a basic and precious good, but it is a good to be preserved precisely as the condition of other values. If these values cannot be realised, then the duty to preserve life is reduced. In short, we cannot and should not refrain from judgements about the quality of human life.

McCormick does not embark on a long list of qualitative criteria as Fletcher does. Clearly he would be willing to grant the status of 'person' or 'human' to those who lack many of the capacities named by Fletcher. But he does think that there comes a certain point when life is not worth living, and therefore not worth trying to save. Two considerations are determinative in helping him to identify that point.

Firstly, McCormick argues that 'in Judaeo-Christian perspective, the meaning, substance, and consummation of life are found in human *relationships*, and the qualities of justice, respect, concern, compassion, and support that surround them'.⁴ There appear to be certain handicapped infants whose potential for human relationships is non-existent. Secondly, there are some handicapped infants who (implicitly) do have a capacity for relationships, but the importance of relationships gets lost in the struggle for survival.

One who must support his life with disproportionate effort focuses the time, attention, energy, and resources of himself and others not precisely on relationships, but on maintaining the condition of relationships. Such concentration easily becomes over-concentration and distorts one's view of and weakens one's pursuit of the very relational goods that define our growth and flourishing . . . The very Judaeo-Christian meaning of life is seriously jeopardised when undue and unending effort must go into its maintenance.⁵

If we now seek to apply McCormick's criteria to the three children there is no doubt that he would approve the operation to save Angela. He thinks that Downs children have some capacity for human relationships (as can hardly be questioned). With reference to the controversial Johns Hopkins decision, he argues that those who disagree with it were saying, in effect, that for that infant, 'involved human relationships were still within reach and would not be totally submerged by survival.' As for Benjamin, I have read a brief, issue-raising discussion of McCormick's on spina bifida treatment but I do not know of any detailed judgements he has offered on this matter. However, it appears consistent with his position that he might well approve a decision not to operate in the case of Benjamin. Ben is going to require a whole succession of operations if his quality of life is not to deteriorate to a state where he is incapable of having meaningful relationships. For instance, he will require the repeated surgical insertion of a shunt, a tube which drains off the fluid on the brain. McCormick might very well judge that the effort required to keep Ben in an improving rather than deteriorating condition was likely to be such that Ben (and others)

would have no energy left for human relationships. Perhaps I am doing McCormick an injustice; perhaps he would give Ben the benefit of the doubt; but I have little doubt that if the majority of doctors and parents were working on McCormick's guidelines, they would refrain from operating on Ben. As is well known, in the 1970's Sheffield paediatrician John Lorber developed a set of physical criteria for deciding whether or not to operate on spina bifida babies. If an infant was suffering from severe paraplegia, gross enlargement of the head, kyphosis, an open wound on the back and associated abnormalities, Lorber argued that the prognosis for success was such that one should refrain from operating. These criteria won a considerable degree of acceptance. Ben's condition is not quite as bad as that described in the criteria, but it is probably severe enough for most doctors to put him in the 'not worth operating' category.

McCormick's position sounds plausible. It appears to balance the notions of 'quality of life' and 'sanctity of life' in a rather neat way. But in passing I would like to highlight one curious aspect of it. Is it actually true that when individuals are struggling desperately for life, they have no time for the relationships which ideally lie at the heart of existence? Can there not be a comradeship when patient and doctor together struggle for the patient's life? In times of crisis, when life is under threat, when pain and suffering are intense, do we not frequently experience an intimacy, a being thrown back on each other's help and resources, which is often missing at other times? It may be that there are dimensions of human relationships to which experience of serious handicap makes one especially open. McCormick seems to be peculiarly blind to this possibility.

Ramsey

In contrast to Fletcher and McCormick, Ramsey comes closer to the deontological end of the spectrum of ethical thought. A deontologist believes that certain things are intrinsically right or wrong. He places greater weight on specific rules, rules which will usually coincide with what makes for overall happiness but which should be kept even when this *appears* not to be the case. Ramsey thinks that certain rules should be regarded as exceptionless; of others, he is ready to concede exceptions but only in carefully circumscribed circumstances, according to principles which he claims are consistent with the purpose of the rule itself.⁶

Ramsey summarily dismisses Fletcher's 'indicators of humanhood' and gives a rather more considerate but equally decisive rejection to McCormick's 'quality of life' criteria. He argues that it is not for us to judge the quality of other people's lives. We simply do not know what it is like to be in someone else's shoes. Adjudicating whether a handicapped child should live or not is especially invidious when considerations like the stability of its parents' marriage, or the state of their bank-balance, come into view. Ramsey writes thus:

One can understand - even appreciate - the motives of a physician who considers an unhappy marriage or family poverty when weighing the tragedy facing one child against that facing another; and rations his help accordingly. Nevertheless, that surely is a species of injustice. Physicians are not appointed to remove all life's tragedy, least of all by

lessening care now and letting infants die who for social reasons seem fated to have less care in the future than others.⁷

It is possible for the modern doctor to think of himself as *too* responsible for the alleviation of suffering. If tragedy occurs in a family because of the burden of looking after a handicapped child, the doctor should not assume personal responsibility; there are others in society who should be sharing in the burden of care.

Ramsey calls on the medical profession to abide by strictly *medical* criteria in deciding whether to operate on the handicapped new-born. If a patient is seen to be in the final stages of dying, and medical intervention is likely simply to prolong the dying process rather than offer real hope of cure or substantial improvement, then his advice is simply to provide normal care. Like Fletcher and McCormick, Ramsey would see no useful purpose in putting Charlotte on an artificial respirator. Brain cancer has sealed her fate, and we are called only to care for the dying, not to do everything in our power to postpone the supposedly evil hour of death. But Ramsey rejects the mode of thinking and practice which would substitute 'the severely handicapped' for 'the dying', and would regard a policy of non-intervention as equally appropriate in their situation. On the contrary,

the standard for letting die must be the same for the normal child as for the defective child. If an operation to remove a bowel obstruction is indicated to save the life of a normal infant, it is also the indicated treatment of a mongoloid infant. The latter is certainly not dying because of Down's syndrome. Like any other child with an obstruction in its intestinal tract, it will starve to death unless an operation is performed to remove the obstruction to permit normal feeding.⁸

There is no doubt, then, that Angela would be safe in Ramsey's hands. But unlike Richard McCormick, this is not because her expected quality of life is deemed to be sufficiently high; it is sufficient for Ramsey that mongolism is not a lethal condition, and the prognosis for recovery from the bowel operation is extremely favourable.

In the case of Benjamin, the spina bifida child, it is also likely that Ramsey would favour immediate operation. This is not because he believes that *all* spina bifida infants would be treated in this way. There are some whose handicap is so severe that they can be said to have been born in a dying state. They may already have developed severe hydrocephalus, and in addition to the usual spina bifida problems they may be suffering from heart disease. They are likely to die within a few days or a couple of weeks, and the prospect of an operation helping them to survive much longer is remote. Alternatively there might be sound medical reasons for not operating, e.g. the wound on the back might be so wide that it was unlikely to heal properly, so that it is better to leave the wound open and apply a simple dressing. The infant's condition may improve, but it is ordinary nursing care rather than the surgeon's tools which will facilitate that in such a case.

As I have described him, Ben has an open wound, but not an exceptionally wide one; and the fact that he has slight movement in the hips and legs suggests that he may not be

fated to suffer from severe paraplegia. In the view of another Sheffield paediatrician who takes a less pessimistic view of many spina bifida cases than John Lorber, Dr R. B. Zachary, immediate operation can do such infants a great deal of good. Surgery can preserve and increase activity in the muscles, and this will improve the infant's chances of sitting up, standing and maybe walking at a later date.

Zachary recognises that some of these children will die, that he might not 'add years to their lives', but he thinks that it may be possible to 'add life to their years'. The range of movements open to them may be significantly increased. Ramsey, following Zachary, would hope that an operation or series of operations might achieve this for Ben.

The difference in policy between Lorber and Zachary might appear simply to be one of medical judgement, of what does and does not constitute a hopeless case of spina bifida. I have talked to Lorber's successor in the Sheffield hospital and he feels that there is a middle way which is actually truer to the facts, which more accurately reflects which babies can be helped and which can't. But whatever the merits of their medical judgement - on which I am not competent to pass a verdict - Zachary's approach commends itself to me because he does restrict himself to what Ramsey calls 'medical indications'. Lorber, in contrast, speaks much of the misery of the most handicapped sort of child, of the parent's marriage break-ups which are liable to occur, and of the poor prospects which spina bifida children who do survive have of marriage or employment for themselves.⁹ Such talk is often in a highly generalised vein. It ignores the fact that there is no clear correlation between happiness and handicap; it is not necessarily the most severely afflicted who give evidence of most misery. It also betrays the same mistaken assumption revealed by Fletcher, that for life to be worth living one has to have access to all 'normal' human activities. One does not have to think about this assumption very long to see how absurd it is. As for Lorber's medical judgement, it actually appears that the way in which he treated patients on whom he did not operate helped to reinforce the impression that they were hopeless cases. Giving these infants sedatives ostensibly to ease their pain, led them to demand to be fed less often, and this in turn led to an early death from starvation or infection related to malnutrition. If the infants had been given normal care (including e.g. routine antibiotics), many might have survived much longer, as they have in other hospitals.

Conclusion

By now it will be evident that, of the three thinkers I have considered, I am most in sympathy with Paul Ramsey. This is not to say that his position is without problems. For instance, I think that it may be more difficult than he acknowledges to identify when a patient is in a dying process - which, I agree, should be crucial for determining whether one continues trying to provide corrective treatment. Doctors admit that they often do not know whether death is imminent or not. Yet in other cases it is transparently clear that they do. The important point is that this is a medical judgement on which I, like Ramsey, am entirely happy to trust a doctor's competence. Where neither he nor I are prepared to trust doctors' competence is when they presume to judge whether a person's life is worth living.

Of course, when doctors do decide to abandon a child who might have been saved (a child such as Angela or Ben) they rarely do so entirely on their own initiative. The fact that the parents do not want the child to live is often a factor in their considerations. Where doctors have fallen foul (or nearly fallen foul) of the law through conniving at a child's death, they invariably claim parental support. The prospects for a seriously handicapped child's survival depend on whether it evokes its parents' affections as well as the attitude of paediatric surgeons. This makes for a considerable measure of arbitrariness and inconsistency in the way such children are treated (something that is even more true of fetuses in societies like ours, which sanction a liberal abortion position). Where doctors are subservient to parental wishes the result is an extremely unjust situation. Admittedly, a severely handicapped child whose parents reject it is likely to be in an extremely unhappy situation. But an initial attitude of rejection will not necessarily lead to a permanent attitude of rejection. As one doctor has written, 'The Mongoloid child who has broken his mother's heart will usually mend it again in 2-3 years.'¹⁰ Where a parental attitude of rejection or, more likely, one simply of not being able to cope, does persist, it is possible to turn to institutions and homes which specialise in the care of the severely handicapped. The recent improvement in facilities and care for handicapped children who 'get through' teenage and adulthood provides an ironical contrast to the obstacles which are increasingly being put in their way before birth and immediately after birth.

There is no easy solution to all this. We live in a pluralistic society, where people's opinions are divided on this as on many other moral issues. The state of Western medicine reflects this pluralism; so, even sadder to my mind, does the state of Christian ethics.

I believe that there is a right way forward on the question of treating the handicapped new-born, one that I have sought to outline here, but there is a major task of persuasion to be done (both in the Christian and wider secular community) before we can hope to see it reflected in some generally accepted standards which ensure a just consistency of treatment for the severely handicapped child.

Notes:

1. For a systematic presentation of this position, see Joseph Fletcher, *Situation Ethics*, SCM, 1966.
2. See Joseph Fletcher, *Humanhood: Essays in Biomedical Ethics*, Prometheus Books, Buffalo, 1979, pp. 7-19.
3. Joseph Fletcher, 'The Right to Die: A Theologian Comments', *Atlantic Monthly*, 221, April 1968, pp. 63-64.
4. Richard A. McCormick, S. J., 'To Save or Let Die: The Dilemma of Modern Medicine', *How Brave a New World?* SCM, 1981, p. 346.
5. *Ibid.*
6. See e.g. Paul Ramsey, 'The Case of the Curious Exception', *Norm and Context in Christian Ethics* (eds. Gene H. Outka and Paul Ramsey), SCM, 1968.
7. Paul Ramsey, *Ethics at the Edges of Life*, Yale Univ. Press, New Haven and London, 1978, p. 203.
8. *Op. cit.*, pp. 192-193.
9. See, among other writings, John Lorber, 'Early Results of Selective Treatment of Spina Bifida Cystica', *British Medical Journal*, October 1973, pp. 201-204.
10. Eugene F. Diamond, 'The Deformed Child's Right to Life', *Death, Dying and Euthanasia* (eds. Dennis J. Horan and David Mall), University Publications of America, Inc., Frederick, 1980, p. 130.

The Ambiguity of Progress and Medical Ethics

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About 25 years ago President John F. Kennedy is reported to have said: 'If somebody asks us why we want to go to the moon, we have the answer ready: because we *can*. No other answer is necessary.' Some 300 years earlier one of the fathers of the modern belief in progress, Francis Bacon, wrote that 'man's understanding now is emancipated and come as it were of age, whence there can but follow an improvement in man's estate and an enlargement of his power over nature. For man by the fall fell at the same time from his state of innocency and from his dominion over creation. Both these losses however can even in this life be in some part repaired; the former by religion and faith, the latter by arts and sciences.' (*Novum Organon* II, lii).

Bacon and Kennedy are placed respectively at the beginning and the end of an era, the one as a pioneer of optimistic belief in progress, the other as a last Mohican of the naive version of the same belief. For Bacon there was no doubt that the enlargement of man's power over nature could only be a progress, and the same holds increasingly good of the view in the succeeding centuries. It was beyond doubt that the more man was able to do, the more man's estate would be improved. That it also could be endangered was realized only by a few.

But already when Kennedy launched his 'Because we can', a certain scepticism in regard to progress had started. More and more became aware of the ambiguity of progress. 'Because we can' was no longer regarded as a sufficient answer to the question whether we shall. The most striking example of this ambiguity is man's command of nuclear power. Another obvious example are the ecological problems that follow as a shadow every increased utilization of nature.

An explanation as to why it is not an unambiguous advantage that the ability and power of man increase could perhaps be found in the above-mentioned passage of Francis Bacon. He speaks of two losses, the loss of man's innocence and the loss of man's dominion over nature. Both can be repaired in some part, he says, but it is evident that Bacon and his successors were most preoccupied with the repair of the last loss; it is from this he expected progress. But if the loss of man's innocence is not repaired in the same measure, then the increase of man's dominion is not only an advantage. Hence the ambiguity. The American theologian Reinhold Niebuhr, who was very much aware of the ambiguity of progress, finds that the modern idea of progress is a secularized version of Christian eschatology, eliminating the Christian doctrine of the sinfulness of man.

Now the problem is that the two losses Bacon speaks of are not repaired in the same process. Man does not become more innocent because he becomes more powerful, neither does his sense of what *ought* to be done increase with his knowledge of what *can* be done. Ethical problems are not solved concurrently with scientific problems. When it comes to ethics there are no professionals, because ethical questions do not refer to what we can and what we know, but to our *attitude* to what we can and know; and attitude is not a professional or technical matter, but a simple human matter. Scientifically and technically we know far more than our grandparents. Ethically we know no more to-day than Socrates. Scientific knowledge is cumulative, ethical knowledge is not.

It would be easier if for solving an ethical problem you could just send for an expert as you can for solving a medical problem. But in ethics there are no experts. There are experts when it comes to knowledge of the history and philosophy of ethics, but making ethical decisions and passing ethical judgements is not a matter for experts. This is also considered in the proposals for forming ethical review committees by the Helsinki Declaration II. These committees may include both laymen and health professionals. The professionals know what can be done, and both laymen and professionals must consider what shall be done. In that respect they are equally equipped.

In ethical matters we are all laymen, or if there be experts, we are all experts. You have sent for me as a theologian to take part in this discussion, and a theologian might be an expert in knowing something about the Christian view of ethics historically and systematically; but when it comes to making ethical decisions I am no more expert than anybody. Here we are on equal terms as human beings. As human beings we are forced to make ethical decisions, for better or for worse. We cannot avoid it because, speaking theologically, the law is written in our hearts (Romans chapter 2).

Before I take up the question of a Christian approach to the problem of fetal therapy, I will have to say a few words about the Christian view of ethics generally. The Christian view of man is that he is a created being, and as such he should live in accordance with the will of the creator. Now, of course, the Christian view is not that only Christian people are created by God, and accordingly it is not only Christian people who should follow the will of God. For example, you shall love your neighbour as yourself not because you are a Christian, but because you are a human being. To say that the commandment of love applies only to Christians would be a quite

unchristian statement. In that respect there is no special Christian ethic, understood as a body of certain ethical injunctions. Culturally and historically you might speak of a special Christian ethic in the parts of the world where Christianity has been preached. But theologically the commandment of love and the golden rule, 'Do as you would be done by', concerns every human being as a *created being*. Christianity is not the promulgation of a moral discovery, but it is addressed to the penitent who admit their disobedience to the already known law. Only when it comes to the foundation of ethics can you speak of a Christian ethic; it is founded on and motivated by belief in God.

'I will maintain the utmost respect for human life from its beginning – and I will not use any medical knowledge contrary to the laws of humanity.' This pledge from the Declaration of Geneva presupposes what is called 'the laws of humanity'. It also presupposes a certain consensus about the 'laws of humanity'; it presupposes, as it were, the law written in the heart of man.

'To maintain the utmost respect for human life' is part of this presupposed law of humanity. You find it all over the world, often violated, but still maintained. As John Locke puts it: 'By the fundamental law of Nature man is to be preserved as much as possible.' And as all ultimate ethical injunctions it is not a conclusion, but a premise.

In the Jewish-Christian tradition you have it in the fifth commandment, 'Thou shalt not kill.' Luther, in his small Catechism, gives this explanation of the commandment: 'that we should not do any harm to our neighbour's life or inflict on him any suffering, but help and support him in every bodily need.' This indeed could be part of a doctor's vow, whether he is a Christian or not. The Christian part of it is expressed in the main clause or motivation: we shall fear and love God, *so that* we do not do our neighbour any harm Again, the content of the ethical norm is the same, the foundation and motivation are different.

Now the same ambiguity appears also in regard to progress in the direction of preserving human life, both at its end and at its beginning. We find it a result of progress that medical science today is able to preserve and prolong human life where before it was impossible. But just here the problems arise, problems that were unknown to medicine at a less advanced stage. Today the answer 'Because we can' is not sufficient, when it comes to prolonging the life of a patient in the terminal phase, by all the means advanced medical technology has at its disposal, when it will only prolong his sufferings. Here the question arises whether it is in accordance with the utmost respect for human life and the laws of humanity to do all we can, when we can do so much as we actually can today.

Similar problems, caused by the progress of medical science, arise at the beginning of life. By fetal therapy we are today able to extend medical treatment of a human being to the prenatal stage. Should that be done, just because we can? Is there a principle difference between treating a person as a patient after birth and before birth? Should we do all we can, if it will only prolong the patient's sufferings? Should a treatment of no purpose be

started? How much risk should the mother be subjected to in the cause of possible treatment of the fetus?

1. The attitude we take to these problems depends first of all on our attitude to the fetus. The question we have to begin with therefore is: What is a fetus? Is it something or someone? Or is it something up to a certain point of its history and then someone? Historically the Christian answer from the very beginning of the Christian church has been, that the fetus or embryo is someone and should be treated as such. A similar attitude you find already in the Hippocratic Oath, though this was far from the general attitude at the time. But in the Hippocratic tradition the church found a view in regard to the 'laws of humanity' that coincided with its own and which it could carry further. Until now that has been the general view of the Christian church; but today it is not alone, although it remains the dominating view of the church. In the Roman Catholic Church it is still the only official view. The Catholic Archbishop of Westminster has observed about the fetus, that it is not a potential human being, but a human being with potential. In the Protestant churches it is the dominating view, but there are deviations from it. The Anglican Board of Social Responsibility and the Methodist Church in England, for example, have agreed to the Warnock Report's recommendations on embryo research, but this has led to a contentious debate in the churches concerned. But generally there should be a wide consensus in looking at the fetus as a human being from the beginning.

2. If the fetus is to be regarded as a human being from the time of conception, it should never be used simply as a means to an end. It is remarkable how many theologians from different churches take up this Kantian formulation when they speak of the topic, just as the theologians in the early church took up the Hippocratic formulation. In the response to the Warnock Report from the British Catholic Bishops it is said that 'the principle that human beings are not to be used as mere means to ends of other human beings holds good even if those ends are as worthy and useful as the advance of biological and medical science'. You can find similar remarks from Anglican and Protestant theologians (and also, by the way, from the Christian Danish Medical Association). That human beings should never be used as mere means to an end is a philosophical way of saying that man is created in the image of God.

3. The principle of means and ends is in these quotations used in regard to research on fertilized human eggs, but the same principle holds good when it comes to fetal therapy. Fetal therapy should always be in the interest of the fetus itself. The principle of the Helsinki Declaration II should also be observed here: 'In the research of man the interests of science and society should never take precedence over considerations related to the well-being of the subject.' On the whole the same rules should be observed in treating a fetus as a patient as are observed in treating any patient.

The way we look at and treat fetuses with abnormalities will inevitably influence the way we treat and look at existing persons with similar abnormalities. If, for instance, we terminate the existence of an abnormal fetus, we may easily look at an existing person with the same

abnormalities as *someone* who should not exist, and not only at his abnormalities as *something* that should not exist.

4. Experimental methods should only be used when no other methods are available for the good of the fetal patient. As most methods in this area are at the experimental stage I think it right, as it has been said, that a healthy scepticism about fetal treatment should be observed. A fetal abnormality of any type should not be treated simply because it is there.

5. You might ask whether a *certain kind of life* with such and such abnormalities is worth living, though it is a risky question. It is like entering a slide; how do you stop again? But you can't ask the other way around; whether a *certain kind of human being*, with such and such abnormalities, is worthy of living is beyond questioning. It is unchristian, and inhuman, to let this idea of contributing to the common good be a criterion for determining the worth of a person as a human being. As we said before, the existence of any human being is beyond being made a mere means to any purpose; but it is also beyond being looked at as of no purpose.

6. The rule that a treatment of no purpose and thus not in the interest of the patient should not be started, or should be stopped if already started, holds good also for the fetal patient. No treatment should be for the sake of the treatment only, but primarily for the sake of the patient. Abstaining from treatment which will only prolong the short life of the fetus (whose death soon after birth is foreseen) could be compared with passive euthanasia. But what if you through fetal therapy could secure a fetus a long post-natal life, but a life with serious abnormalities? Should you then carry out the treatment? The situation calls for much discernment; in dubious or marginal cases I would adopt a healthy scepticism and let nature take its own course.

7. While refraining from fetal therapy of no purpose could be compared with passive euthanasia, abortion resulting from pre-natal diagnosis could be compared with active euthanasia. As such, abortion is a different thing from refraining from treatment. I agree with those who call the term 'therapeutic abortion' a kind of doubletalk. Nature is wasteful of life, including human life, but this is a privilege of nature which cannot be used as a justification for man being the same.

Speaking of abortion generally there is a discrepancy, however you look at it, between the efforts and ingenuity that are used to improve the possibilities for an unhealthy fetus and the abortions of tens of thousands of healthy fetuses which take place yearly.

8. With decisions about treatment of patients in general, the prospects of good results should normally override the risks. This applies also to fetal therapy.

9. The close relationship between mother and fetus creates a special problem, and a difficult one. The relationship is unique. You have no other cases where by treating one patient you are automatically also treating another person. The relationship is other than that of parent and child. There the interests and feelings of the

parents are deeply involved, but in the fetus-mother relationship the body of the mother is directly involved as well.

This unique relationship implies that neither the health and welfare of the fetus nor the health and welfare of the mother should *solely* be considered when therapeutic decisions are taken. Both are so deeply involved in each other that the welfare of both should be mutually balanced. It could then be asked whether it is a mother's duty to an unborn child to undergo a medical or surgical procedure that might prevent it from being born in an avoidably unhealthy state. I should say that the answer depends on two things. Firstly, whether the methods employed are experimental or established. Her moral duty could be said to be inversely proportional to the degree to which the method employed is experimental. Secondly, the risk to the mother's life and health should be considered. The greater the risk, the more justified is her refusal to subject herself to *in utero* therapy. Not only should the worth of her life and health be taken into consideration for herself, but of course also their worth and importance for any existing family.

10. Finally, a word about a future possible genetic therapy. Here I, remaining a Lutheran, can quote with approval the Pope from his address to the World Medical Association on 'The Dangers of Genetic Manipulation', on October 19th, 1983:

To tell the truth, the expression 'genetic manipulation' remains ambiguous and should constitute an object of true moral discernment, for it covers on the one hand adventuresome endeavours aimed at promoting I know not what kind of superman and, on the other hand, desirable and salutary interventions aimed at the correction of anomalies such as certain hereditary illnesses, not to mention the beneficent applications in the domains of animal and vegetable biology that favour food production. For these last cases, some are beginning to speak of 'genetic surgery', so as to show more clearly that medicine intervenes not in order to modify nature but to favour its development in its own life, that of creation, that intended by God.

It has been said that the use of advanced medical technique and especially of genetic manipulation is a kind of playing God. But the attempt to play God is nothing new. Adam and Eve already launched into the project. To play God is not a matter of what you can and what you know, but of your attitude to what you can and know, and the way you use your knowledge and ability. Whether you are a nuclear physicist or a blacksmith, your possibilities of playing God are the same. You are not nearer the secrets of creation when you splice genes than when you splice ropes.

Maybe you find what I have delivered nothing but common considerations, not differing from ordinary human discernment. But, as I said at the beginning, the Christian character of ethics does not show itself so much in the body of moral injunctions as in their foundation and motivation. Christianity does not deliver a master key to all ethical problems that frees you from troublesome deliberations and conscientious discernment. There are no ready-made solutions.

Review

Life in the Balance: Exploring the Abortion Controversy

Robert N. Wennberg

William B. Eerdmans, Grand Rapids, Michigan, 184pp.,
£7.95, Paperback, ISBN 0-8028-0061-0

Professor Wennberg's argument begins with some cautionary words to both sides on how and how not to go about arguing the abortion issue. He nails his own colours to the mast of the biblical tradition, and urges others so minded to ensure that the implications of their theories cohere with their theological frame of reference, then goes on to urge consistency on all who are engaged in this argument whatever view they take of it. One cannot adopt a liberal moral theory of abortion that logically leads to a liberal theory of infanticide and then condone the former and express revulsion at the latter. However, he also warns us of the dangers of the 'slippery slope' type of argument: that acceptance of abortion will lead on to acceptance of infanticide, euthanasia and even genocide; and of the 'more of the same' argument: that if abortion is allowed, it will proliferate out of hand. Both arguments are based on the assumption that abortion is itself bad, and will not impress those who regard it as acceptable.

It comes as no surprise to learn that many philosophers decry the use of Scripture as an authority 'since there are so many conflicting interpretations'. Having assured us that this is equally true of the arguments of moral philosophers, Professor Wennberg urges us to 'think for yourself', after reading what expert opinion we can. We are warned, however, of the danger of baptizing moral conclusions, that is, of deciding that something is the will of God because we already agree with it. We are also warned against using either highly inflammatory language, or the opposite extreme, bland antiseptic language. Talk of mothers who 'slaughter their innocent children in the womb' does nothing to strengthen a pro-life argument. Nor, on the other hand, do references to 'removing the products of conception' sweep the moral problem under the carpet. Abortion is not a *moral* problem for those who consider it to be murder, nor for those who see it as cosmetic surgery. It is only a moral problem for 'conscientious, thoughtful persons'. The use of psychological persuasion as a substitute for rational argumentation is condemned by the author, who deplores the polemic style employed by both the pro-abortion and anti-abortion forces.

Some facts and figures follow. Prior to 1850 all methods of terminating a pregnancy posed a serious threat to the woman's life. Formerly, abortion would only have been considered as an option where there was a severe risk to the mother's life or health, but now some would consider the risk of having to cancel a holiday abroad sufficient grounds.

The above section, and the following one on fetal brain development were interesting to someone confronting the material for the first time, and I must confess, easier going for my pragmatic brain. Here, as in several subsequent sections, Professor Wennberg raises the issue that abortion is logically no different from infanticide. 'The one-month old baby is plainly still a sub-cortical organism.' Birth is simply a continuation of fetal development. 'After all, we don't kill *children* who are unwanted, or deformed, or retarded, or the product of rape, or who stand in the way of our career opportunities, or are the source of our psychological problems, or constitute a financial liability.' On the other side of the argument, although brain waves can be detected at forty days, 'if our brain stopped developing at this stage we'd rank with the primitive fish on the IQ scale'.

This begs the question of whether fetuses are persons or potential persons, and Professor Wennberg persuasively argues that whichever view one takes does not influence the answer to

whether or not they have a right to life. Newborn humans function at a mental level below that of many newborn animals (horses, for example) but few would suggest that even if such infants were merely potential persons they had no right to life. Or again, if fetuses do not yet bear the image of God, depending on how one construes that theological concept, do anencephalic adults? Would we therefore kill the latter? As to whether fetuses have souls, the author regards this as irrelevant to the abortion debate, unless one considered abortion as also being an act of damnation, which has no support in the biblical tradition.

He suggests that the closest scripture comes to dealing with the abortion issue is in Exodus 21:22-25, where if two men fighting hurt a pregnant woman so that she miscarries they are liable to a fine. But if the woman herself is hurt, then 'an eye for an eye, a tooth for a tooth' applies. The fetus has the status of property. (But also, I would add, the same status as a slave – or a beast of burden – so where does this argument lead us?)

There is a lengthy discussion on 'The Case of the Famous Violinist' – a hypothetical comatose individual invented by a 'pro-choice' writer to argue the case for 'the right to bodily self-determination'. It concerns an unfortunate woman who wakes up one morning to find herself kidnapped by the Society of Music Lovers, who have connected her circulatory system to that of an unconscious violinist with a fatal kidney ailment. She is told that his life may be saved if she consents to remain tubed-up to him for nine months. Professor Wennberg rightly points out a number of flaws in the analogy. He suggests that if we see the woman as being not a total stranger but the violinist's mother, and as having voluntarily tubed herself up to him, we have a truer analogy. The moral issue then becomes whether, having got herself into this situation, she has the right to back out of it.

Professor Wennberg concludes that there could be no *legal* obligation for the mother to agree to continue to be connected to her son, but that there would certainly be a strong *moral* obligation. From this he concludes that it is misguided to campaign for the criminalisation of abortion, and that the efforts of the anti-abortion lobby should be concentrated on moral persuasion, through an educative and counselling programme. (He concedes, however, that many people take the simplistic view that if something is legal it must be all right to do it.) Clearly to un-tube oneself from an invalid son, however morally reprehensible that act was, could not be legally construed as murder. However the likening of that act of un-tubing to an abortion was somewhat vitiated by the author's conclusion that neither a D and C nor a vacuum aspiration killed the fetus (although certainly dismembering it), but simply disconnected it from the mother. However, he continues, 'As far as the unconscious person is concerned, there is no important difference between being killed as a result of being unhooked and being killed as part of the process of being unhooked, and the same is surely true of the fetus'.

My impression was that he did not go far enough in questioning the validity of the analogy. For example, the fetus is not unconscious, as the film 'The Silent Scream' so graphically indicated; nor, in most cases, is it ill.

Professor Wennberg accepts both that the fetus has a right to life, and that the mother has a right to bodily self-determination. As to how one balances these rights where they compete, he concludes reluctantly, 'the right to life possessed by a fetus does not override the right possessed by the pregnant woman to control what happens in and to her body'. Whatever one's view on this conclusion, we must agree with his further comment that 'the appeal to a right to bodily self-determination is frequently no more than a pretext for securing the death of the fetus.'

The book is an informative and thought-provoking survey of the abortion controversy.

Allan Webster