

## THOUGHTS ON THE ETHICS OF TREATING OR OPERATING ON NEWBORNS AND INFANTS WITH CONGENITAL ABNORMALITIES\*

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The tremendous advances in paediatrics since the Second World War, through energetic and sometimes exciting research, have undoubtedly benefited many children and their parents. For example, the survival of children after surgery for potentially lethal conditions such as atresia of the small intestine, gives joy and satisfaction to both parents and doctors.

Less publicized is the havoc caused by the short- or long-term survival of infants and children with severe physical and mental handicaps who, through the efforts of medical, nursing and para-medical personnel are a burden to themselves, their families and the community.

It may be that only in years to come will we recognize the more profound consequences of modern trends in the management of patients with inherited potentially lethal and crippling diseases or congenital malformations. A new generation of parents, saved by medical and surgical advances, is growing up—a generation which may carry a genetic predisposition to disease that may manifest itself more severely in their offspring.

In South Africa we must also face the fundamental moral question of whether the large expenditure of skilled medical, nursing, educational and rehabilitation time, as well as financial cost is justifiable even if all the infants with severe congenital abnormalities saved, grow up to be perfect and normal human beings. It has been estimated that in the USA one brain-damaged child admitted to an institution may impose a financial burden on society of \$200 000 or more during his lifetime. I do not know the cost in the Republic, but it must be considerable. I also know that much still needs to be done to reduce mortality and morbidity from malnutrition, undernutrition, measles and other preventable diseases. The infant mortality rate for all races in the Cape Town municipal area alone is 50.5 per 1 000 live-births (1969), and most of these infants die of preventable conditions.

In this article I wish to discuss only one aspect of the question—the dilemma in which the doctor finds himself when he is faced with a newborn infant with congenital abnormalities or a disease known to result in severe physical or mental handicap should the child survive because of medical treatment or surgical intervention.

When faced with a foetus or newborn with an inherited potentially lethal disease or life-threatening gross congenital abnormality or with evidence of severe asphyxia or intracranial haemorrhage, the general practitioner, obstetrician, paediatrician or paediatric surgeon is faced with a number of alternatives. Should he:

(i) *Kill the foetus or newborn*—an unacceptable course of action at present as far as the newborn is concerned, but permissible in the eyes of many in the case of the foetus

in which cytogenic and biochemical defects can be diagnosed antenatally from the study of amniotic-fluid cells, e.g. mongolism or fibrocystic disease.

(ii) *Actively encourage the child to die*, offering no medical treatment, surgical intervention, or feeding.

(iii) *Allow 'nature to run its course'*, offering no treatment for complications such as pneumonia, no antibiotics, or active feeding either orally by tube or intravenous fluid therapy. The infant is simply offered a feed and allowed to take in as much orally as it can manage.

(iv) *Actively encourage the child to live by using all means at his disposal*. The doctor may follow this course of action because he believes it to be the correct one or because it is the line of least resistance. It is far easier to treat than not to treat.

In making an objective assessment of the situation the doctor may be hampered by time-honoured clichés and quotations which may come to mind, including: 'Our duty as doctors is crystal clear—to preserve life' and 'Life is the most precious thing in the world'.

These are of very little comfort to the attending medical practitioner and he must resolve important ethical and other questions such as:

*Should life-saving measures be instituted?*

*Should the decision on these measures be left mainly to the parents, or be made by the doctor alone; or should the decision be made by the doctor after discussion with other colleagues and with the parents?*

Answers to the above questions are likely to be based on matters of opinion, religious and moral beliefs, emotion and subconscious factors. The course of action of the medical practitioner is likely to be influenced by past personal experiences and moral convictions and to a far lesser extent by 'words of wisdom' from experts.

In arriving at a decision the doctor must as far as possible satisfy himself that the institution of life-saving measures, or conversely, the withholding of active measures, will not make the situation worse by causing the survival of a child in an even more damaged or unhappy state; and that the future care of the infant is ensured, should he survive after the institution of life-saving measures.

In my opinion the responsibility for the future care of infants who survive with severe mental and physical handicaps rests with the doctor who instituted life-saving measures. He cannot escape this responsibility and he must satisfy himself, before instituting such measures, that educational or institutional facilities, community help, guidance of parents, later work opportunities, etc., will be available to the individual allowed to live through his intervention.

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I must stress that the situation in the Republic in this respect differs vastly from that in the United States and in Britain. I think it is true to say that parents in the higher socio-economic groups here experience many difficulties in the care of their handicapped children. In the lower socio-economic groups, life for the handicapped child can be tragic, and for responsible parents falling into this group it can be misery and catastrophe giving rise to unbearable emotional and economic stresses.

The doctor must also satisfy himself that the parents are not likely to reject the child, that the family is not likely to disintegrate because of guilt and emotional complexes engendered by the presence of the handicapped child in an already unstable family, and that siblings are not going to suffer unduly.

Parents have emotional ties and the responsibility of caring for their infant as a dependant being, and they should be informed as early as possible of the diagnosis, prognosis, and possible management of their child and have a right to express their feelings if they wish to do so. It is, however, my sincere belief that parents should never be expected to participate in the actual decision whether or not to implement treatment.

There are many good reasons for this point of view: (a) they may make decisions contrary to their real beliefs, because they may think that their church, relatives, friends, or doctor will not approve; (b) feelings of guilt may be aroused if they come to believe at a later stage that they made the wrong decision; and (c) most parents have no previous experience or training with which to face these problems.

I believe that one must always be honest with parents, even if the facts pertaining to their infant at the time seem cruel and their presentation seems unnecessary.

With the years, I have come to the firm conclusion that in many instances death with peace is preferable to the poor life that remains, if the quality of that life is so poor

as to make it a burden and misery for the family and the community. In certain specific situations where gross handicap on recovery seems inevitable, I accept the responsibility for the discontinuation of active therapy which encourages the infant to stay alive.

I further believe, and here I recognize that I am on dangerous ground, that the survival of an infant may not be of equal importance when assessed in the light of different known circumstances. I am willing to manage the immature infant of less than 1.36 kg with hyaline-membrane disease by artificial means such as IPPV when it is the child of an elderly mother with a history of numerous miscarriages, but think it is wrong to do so in the case of an unwanted infant of a young unmarried mother.

The carrying out of a decision not to institute active life-saving measures may be difficult to implement and may have a demoralizing and disturbing effect on junior nursing and medical staff. It is extremely difficult to let 'nature take its course' in the case of an infant with an abnormality or disease likely to give rise to death within days if left strictly alone, and not to tube-feed an obviously hungry child, although the procedure may unnecessarily prolong life and the misery of the parents.

An Editorial in the *Medical Journal of Australia* suggested that many doctors over-treat patients, and tend to forget the value of death. For paediatricians dealing so much with the beginnings of life, it is perhaps even more difficult to accept death as an inevitable part of life.

It is also difficult, and sometimes impossible, in individual cases, to practise what I preach. The temptation not to accept responsibility or to take the line of least resistance by tube-feeding an infant or to 'pass the buck' to a surgical colleague is always there. I must admit in all honesty that I still at times succumb to this temptation.

#### REFERENCE

1. Editorial (1966): *Med. J. Aust.*, 2, 710.