

A MORAL DILEMMA

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The wonders of modern medicine are truly amazing. Doctors can now operate without incisions and replace joints and organs with animal transplants or synthetic materials. Sometimes, it appears they can do most anything. But they can also pose moral dilemmas. This article, more precisely entitled, "The Moral Dilemma in Neonatal Care for Severely Imperilled New-Borns," raises the moral dilemma of whether one should sustain life of a severely handicapped new born baby. As Christians we need to think through the issues of life and death and who has final authority over the life of another, even a severely handicapped new born baby.

INTRODUCTION

Once in a while a severely handicapped baby is born who may be a victim of Down syndrome, spina bifida, anencephaly, hydrocephaly, Tay-Sachs disease, incomplete oesophagus or intestinal blockage. Down syndrome, commonly known as mongolism, is an abnormality of the twenty-first chromosome, the same chromosome which controls collagen (connective tissue) development. The neurones of an unborn baby with Down syndrome are like those of a normal infant. But about four months after birth, an excess of hydrogen peroxide in babies with Down syndrome causes apoptosis (neural cell death), leading to mental retardation.

Spina bifida is a cleft spine through which the membrane that covers the spinal cord protrudes. It is caused by the failure of the

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vertebrae to form over the back of the spinal cord, leaving the nerve unprotected. It usually occurs in the sacral or lumbar regions at the base of the spine, the final section of the neural tube to close. Tay-Sachs disease, also known as amaurotic familial idiocy, is a hereditary metabolic disorder causing progressive mental and neurotic deterioration, resulting in death in early childhood. The disease is caused by a recessive genetic trait and can be detected by prenatal tests. Victims may appear normal at birth, but become inattentive during the first few months of life. As the disease progresses, the child loses motor abilities already gained, such as crawling and sitting, and eventually is unable to raise its head. A cherry-red spot develops on the retina, and blindness and a general paralysis usually precede death (Micropaedia, 11:587).

Hydrocephaly is an accumulation of cerebrospinal fluid in the brain ventricles, causing seizures, mental retardation, and progressive enlargement of the brain, the skull, and the head due to fluid pressure. It may result from a congenital malformation blocking normal drainage of the fluid, or from complications of head injuries or infections. Untreated hydrocephalus carries a high mortality, but most victims are successfully treated by surgery to drain the fluid into the blood or abdomen (Micropaedia, 6:190). In anencephaly, the cerebrum is poorly developed or absent and the skull does not form. The condition is usually lethal and the affected foetuses are usually stillborn. Where the skull forms but the forebrain is missing, affected children may be born alive, but do not survive long. In cyclopia, the baby is born with a single central orbit, or eye socket, with or without the eye, and a tube-shaped nose is set above the orbit (Micropaedia, 8:620).

Left on their own for nature to take its course, most of such children normally die within a few days of life. However, due to technological advancement in the field of human medicine, it is possible to lengthen the lives of such infants, some of whom live well into adulthood.

An ongoing debate is on a few ethical issues on the intensive neonatal care for imperilled new-borns. Although many lives of imperilled infants are saved and lengthened, a number of them remain technology-dependent, and cannot in any way, interact with

the surroundings. Many remain handicapped for life and have to be on constant medication. The phenomenon has led some physicians and ethicists to question the validity of using modern medical technology to save such lives. The debate is on whether or not to use the prospective length and quality of life of an infant to judge the appropriateness of treating him or her. T

The author affirms the sanctity of life position and concludes that, no matter how badly human life may be scarred or disfigured, it is still in the image of God and deserves to be treated as sacred.

Another issue revolves around the uncertainty of medical judgement, since it cannot be ruled for certain that one infant will live longer or better than the other. Patients respond to various treatments differently. Whether treatment should be initiated on all, including those who will die, or whether only a certain category of potential survivors should benefit is an unsettled ethical debate. Then there is the question of consent. Who makes the decisions as to whether treatment may be withdrawn or sustained? Is it the parents, the physicians and nurses, the courts of law, or the state? Worldview conflicts come out strongly in the discussions. Should medical ethics be guided by secular humanist worldview, or should it receive guidance from the traditional Judeo-Christian perspective of human life?

These moral dilemmas are real for all Christians, especially those involved in the neonatal care of severely imperilled new-borns. Although no clear-cut lines may be drawn, certain Christian principles and guidelines may be proposed which may prove valuable to both physicians and ethicists. In this brief essay the author attempts to clarify these moral dilemmas, and make suggestions on the course of action to pursue.

LIFE VIEW: SANCTITY VERSUS QUALITY

In an effort to determine whether a particular new-born is worth the medical treatment or not, the decision makers are usually influenced by either a sanctity-of-life standard or a quality-of-life standard. Usually the quality-of-life arguments are derived from secular humanistic ways of thinking, while the sanctity-of-life

arguments are derived from the traditional Judeo-Christian worldview.

Richard B. Brandt (1996:177), in discussing the subject of defective new-borns, presents certain considerations which lead to his conclusion that, in some cases, euthanasia is the best thing to do. Brandt's conclusion is based on the prospective quality of life of the defective new-borns. In one of his considerations, he supposes a situation in which, as some times happens, that a child is hydrocephalic with an extremely low I.Q., is blind and deaf, has no control over its body, and can only lie on its back all day and have all its needs taken care of by others, and even cries out with pain when it is touched or lifted. Brandt uses the "happiness" criterion to conclude that such a life is not worth living because it is boring and uncomfortable. Such a child will suffer from "severe sensory deprivation" and not get any interesting stimuli, and should not be subjected to treatment which would prolong life.

The assumption in Brandt's case is that deafness, in addition to one's inability to care for oneself, are signs of a very low quality of life which must be terminated. Death is seen to be the baby's best interest, even if it is to be achieved through dehydration and starvation. This view of life is based on a false presupposition. It is founded on what Hans O. Tiefel (1985:154) calls "individualistic liberalism". In this view, in order to qualify as a person "one must have attained at least minimal capacities to reason, to speak, and to relate consciously to others". The unborn, the new-born, the retarded and the senile have no role to play in a society dominated by the philosophy of individualistic liberalism. Tiefel (1985:159) strongly presents the case in saying that such liberal expressions as "Every child has a right to a life free of suffering", are indeed, misleading. It only allows a choice of either life without any suffering, or death. Since, in the lives of the imperilled new-borns the former is unattainable, the latter must be the only possible choice.

In a Judeo-Christian world view, however, human life derives its significance from the fact that it is created by God. God the Creator and Sustainer of all human life, has directed humanity to love God and the human neighbour. The human neighbour

includes the unborn, the new-born, the retarded and the senile. It is a call to share in the divine responsibility of taking care of others. It is a call to bear one another's burdens, "particularly the weight of those who cannot shoulder anything" (Tiefel 1985:169).

Kathleen Nolan (1987:13), however, dismisses the sanctity of life standards as "... a vague slogan rather than a meaningful guide to decision-making". She presents "vitalism" as an extreme position in which the mere presence of a heartbeat, respiration, or brain activity is a compelling reason to sustain all efforts to save the child's life". She also dismisses strongly the medical indications policy in which each child possesses equal dignity and intrinsic worth and therefore should not be denied life-sustaining medical treatments simply on the basis of his or her "handicap" or future quality of life. Such treatment must be provided to all handicapped infants, except when the infant is judged to be in the process of dying, or when the contemplated treatment is itself deemed to be medically contraindicated (Nolan 1987:13). Nolan, instead, argues strongly in support of the quality of life position, on the grounds that external circumstances are crucially important in the outlook for certain new-borns and because of the increased stress families undergo in raising children with disabilities.

Quality of life standards ignore the intrinsic value of human life, and puts its regulation and control into human hands. Besides, there are reports of restoration to normal life. Edmund Santurri (1985:120) reports that,

Under certain circumstances – for example, some cases of spina bifida – postnatal therapy can restore the hope for a reasonably normal life. But much depends in such instances on the affliction's degree of severity, a matter which typically cannot be evaluated at the time of prenatal diagnosis.

According to Santurri (1985:121), an infant with Down's syndrome can be helped through the use of antibodies related to the condition, and with special education, can achieve a substantial measure of independence and in many cases do lead a long, often happy life.

Although a person's projected quality of life is important, treatment must never be denied on the basis of a prospective poor quality of life. Instead, society must learn to be responsible for every human life in their midst. The emphasis must shift from human rights to human responsibility. As long as the baby is not in the process of dying, he or she is entitled to medical treatment to relieve pain and to make his or her life comparatively better. And as long as the treatment is considered medically beneficial, it should be sustained. God must be trusted to make the right judgement as to when human life is no longer worth living.

MEDICAL UNCERTAINTY

Despite significant technological and professional advancements in the field of medicine, especially in relation to the neonatal care for imperilled new-borns, medicine remains a probabilistic profession. Decision making is, therefore, quite difficult for both physicians and nurses on the one hand, and parents on the other hand. Although modern neonatal care now includes the use of respirators, sensitive monitoring of biochemical parameters, and other upcoming medical technologies, uncertainties remain a real challenge. Nolan (1987:11) outlines three different approaches in response to medical uncertainty with regard to the treatment of imperilled new-borns.

Firstly, there is the the statistical approach as currently used in Swedish hospitals. This is an approach in which physicians or other decision makers make an across-the-board determination that infants fitting a particular statistical profile are unlikely to benefit from treatment. For such infants, treatment is never initiated at all, and they are left to die on their own. This approach sees the saving of severely impaired baby as the worst possible outcome which much be avoided at all costs. As Nolan accurately states it, "some babies will die who could have thrived, although doctors and parents will never know which individual babies they were".

Secondly is the wait-until-near-certainty approach which is commonly practised in hospitals in America. The practice is to begin treatment for every infant that is even potentially viable and

to continue active treatment until it is certain that a particular baby will either die or will be so severely impaired that parents could legitimately opt for termination of treatment. Unjustifiable death is the worst enemy in this case. The price for this policy, according to Nolan, is the keeping alive of some babies who might have experienced an early death "as the lesser of two evils".

Lastly, there is the individualised approach as practised in British neonatal units. The idea is to begin treatment for every infant, but to allow parents the option of termination before it is absolutely certain that a particular infant will either die or be too severely disabled to relate to the environment. This is the position favoured by Nolan who argues that it takes an intermediate route and "avoids identifying either undesirable result – unjustifiable deaths or severely impaired survivors – as necessarily the worst possible outcome" (Nolan 1987:11).

Nolan's second proposal of waiting until near-certainty is preferable here since it avoids passing early, and irreversible, death sentences on potential survivors. The struggle here is not merely that of keeping people alive for the sake of it, but that of constant monitoring of each individual infant's progress or regress. Once it is medically determined that the efficacy of medication is nil, and that the infant will eventually die, treatment can be terminated. In this way the responsibility of death is not in human hands, but in God's hands. In the process human medicine will have played its role of assisting the patient in life. This is the doctors ministry of compassion to the patient.

CONSENT AND DECISION MAKING

There have arisen incidents of controversy on who qualifies to decide on the course of treatment for an imperilled new-born. A case in point is reported by Teifel (1985:151) to the effect that in April 1982 in Bloomington, Indiana, a new-born baby needed surgery to repair his incomplete oesophagus so that he could eat. His parents denied permission for the operation and the baby died after six days without food or water. Despite Indiana laws on child neglect and discrimination against the handicapped, State Courts

upheld the parents in their refusal to permit treatment. Though it seems alarming, this case is not unique, for other children with intestinal blockages have at times also been denied surgery and have died slowly of dehydration and starvation. The Indiana case vividly illustrates the dilemma in which the physicians and nurses find themselves after a diagnosis of a case which needs surgery, an operation which they are willing to undertake. Their efforts are thwarted by both parents and the courts.

An incompetent patient, such as an imperilled new-born, may have no means by which to express his or her best interests. Sometimes it may be true that the interest of such a patient may be in not having his or her life sustained, but no one is sure. But even if they were to prefer death, certainly they would be interested in not suffering while dying. Helga Kuhse in her essay, "Death by Non-feeding: Not in the Baby's Best Interest" (1986:85), describes death from dehydration or malnourishment as "a most distressing way of dying". The decision to withhold all forms of feeding to the infant is as cruel and inhumane as it is inconsistent with principles of proper medical practice. What some regard as "beneficent euthanasia" in shortening the lives of imperilled infants may in fact be infanticide. A variety of suggestions have been made as to who should make such final decisions: parents, physicians and nurses, the state, the courts or law, or hospital ethics committees.

Parents are seen as the best decision makers regarding the life and well-being of a severely handicapped new-born. Parents are understood to be in possession of a natural love and tender devotion towards their own offspring. They are, therefore, most likely to choose the best options available for their children. Nolan (1987:17) agrees with this option and adds, "The ethical basis for according parents primary authority over decisions concerning medical care is rooted in the strong ties of affection and concern that parents have for their offspring".

However, parental decision making can sometimes be negatively influenced by their own individualistic good. Many a parent begets a child in order to attain some self-fulfilment and true happiness. A child provides a parent with the opportunity of passing on one's name. In the African world view, for instance, an offspring is an

assurance of the continuation of the existence of one's own lineage for generations to come. Having a child, in African communities, provides opportunity for the parent to attain ancestral status when they die (Obengo, 1997:46). A seriously handicapped new-born will frustrate all of these aims to a significant degree. It frustrates the parents' expectations of a perfect baby who is supposed to take up a role in the community through work, marriage, family life and other activities in order to ensure the survival of the family and clan.

The birth of an impaired baby shocks parents so much that the reaction is paralleled to the mourning of the death of a family member. Such a parent has so much emotional stress that he or she may choose an option which may turn out to be quite unethical. Parental decisions, in such circumstances, may focus more on the misfortunes of parents rather than the interests of the child and the child's Creator, God. In western families, parents may feel unable to have a social life because it is uncomfortable to have guests to a meal due to the unpredictable behaviour of the defective family member. Such fears may influence the decisions of some parents to have treatment of handicapped children withheld or withdrawn.

Due to the emotional stress parents go through upon the birth of a handicapped new-born, some ethicists propose that physicians and nurses be the only persons to make treatment decisions concerning infants. Physicians and nurses have had previous experience in dealing with such complex cases, and are less likely to be vulnerable to the stress and emotional turmoil parents experience at the birth of an imperilled new-born. In any case physicians are, by call, involved in a ministry of compassion to suffering humanity. However, doctors' and nurses' decisions are also, sometimes, influenced negatively to the disadvantage of the patient. Medical technology keeps getting better and the desire of some physicians is to employ the use of every available technology to its fullest extent. This has sometimes, rather than leading to a better condition in the patient, produced technology dependent human beings who have no interaction with the surrounding. Medical experimentation is another driving force behind physicians' decisions. Decisions by those in the medical profession

are still the best whenever accompanied by honest professional review of each patient's condition and prognosis.

The involvement of the state and courts of law are not normally appropriate in cases of this nature. Courts of law take long to make decisions, and by the time a decision is arrived at, certain events will have taken place in the life of the handicapped infant. Besides, judges and lawyers normally do not possess the professional competence on the intricate details of each individual patient. Their tendency is to generalise on the basis of past experiences and judgements.

In countries like the United States of America, hospitals have come up with ethics committees whose main responsibility is to make treatment decisions on patients such as imperilled new-borns. Ethics committees work with consensus and with first-hand information available. The only problem which may be experienced by such committees is the bureaucracy involved in organising for meetings and arriving at decisions.

It is the author's opinion that treatment decisions be made after thorough consultations among parents, doctors and nurses, as well as a hospital's ethics committee. Such an arrangement helps in the management of accurate information provided to the parents by medics and verified by an independent ethics body. And rather than stipulate regulations on who receives treatment and who does not, each handicapped new-born must be evaluated independently. As Paul Ramsey has put it (Nolan 1987:13), treatments may be compared in order to see which will be medically beneficial for a child, but abnormal children may not be compared with normal children in order to determine who shall live.

WORLDVIEW CONFLICT

An undeniable rift exists in bioethical scholarship between the Judeo-Christian worldview and the secular-humanist worldview. This rift is based on a few basic presuppositions which influence the views presented by each worldview. For instance, the traditional Judeo-Christian position has always recognised that healing is the preserve of God alone, and that all medical

professionals are merely his servants, whether they recognise it or not. Whereas the Judeo-Christian perspective holds that man is a special being created by God, the secular-humanist ideology is of the opinion that man evolved from animals. This difference in the basic presupposition makes the former to stand strongly for the sanctity-of-life principles, over against the quality-of-life principle held by the latter. In the final analysis, it boils down to who is sovereign over human life: whether God is or human beings are.

The conflict is not an easy one to resolve, and may require the theological ethicists to stretch into the realm of apologetics in order to effectively evangelise and influence the secular-humanist world of scholarship. Such an endeavour has to, however, be carried out with respect and sincerity on the part of the Christian ethicist. It is a show of insensitivity to impose a Christian opinion on another human person whose entire security is bound up in his or her belief structure.

But a good beginning is for Christian doctors to have a proper understanding of their calling as a divine one. The science of medicine must not be seen as an end in itself, but as a means to glorify God in ministry to patients. As Peter Chapman (1997:88) has expressed it, "Christian doctors equip themselves with the best that scientific medicine can offer and pour out these painstakingly acquired skills in ministry of compassion". The Christian doctor must not allow the technological sophistication of modern medicine to distance him or her from the patient. Instead, the patient must constantly be viewed as a person and not merely as a case.

The Christian doctor must be careful enough to leave room for God's specific supernatural intervention in the form of miracles. Even when dealing with hydrocephalus, Down syndrome, spina bifida, or other difficult impairment of a new-born, God's intervention should still be expected. Chapman (1997:90) quotes Martin Lloyd-Jones to have cautioned, "God can work miracles today as he has done in the past ages. We must not exclude dogmatically, as we have often tended to, the manifestation and demonstration of the power of God to heal disease.". Martin Lloyd-Jones cannot be described as part of the "enthusiastic fringe" by any stretch of imagination. His caution should enable us to exercise

care. Of course the disappointment, disillusionment and despair brought about by the exaggerated claims of false faith healers has caused some to be sceptical of any possibility of God's healing of difficult cases. However, we must be careful, lest we throw away the baby with the bathwater.

God's command to love the human neighbour extends to the severely handicapped as well. The afflicted must not be expected to bear their share of the society's burdens in addition to their individualised suffering. Caring for the imperilled new-borns comes with significant portion of suffering reflected in the emotions of family members, huge financial expenditure, and physical stress. But that is our share of the cross of Christ in a paradigmatic way.

CONCLUSION

Neonatal care for imperilled new-borns is a human responsibility which we must carry out, despite the moral dilemmas and financial implications involved. Human life would be much easier without any handicapped new-borns to take care of, and that is what we would appreciate. But human life is full of reflections of imperfection. The author is not insisting that every imperilled new-born must be kept alive indefinitely. Instead he proposes that honest medical diagnosis and prognosis be the basis upon which treatment may be initiated, continued, withdrawn or withheld. The sanctity-of-life principle, though not appealing to the secular-humanist ethicist, must remain a key guiding principle among theologically informed medical professionals. It is, therefore, significant that all imperilled new-borns be beneficiaries of treatment, until medical evidence rules them out, or until parents legally withdraw consent for continued treatment. And in cases where treatment must be withdrawn, the child's handicapped nature must never be the determinant factor. Decisions regarding treatment should be made by physicians, parents and small ethics committees in hospitals. Above all, it is important to uphold human life as God's special creation over which he has the sole prerogative in ending. In addition, his supernatural intervention must never be ruled out. If a half a loaf of bread is better than none at all, handicapped life is

better than the escapist's death alternative. Christian ethicists and physicians must get involved in persuasive discussions with secular-humanist medical professionals and present a strong case for the sanctity of life ethic.

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