

# ETHICS & MEDICINE

## AN INTERNATIONAL CHRISTIAN PERSPECTIVE ON BIOETHICS

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## Professor Gyula Gaizler

Professor Gyula Gaizler, the President of the Hungarian Bioethics Society and a Corresponding Member of the Board of *Ethics and Medicine*, died on 22 November 1996. Professor Gaizler, who was well-known among bioethicists all over Europe, will be long remembered for his warm smile and charming Central European manners as well as for his ecumenism and efforts to promote dialogue between East and West. His Society was among the first from Central Europe to join the European Association of Centres of Medical Ethics.

Deeply religious and trained as a Roman Catholic theologian as well as a medical doctor, Professor Gaizler was especially keen to cooperate with other Christian bioethicists in promoting Christian values and *mores* in European bioethics. In 1993 he helped organise a conference jointly sponsored by the Hungarian Bioethics Society and the London-based Centre for Bioethics and Public Policy (CBPP). Two years later the CBPP returned to cooperate with Professor Gaizler and hold another conference in Budapest, focusing on Christian and Hippocratic values in medicine. The date of this conference and that of a conference organised by the Hungarian Bioethics Society were coordinated,

so as to give the participants of either conference an opportunity to attend both events and to exchange ideas.

One of his last public speeches was that given at the conference organised by the Institute for Medical Ethics and Bioethics in Bratislava last summer. The theme of this conference, sponsored by the CBPP, the Dutch Lindeboom Instituut and the American Centre for Bioethics and Human Dignity, was health care resource allocation and the problem of maintaining integrity in the face of scarce resources. As always, Professor Gaizler's speech was most moving and thought-provoking. Talking of the changes and the difficulties encountered in his own country—as well as in other eastern and central European states—since the fall of socialism, and using the analogy of the good Samaritan, he raised the delicate question of to what extent western European countries have a responsibility to respond to the needs of their neighbours in eastern and central Europe. (The text of this address appears below).

Professor Gaizler, who was a Member of the Pontifical Academy for Life, is survived by his wife, Judit, and their daughter and two sons.

## The Transition from a Social to a Competition-based Health Care System

*Professor Gyula Gaizler, President of the Hungarian Bioethics Society*

Bioethics is an interdisciplinary subject, involving doctors, philosophers, theologians and many other professions. But if any one of us tries to speak in an interdisciplinary manner, he exposes himself to the danger of being accused by the experts of not being, for example, scientific or theological enough.

I spoke once in Nitra about ecumenism—another subject that might be described as interdisciplinary. I spoke about 'ecumenism' not only in relation to Christian denominations but also in relation to nationalities. With some hesitation I mentioned the Slovak, Czech and Hungarian nationalities. Today, I would mention also those of the Croatia, Bosnia and Serbia, and the people in Northern Ireland as well as those in Burundi. Why? Because calling to mind ethnic and religious and other

differences is a way of calling to mind the well-known parable of the good Samaritan.

This parable raises the question of care and for whom we should care. Bioethics might be interdisciplinary, but I think that all of us are firmly convinced that this question is central to bioethics, and that bioethics must be founded on what we might call an 'ideology'.

The transition from a social to a competition-based health care system may be analysed at different levels. I shall proceed to describe what has happened before discussing certain theological aspects of the events.

The principles of 'the planned economy' have not produced the anticipated results. The rapid progress in medicine has not necessarily been matched by

improved health care in most countries. Allocation of resources is a world-wide problem. But few countries deal with the question of allocation on the basis of equality. No, competition is the name of the game. This, of course, increases the differences, the inequalities, between one person and another.

On the other hand, while promoting a feeling of social security, the 'nanny-state' discourages self-determination or private initiative. In this situation those who are willing and able to help themselves are numbered. Everyone is expecting help from the authorities, from the 'Uncle State'—to use an expression that is well-known in former socialist countries. The inclination to take any initiative is diminished, and 'paternalism' is not only accepted but expected.

Indeed, this is true not only in the former socialist countries but also in capitalist ones! Bearing witness to this is the indignation everywhere felt at the shrinking of state-funding health care services. This is true even in capitalist welfare states such as Germany and Sweden.

In the former socialist countries, people are slow to forget that medical services and medicines used to be free of charge. 'But in reality', as we read in the World Development Report of 1993, entitled *Investing in Health*, the 'better-off consumers' used to 'make informal out-of-pocket payments to get better care'. Thus about 25 percent of health costs in Romania and 20 percent in Hungary, for example, were under-the-table payments for pharmaceuticals and gratuities to health care providers. It is noteworthy that the official salary of medical doctors was very low under the socialist system. Indeed, the salary of a medical doctor was much the same as that of a shop-assistant.

Inefficiency was widespread, as the report explains, because the government run health system was highly centralised, bureaucratic and unresponsive to citizens. Governments were slow to regulate work-place safety and environmental pollution and failed to mount effective campaigns against unhealthy habits—especially alcohol abuse and smoking. Then with the transition in recent years to a more market-oriented approach, the public sector has suffered a shortage of drugs and equipment as well as of skilled labour. Of course, the drain on resources is linked to social and personal habits. In many cases people go to the doctor instead of looking after themselves by means of a proper diet and a healthy lifestyle. Bad habits are costly for the health services and affect the state budget. This is true in rich as well as in poor countries. This raises the question of what the state should or should not pay for. Should alcoholism and other addictions be classified as illness; and should the treatment for these 'ills' be paid by the community?

In socialist countries especially, sickness benefit has sometimes been abused. As I once said, under the old socialist rule, a doctor can tell whether a health care system works well or not by counting the number of patients on sickness benefit and the number of weeks they remain ill. The more patients on sickness benefit and the longer they stay on it, the worse the system. Effectively, what this meant was that the so-called patients could earn more if they worked in the black

market *and* received sickness benefit as a bonus, than if they continued to work in the factory. Indeed, even today this state of affairs remains true.

Another factor of note in the former socialist countries is the fact that the standard of living has fallen; and this has had an impact on health. Poverty itself is a cause of disease. Together with the collapse of the social or socialist welfare system, this has led to social disquiet. It is widely recognised in Hungary—and probably also in other former socialist states—that many sick people feel that society has forsaken them. And our social conscience tells us that the state cannot withdraw all support from the healthcare services.

In Hungary, as in other former socialist states, we have to find ways out of this general pessimism. The old, enthusiastic slogans have gone out of fashion. We no longer hear. 'Workers of the world unite!' But where do we go now? Should we adopt monetarist policies? Are we to opt for a humanitarian system? Should we choose an egalitarian system? We have seen the systems come and go. Years ago, in rolled the Soviet tanks; today it's the turn of the banks. The new slogan is: 'Tanks out, banks in!'

After the fall of the socialist system many people hoped that the church would come forward with practical ideas. But, as Pope John Paul II said in his Encyclical Letter *Sollicitudo Rei Socialis*: 'The Church does not have the technical solutions to offer for the problem of underdevelopment as such, as Pope Paul VI already affirmed in his Encyclical Letter *Popularum Progressio* (n.87). For the Church does not propose economic and political systems of programs, nor does she show preference for one or the other, provided that human dignity is properly respected and promoted, and provided she herself is allowed the room she needs to exercise her ministry in the world' (n.41).

According to the so-called voice of reason, the number of hospital beds in Hungary should be reduced to 10,000 in the coming year. We are told that there are too many hospital beds and that they are too expensive. This reasoning is another attempt at 'Planned Economy'. Theoretically, it may be true that there are superfluous hospital beds. We have presently some 93,000 beds in hospitals and clinics. And it is true that sometimes patients are kept longer than necessary. But in many cases they are kept in hospital because they cannot cope at home, especially if they live alone. Of course, home care might be cheaper than hospital care. But that kind of care is not widely available; and developing such a service would mean extra costs initially. There is also the fear of inefficiency.

Theoretically, many new ideas concerning Hungarian health care may be good. The difficulty is that nobody knows how to realise new ideas in practice. We have to decide what kind of health care model we should adopt in Hungary. Should we follow the German, the American or the British example? Which system is most compatible with our needs and values? For more than forty years we have been under socialist rule. Anyone who broke ranks would be thrown into prison. Now a socialist-liberal coalition is in power. Nobody is thrown into prison for breaking ranks, but anyone who does so could lose his job. Everyone fears unemployment—a



new phenomenon in the former socialist states! We live in the age of 'Wild Capitalism'. Perhaps *The Economist's* suggestion is to the point. Analysing the situation in Eastern Europe, it asked the question: 'Is Capitalism Lethal?' As the paper pointed out, life expectancy in eastern and central Europe has fallen and healthcare funding has decreased with the fall of communism. Yes, the paper is right; this is indeed lethal, not least in the sense that it kills all hope and idealism. People are sick and tired of *ideas!*

So what can we doctors do? The answer is: we can be patient advocates. We can be the first advocates of the poor. We have been told that a 'two-level' system will be introduced: one for those who are really poor and cannot pay for their healthcare; and one for the rest. However, I cannot really understand what can be meant by the introduction of a two-level system. In reality, there was always a multi-level system. Some had access to better care because they were in positions of power, others because they had money. The poorest always had to make do with less. But they too need their fair share. The poor man is our neighbour. He who suffers is our neighbour irrespective of race, age or faith. And one need not be Christian to recognise this truth.

Yet, to quote again from *Sollicitudo Rei Socialis* (first translated by the Communist Party):

But the Church is an expert in humanity, and this leads her necessarily to extend her religious mission to the various fields in which men and women expend their efforts in search of the always relative happiness which is possible in this world, in line with dignity as persons.

Following the example of my predecessors, I must repeat that whatever affects the dignity of individual peoples, such as authentic development, cannot be reduced to a "technical" problem. If reduced in this way, development would be emptied of its true content, and this would be an act of betrayal of the individuals and peoples whom development is meant to serve (n.70).

Yes, the betrayal of the individuals and peoples leads to pessimism and disillusionment, as witness the situation in most former socialist countries. The rôle of psychological factors in suicide is well known. When people lose the will to live they turn to drugs, alcohol and other poisons. People who do not wish to live on through their children turn to abortion and sometimes

to infanticide. Birth rates are decreasing. The Encyclical Letter *Evangelium Vitae* was clearly to the point. We can now speak of the 'structures of sin'.

What can we do about the situation? The church's social doctrine is not a 'third way' between liberal capitalism and Marxist collectivism; it constitutes a category of its own. In today's world there are many forms of poverty. The denial of human rights (for example, the right to religious freedom or the right to share in the building of society) impoverish people as much as deprivation of material goods.

In the old socialist times we taught the slogan: 'The highest value is man'. Every one of us knew that in our countries the reverse was the reality. Trust turned into distrust, but in the years between 1956 and 1968, faith and hope returned.

In a recent issue of the *Journal of the World Medical Association* we read:

While western European countries are presently facing exploding costs in their health care systems, the countries of the former Eastern Bloc are confronted with the restructuring of the former centralised system into a decentralised, efficient and cost-containing healthcare system.

In general, Eastern European healthcare systems are characterised by strongly hospitalised specialisation of doctors, weakness of management, discredited healthcare expenditure and the emergence of an unregulated private healthcare sector . . . Reform targets include personalised healthcare, strengthening of the primary care system and reduction of in-patient care.

These are the impartial, objective words of an outsider.

But we are insiders! And so we ask, how can we help ourselves? Or do we need the help of neighbouring countries?

Has modern man forgotten the second commandment 'You shall love your neighbour as yourself? Has he forgotten the Golden Rule?

Who now remembers the parable of the good Samaritan? Unless we remember, we Christians cannot fulfil the expectations of our fellow-men. We so often speak in scientific terms using neutral words. Let us not forget that it is impossible to fulfil the second commandment if we do not fulfil the first. Let us try and try again to return to Our Lord.

*For Publication July 1997*

## **Genetic Ethics: Do the Ends Justify the Genes?**

*Eds. John Kilner, Rebecca D. Pentz & Frank E. Young*

*Horizons in Bioethics, No. 3*

The ethical issues raised by the revolution in genetics form the subject matter of this important symposium.

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# Anencephalic Neonates as Organ Donors Revisited: A Response to the Council on Ethical and Judicial Affairs of the American Medical Association

Gregory W. Rutecki, M.D.

The May, 1995 issue of the *Journal of the American Medical Association* (JAMA) contains the most recent report from the Council on Ethical and Judicial Affairs of the AMA regarding the utilization of anencephalic neonates as organ donors.<sup>1</sup> In 1988, the same Council concluded that it is acceptable to retrieve organs from anencephalic neonates *only* after they die—that is, after they sustain whole brain death or cardiac complete arrest.<sup>2</sup> The updated report—the result of more than a year of further deliberation—proposes a diametrically opposed position. Retrieval of organs from anencephalic neonates is now favoured, 'even *before* the neonates die, as long as there is parental consent and certain other safeguards are followed'.<sup>3</sup> The radical change in philosophy necessitates a response from a Christian-Hippocratic perspective and such a response is the *raison d'être* of this paper. It is disconcerting that the revision published by the Council in 1995 affecting the status of anencephalic neonates as potential transplant donors represents a serious challenge to the 'dead-donor rule'—another attempt to break if not break a golden rule of transplantation ethics.<sup>4</sup> There is also here a substantive revision of the definition of personhood—a revision in which sentient behaviour becomes the condition for full membership in the human race.

## Definition of Terms and Ethical Issues

*'Anencephaly is a congenital absence of a major portion of the brain, skull, and scalp with its genesis in the first month of gestation. The primary abnormality is failure of cranial neurulation, the embryologic process that separates the precursors of the forebrain from amniotic fluid.'*

*The Medical Task Force on anencephaly.*<sup>5</sup>

Contained within the convoluted vernacular of medicine is the descriptive term anencephaly—a fatal affliction defined by a total or nearly total, congenital absence of functioning cerebral cortex, cranium and scalp. Subcortical neural tissue (i.e. the brain stem), however, varies significantly in its degree of development and function. As a result of the profound central

nervous system deficiency, neonates with this abnormality who survive gestation are at best already physiologically dying at birth. In the context of this hopeless situation, could not another child benefit from the donation of the anencephalic neonate's organs? The degree of brain stem dysfunction is the key to the drastically abbreviated survival of anencephalics while at the same time germane to ethical issues impacting the anencephalic neonate as a potential organ donor. Utilization of the whole brain definition for death requires a functional absence of the *entire* brain—cerebral cortex as well as brain stem. The brain stem is indeed 'the rub' of the anencephalic neonate's candidacy as an organ donor: the presence of even minimal brain stem function means that despite the absence of cerebrum, anencephalics do not qualify for the presently accepted 'whole brain' definition of death. Furthermore, if a cardiopulmonary definition is substituted, anencephalic organs are damaged irreparably. As this will demonstrate, the fact of these anencephalic neonates has led to the attempts to replace the whole brain definition of death with a neocortical definition or in essence to redefine death as the absence of cerebral cortical function despite a functioning brain stem.<sup>6</sup>

The natural history of anencephaly is associated with a dramatically shortened survival, with life expectancies measured in hours to at most weeks. The cause of an anencephalic neonate's death is often the gradual or accelerated deterioration of respiratory and cardiovascular function, due to the severe degree of central nervous system injury and deteriorating brain stem function. These lead to progressive hypoxia, further ischemic organ dysfunction and death. Furthermore, 1/3 to 1/2 of anencephalic children have also associated gross malformations of at least one other organ system, further precluding their ability to donate solid organs, regardless of which definition of death is utilized.<sup>7</sup>

Inclusion of anencephalics into the transplant donor equation is fraught with serious ethical and logistical dilemmas. If these children deteriorate relatively quickly and without ventilator support, as is typical, their ischemic organs are unsuitable for donation. Thus, by the time their brain stem fails and qualifies them for whole brain death, their organs have become

irreversibly injured and unusable for transplantation. As a result, selected anencephalic infants may receive vigorous care after birth, by ventilator support, in the expectation that whole brain death will eventually supervene, but only in circumstances controlled by the health care team and designed solely to protect the anencephalic organs from hypoxia. In this way, the process of dying for anencephalic neonates is altered invasively in order to preserve their organs for someone else. Ventilator support is not indicated in the medical care of anencephalic neonates, but is interposed—preserving donor organ viability—within the boundaries of the dead-donor rule (the so called organ prolongation technique).<sup>8</sup> The result from the perspective of the anencephalic child is a prolongation of the dying process contrary to comfort or medical benefit for the donor child.

Another controversy in the discussion of neocortical and whole brain deaths in anencephaly arises from the well established fact that whole brain death is more difficult to diagnose in infants than adults.<sup>9</sup> Even an EEG—a valuable tool for establishing brain death in adults—is an unachievable test because of the severe central nervous system deficiency of anencephaly and is not as informative in non-anencephalic infants as it is in adults. Thus, neurological examination and carefully conducted apnea tests (at least two) consistent with loss of brain stem function must be relied upon for a definitive diagnosis of death in neonates. Reliance on clinical criteria for the diagnosis of brain death in infants does not imply inferiority of such examinations, but this information is necessary to the understanding of the complexity of death determination in neonates.

To summarize, the severe neurological injury in anencephalics leads to a shortened survival with deteriorating brain stem function and resultant multi-organ ischemic failure. The expeditious retrieval of viable organs from these infants to benefit others would necessitate any one of the following: (1) changing the whole brain definition of death to a neocortical one, thus equating personhood with cerebral function; (2) placing such children on ventilators for organ support, in the expectation that brain stem function will eventually cease, permitting a whole brain definition of death within a convenient time frame for organ retrieval; or (3) placing these neonates in a unique category outside the accepted rules of transplant donation which is, in essence, an outright denial of their personhood.

### **History of the Question: Anencephalic Neonates and Organ Donation**

*‘Widespread public interest in organ procurement from anencephalic infants is a recent phenomenon (1986). It was prompted by the first successful heart transplant from an anencephalic newborn Canadian baby, Gabrielle, to Paul Holc, a newborn afflicted with hypoplastic left heart syndrome.’<sup>10</sup>*

A historical review of the question has been provided in detail elsewhere.<sup>11</sup> Selected aspects of that review

require closer scrutiny. Three eras of anencephalic neonates and transplantation may then be discerned: an early one (1960s – 1980s); the so-called Loma Linda period (+/- 1986 – 1994) which was followed by a moratorium on anencephalic neonate candidacy; and a revisit or green light to their candidacy with the most recent JAMA report.

First, a number of the early clinical reports regarding the utilization of anencephalic infants as donors are available for review. These have variously described organ retrieval from a live and not still-born anencephalic neonate (37 weeks gestation) without any attempt at resuscitation or a determination of death<sup>12</sup>; novel, ad hoc definitions of death determined uniquely for anencephalic neonates as donors and at the same time involving substantive deviations from usual and accepted criteria<sup>13</sup>; and finally a number of reports wherein the criteria for donor death were not even mentioned in the publications.<sup>14, 15</sup>

In the first reports, the neonate was defined as dead if there was need for a ventilator—a definition not acceptable in potential non-anencephalic donors; in the second, death was *actively* contrived through cooling the anencephalic child’s body while the child was still alive (naturally, the child sustained a cessation of heart beat and conveniently experienced minimal ischemic injury to potential transplantable organs since they were ‘cold’ preserved before death). Reports from the early period often state, ‘after the infant was pronounced dead’, without elaborating further on how the determination itself was made.<sup>16</sup> Fairness demands, however, that one observe and credit the rare initial report that not only defined death carefully as well as legally, but also utilized previously agreed upon criteria for the definition. In one anencephalic child, after respiratory assistance was discontinued, spontaneous respiration and heart beat ceased, and five minutes transpired prior to removal of organs—consistent with an accepted determination of death.<sup>17</sup>

These wide variations in the determination of death—in contradistinction to the carefully prescribed criteria inherent in the dead-donor rule—are at best disturbing. The transition of dying to dead for early (1960s – 1980s) anencephalic donors seems to have been ‘titrated’ solely to procure viable transplantable organs for someone else—a recipient-driven consequentialism.<sup>18</sup>

Two organized but unsuccessful attempts were made to legalize the donation of organs from anencephalic children prior to the Loma Linda protocol.<sup>19</sup> The first was New Jersey Bill 3367 (1986) (rationale: inevitable rapid demise of anencephalic neonates); the second, SB California 2018 (brain absent = brain dead).

More consistent attempts to utilize anencephalic children as donors began in earnest with the Loma Linda experiment alluded to by Walters and Ashwal in the quotation at the beginning of this section (1986). Prior to the Loma Linda experience, anencephalic neonatal organ donation was *ad hoc*, sporadic, and clearly unrestrained by ethical guidelines. Further review of the Loma Linda process—the first organized and coherent policy in this specific area—gives one necessary historical insight.<sup>20</sup>



The requests of parents to utilize their anencephalic children as organ donors prior to 1986 were refused on ethical grounds at Loma Linda University, but stimulated the formation of an *ad hoc* committee to study respiratory support for anencephalic neonates prior to donation. With ventilator support initiated soon after birth—limited initially to the first 48–72 hours after birth and later extended to 7 days—organ hypoxia might be obviated and whole brain death could take place with viable organs maintained for donation. Routine ventilatory support for anencephalic newborns was not accepted medical practice at that time and would be limited to potential anencephalic donors.

The well publicized Baby Gabrielle was an anencephalic newborn in Canada who was attached to a ventilator immediately after birth specifically for organ prolongation. She was then declared brain-dead three days later (by clinical criteria). Though the recipient of Gabrielle's heart—Paul Holc—fared marvellously, his happy story became an exception rather than a rule. Most positive media coverage revolved around this single case. The downside of the protocol was less publicized. The protocol in this specific instance was followed carefully, but had not been formally approved.

Formal adoption of a policy outlining time-limited ventilatory support of potential anencephalic neonate donors at Loma Linda occurred in December 1987. Problems with the new protocol did not take long to surface. Four months later, six infants had entered the protocol but only one met the criteria of brain death. The provision of respiratory support and ICU care (as expected) altered 'the natural course of dying, resulting in a prolongation of the dying process'<sup>21</sup> (in the words of the protocol addendum itself). Anencephalic children who might have died hours or days after birth with supportive or comfort care only, lingered for up to 7 days and even then without the advent of brain death.<sup>22</sup> Fears surfaced that early and prolonged ventilatory support of anencephalic neonates would create an 'organ farm'. Attempts to limit the time on ventilators included withholding intubation until severe respiratory distress was noted. More specifically, out of 13 infants maintained within the parameters of this specific protocol, only 1 heart was retrieved for transplant (Gabrielle's heart) and only 3 anencephalic neonates were determined brain dead within the specified seven-day limit.

The result of this historical evolution in titrating the death of anencephalic neonates became apparent: anencephalic neonates are viable candidates for organ donation rarely and only if agreed upon definitions of death or terminal care are altered in some way to satisfy neo-cortical criteria. Alternatively, if such children are placed on a ventilator (up to one week) solely to protect their organs through an artificially lengthened dying process, a minimum number of organs may be retrieved. The yield of both methods is questionable—especially when considering the prohibitive human cost for the anencephalic infant.

The principle author of the protocol agreed that valid criticism had been levelled against the protocol by outsiders. The programme was temporarily suspended (in July 1988) and the entire subject shelved until recently.

The first of the AMA Council's reports on anencephalics as donors reflected this phase of transplant history. What precipitated the diametrically opposed position apparent in JAMA 1995? One reason seems readily apparent, the other possibly more arguable but worth reviewing nonetheless.

First, the success of transplantation as well as other aspects of contemporary medical care have created a great need in the arena of pediatric transplantation. Approximately 1500 children need heart, liver, or kidney transplants per year in the U.S.A.<sup>23</sup> There is a prohibitive 50% mortality in children under 2 years of age on the transplant list and 80% of children overall may die while waiting for donated organs.<sup>24</sup> Anencephalic neonates appear to offer one solution to the shortage of organs—albeit not a quantitatively significant one (vide infra: conclusion).

The second rationale for the change in philosophy requires some discernment and reflects a change in cultural ethos as it impacts medicine in general and transplantation more specifically. Stated trenchantly by Cameron, 'its (the '60s ethos) settled presupposition has come to take the form of a paradigmatic repudiation of the Christian-Hippocratic tradition as a context for discussion. For that reason, its project is nothing less than re-construction of our culture's idea of what it is to be human.'<sup>25</sup> In the context of transplantation and organ donation, a new definition of what it is to be human has excluded a number of individuals who have somehow come to represent post-consensus culture's 'life-not-worth-living' criterion. These individuals are often terminal, not qualified for a 'whole brain' definition of death and, like the anencephalic neonates, are considered less than human because of severe alterations in consciousness. Their essential ontology—that of human beings who are dying—is altered to suit the consequences of a donor in great need. One way of determining whether this second rationale and accompanying appraisal are accurate is to study the AMA's 1995 statement on anencephalic neonates in closer detail.

## The AMA'S Policy Reversal in Context

*'Our obligation is not to achieve all the good we can, as if our responsibility were god-like, it is, rather to affect what good we can within the limits morality places upon us. Not only what we can accomplish but what we do counts.'*<sup>26</sup>

A number of arguments buttress the AMA's change in policy towards anencephalic neonates as organ donors (Table 1). The arguments extracted and placed in the table were chosen by this author for rebuttal and represent the majority of the arguments in the JAMA policy as well as other reports which are favourable towards the idea of using anencephalic neonates for organ donation. Arguments 1, 2, and 3 will be rebutted first, and then 4 and 5 are discussed in a theological section which follows. The reliance on donor need has already been mentioned, and points 7 and 8 will not be pursued in this particular paper.

**TABLE 1 THE ELIGIBILITY OF ANENCEPHALIC CHILDREN AS ORGAN DONORS REEVALUATED (AMA 1995)**

1. Two-thirds of 'leading medical ethicists' and 'experts in anencephaly' polled agree with the utilization of anencephalic children as donors, thus a change in policy is democratic.
2. Argument by sophistry.
3. Fear of a slippery slope (i.e. specifically that a persistent vegetative state—another group with candidacy for neocortical death—might be considered as having a 'life not worth living' if anencephalic infants undergo an alteration in status) is no longer reasonable.
4. No capacity for consciousness (such as anencephalic children without a cerebrum) is equivalent to *no interest in life*. One is essentially saying anencephalic neonates are *not* living persons.
5. Such donation is ethical and important for the benefit of the parents of anencephalic infants in order to redeem some meaning or purpose from such a tragic and short life.
6. The staggering number of children in need of organs (vide supra).
7. Previous ethical criticism of anencephalics as potential donors relied on the possibility of incorrect diagnoses (so-called false-positive diagnoses for anencephaly). Present diagnosis is more accurate.
8. This change in policy will not undermine society's trust in the transplantation process.

### Majority Ethics as Argument

The 2/3 majority argument may be dispensed with at the outset. How does one define 'leading medical experts in anencephaly and . . . ethics'? The majority of AMA council members are M.D.s and as such are surely aware that statements of this sort presuppose some attempt at randomness and the exclusion of selection bias in the audience surveyed. Was every effort made to include conservative ethicists from religious backgrounds in the survey? And exactly how were the experts in anencephaly selected? Michael R. Harrison has written previously in the Case Studies section of The Hastings Center Report and has discussed the arguments in favour of anencephalic newborns as organ donors.<sup>27</sup> In his discussion, he suggested that anencephalic children be placed in their own 'unique' category as non-persons. Yes, and all the better to use them for transplantation! This 'un-biased' expert who desires that a novel definition of death be applied *sui generis* to anencephalic children is the director of a fetal transplant programme. If other experts were chosen from his worldview perspective, the 'democratic' approach of a carefully selected majority is close to meaningless.

Ethics by majority has also resulted in committee selection bias by the NIH in a number of controversial areas and has offered a green light to some dubious practices. Such has been the case in the arena of embryo cloning.<sup>28</sup> In fact, the AMA Council responsible for the recent opinion on anencephalic neonate donors came under attack from its own constituency, leading one to question the Council's representation of rank and file AMA membership. Louisiana AMA delegate Donald Palmisano, M.D., J.D. commented; 'Repeatedly we have pronouncements of the Council that upset rank and file physicians, and the consternation has brought us to this point.'<sup>29</sup> In fact, despite the Council's convenient application of democracy whenever expedient, it

actually functions like a supreme court in autonomous fashion. The fallout from the response is predictable.

### Argumentation by Sophistry

Next, the accusation of sophistry must be defended. A specific quote from the Council will be studied.

*'Similarly, because the anencephalic infant is incapable of having an interest in staying alive, respect for the essential worth of the infant does not necessarily entail a prohibition on parental donation of the anencephalic neonate's organs before the neonate's death. Instead, society should show its respect for the anencephalic neonate by treating the neonate as it does persons whose organs are removed for transplantation after their death.'*

*(This Author's emphasis) p. 1616. JAMA Report*

How exactly does society show respect for these neonates by retrieving organs *before* their death? According to the council—by not desecrating the corpse and by giving a 'proper burial' (p. 1616). Removing the child's organs before the child dies is *defacto not* treating the child like a donor who is legally dead! As alluded to earlier in the review of early anencephalic neonatal donations, taking organs from a child apparently still alive or cooling a live body to induce cardiac standstill is in no way tantamount to 'respect' for a living being. Interestingly enough, these references from the early period of anencephalic neonate donors—demonstrating the corrosive effect of a loss of respect for anencephalic life—were not contained in the council's report.

Almost unnoticed, one other sleight of hand was accomplished by the Council. Benjamin Freedman is quoted in the report as saying, 'organ transplantation is not simply an ethical enterprise but one that is, in its current stage of development, a moral imperative' (p.1615), seemingly buttressing support for the Council's position. Freedman has unequivocally gone on record against anencephalic neonates as potential organ donors.<sup>30</sup> The utilization of his quote in this context is inappropriate, especially in light of the Council's eventual conclusion which is contrary to Freedman's own belief.

### The Potential Slippery Slope: is Neocortical Death 'Life Not Worth Living'?

*People, it is believed, are valuable; and the quality which distinguishes people—from each other, as well as from other species—is mentation. It does not follow that all human worth is owing to mentation. That which distinguishes a species need not characterize the individual. In the case of humans incapable of mentation, other sources of value come to the forefront—factors which, for those of normal capacities, are obscured in the blinding light of mentation.<sup>31</sup>*

If an act is unequivocally wrong, it appears unnecessary and quite possibly an overkill to condemn it on the

**TABLE 2 JUXTAPOSITION OF PERTINENT NEUROLOGIC FUNCTIONS IN ANENCEPHALY AND PERSISTENT VEGETATIVE STATE (PVS)**

	ANENCEPHALY	PVS
Permanent eyes-open unconsciousness	+	+
Cycles of sleep-wakening	+	+
Reflexive response to pain <i>presumably</i> (vide infra) without the experience of suffering	+	+
Prolonged survival*	-	+
Preceding history of consciousness	-	+
Respiratory function normal	+/-	+
Brain-stem function	+/-	+
Qualify for a neocortical definition of death	+	+
Qualify for whole-brain definition of death	-	-

\* One may not ignore the recent impact of the unfortunate Baby K on the question of prolonged survival in anencephalic children. By court order and at the mother's behest, Baby K was repeatedly intubated and ventilated despite physician protest against the futility of ventilating an anencephalic child. Baby K thus survived for approximately 2 years—the longest 'survival' of an anencephalic child and a new paradigm for futility. Hopefully such prolongation of futility will be an exception to the story of anencephalic children.

basis of a slippery slope which may eventuate. Certain disconcerting similarities between anencephalic neonates and other permanently unconscious groups, however, must be engaged; especially since the Council does not express an appropriate degree of fear towards a slippery slope.

Persistent vegetative state (PVS) may be defined as the condition of patients who have sustained severe brain damage with coma that has progressed to wakefulness without detectable awareness.<sup>32</sup> The reference provided describes no less than thirty-eight separate 'common disorders' responsible for PVS under the rubric of three more general categories—acute brain injuries (e.g. motor vehicle accidents); degenerative and metabolic disorders (e.g. Alzheimer's disease); and developmental malformations (e.g. hydronecephaly). PVS has come to national prominence since a number of publicized court cases involved persons with PVS. The national debate surrounding Karen Ann Quinlan<sup>33</sup> demonstrates the intensity of the contemporary dialogue on this subject.

Recent work with PVS—in fact through actual study of Karen Ann Quinlan's preserved brain<sup>34</sup>—suggests that disproportionately severe injury to the thalamus may be the most important factor in the development of PVS. Most importantly, with intact brainstems, PVS patients do not qualify for whole brain criteria for death and in this regard are similar to anencephalic neonates (Table 2). The Council's report minimized similarities between anencephaly and PVS.

*Anencephalic neonates are unique among persons because they have no history of consciousness and no possibility of ever being conscious. . . . while patients who are in a persistent vegetative state no longer are conscious, they once were conscious and have therefore previously established an identity and a set of interests. . . . there is little force to the analogy between organ removal from anencephalic neonates to organ removal from other persons with severely disabling conditions.*

*The Council (p. 1616-1617)*

Despite a ledger sheet that evinces remarkable similarities between PVS and anencephaly—in fact more than the dissimilarities—the Council itself does not foresee a slippery slope. While not denying substantive differences between PVS and anencephaly, relying on a 'no history of consciousness' vs a 'previously established' history to serve as protection of other unconscious groups seems more than hopeful. With ever increasing pressures to utilize a neo-cortical definition of death, particularly coupled with a level of comfort in the discontinuing support of patients with unconscious states (Cruzan, Jobes), one must be circumspect and cautious about a change in status for anencephalics. This is especially true when the change is essentially tantamount to tampering with a revision in the definition of death. There does not seem to be any guarantee that the redefinition of personhood for anencephalics will not affect similar marginalized groups with impaired and irreversible loss of consciousness. In fact, in this specific context, it is certainly worth noting that PVS *per se* may be a justification for euthanasia in the Netherlands.<sup>35</sup>

*Concerning those with more intact brain stems, it simply begs the question to state categorically that they lack conscious awareness because they lack cerebral hemispheres, much less is there any logical or physiological basis for the claim of some that an anencephalic infant can neither feel nor experience pain 'by definition.' For practical purposes, one should presume, at the very least that anencephalic infants are no less aware or capable of suffering than some laboratory animals with even smaller brains which everyone feels obliged to treat humanly.<sup>36</sup>*

Prior to departing from the discussion involving brain injury, surviving function, and perception in states of altered consciousness, one further observation should be examined. Dr. Shewmon discusses two commonly and almost unanimously held neurologic considerations. First, consciousness in the mature adult brain resides solely in the cerebral cortex. As a result, bilateral destruction of the cortex leads to permanent 'eyes-open' unconsciousness. Second, it has been traditionally assumed that infants' relative lack of cortical function therefore translates into an unconscious state. For example, an infant crying would not reflect subjective or cortical experiences, but mere reflexive activity. It is already apparent from the preceding discussion that the thalamus, at least in part, contributes to consciousness and may be more important than previously believed—adding to a change in traditional thought about PVS.



Shewmon further observes, however, that for these two observations to be true, neonatal or infant brains must be functionally equivalent to adult brains or what he describes essentially as 'miniature adult brains'.<sup>37</sup> This equivalency may not be the case. First of all, decerebrate newborns resemble normal newborns much more than decerebrate adults. Secondly, functional deficits in newborn brains may not be equal to the same loss of function in a fully developed brain. It appears that the earlier the injury, the greater the capacity for other parts of the brain to compensate. Though anencephalics may have enough plasticity to allow some higher function to be compensated for by lower centres, it would be extreme to claim such plasticity would replace function to a significant degree. Shewmon's point, however, is that some severely compromised newborns may have primitive awareness—including awareness of pain. Suffering and pain perception cannot be completely ruled out in anencephalic or decerebrate newborns. Some of the commonly held assumptions about anencephalic neonates may indeed beg the question. How little sentient behaviour must there be to disqualify personhood?

### Theologic Evaluation of Anencephalic Neonates as Persons

*This theme of protection of the weak and innocent is a common one throughout the Bible. Compassion was to be shown for the fatherless, the widows, and the sojourners, and practical steps taken to help them. (Deut. 10:18; Ps. 12:5; Isa. 1:17; Lk. 14:21; 1 John 3:17). God is concerned about the weak and innocent because he loves every one of them. Each person, as an image of God, has the opportunity to practically reveal this caring God by protecting and helping the weak.*<sup>38</sup>

The aforementioned controversy surrounding the application of unique categories to anencephalic children may be reduced to an essential question of personhood. If a case can be made for excluding individuals from the human race for significant deficiencies in higher brain function, the dead-donor rule would not hold in the instance of anencephaly. Approaching the question of anencephalic personhood from a theological perspective must confront the concept of the 'image of God' and its presence or absence in anencephaly. Dónal O'Mathúna has researched this question previously in connection with persistent vegetative state, so his scholarship will be reviewed here.<sup>39</sup>

Despite a historical review explicating the four categories utilized to understand the image of God and humankind (1. substantive, e.g. rationality or freedom; 2. functional, e.g. dominion; 3. relational, ability to relate to God; 4. physical), there is ample evidence that the term 'image of God' is more holistic than any of the single categories suggest.<sup>40</sup> Gen. 1:26–27 is not a discovery of what makes humans distinct, but rather, tells us the purpose in God's creation of humans. *Imago Dei* does not portray a conceptual idea of what it means to

be human—it tells us that we, the bearers of the image, are created to be God's representatives on earth. Imaginers of God act as he would act, 'filled with love and justice and live(ing) in truth'.<sup>41</sup>

O'Mathúna's application of this theology to abortion revolves around the question, 'When does a fetus become a person?' The Bible, in Allen Verhey's words, 'does not provide a moral Esperanto'<sup>42</sup> but rather provides information on how the unborn are regarded by God (Job 10:3,7,8; Ps. 139:13; Isa. 44:2,21,24).<sup>43</sup> Rather than specifically address the issue of personhood in Enlightenment terms, the Bible tells us how God treats the unborn and thus how those made in his image should also treat them.

*The implication is then drawn that since these patients (PVS patients) are no longer able to image God there is no moral obligation to keep them alive by any means. In spite of their desires to develop a Biblical ethic, Emmett and Davis have fallen in the same trap as all those who seek to determine moral obligations by first determining who is entitled to care. But the Bible does not use the phrase "image of God" with the purpose of defining human personhood . . . we can once again see if the idea of treating humans of uncertain personhood as persons leads to a better understanding of their nature.*

D. O'Mathúna

Might there be some inferences drawn from Mathúna's line of biblical exposition? The Bible does not explicitly address the issue of personhood vis-a-vis the absence of cerebral cortical function either. But at best, anencephalic neonates—as well as live patients with PVS—are not explicitly disqualified from personhood based solely on a lack of sentience. If either a functional or substantive category for *imago Dei* is inadequate, the ethical construct utilized to disqualify these infants is reduced to a Cartesian dualism. Since no interpretation of *imago Dei* will permit us to say with certainty that anencephalics newborns are not images of God, they must be treated with the justice, love, and mercy of God—essentially as we would treat *persons*. Placing anencephalics outside the realm of humankind is arbitrary when judged from a theological context.

*No one faults the desire of parents to 'redeem' the death of their anencephalic baby. But, it is a profound misreading of what it is that gives life meaning, no matter how brief that life may be, to say that the only way an anencephalic child's life can have significance is if his (her) organs can be transplanted. The perspective underlying much of the public clamor is an application of this raw utilitarianism, reducing persons to a function.*

Wilke and Andrusko<sup>44</sup>

Arguments permitting a green light to organ donation from anencephalic neonates in order to 'redeem' their tragic lives can no longer be avoided. If, as contended in the last section, anencephalic neonates image God—they need no other purpose to be added to their life for ultimate meaning. Though in this present age we see only a poor reflection (1 Cor. 13:12), thus we are unable

to discern God's purpose amidst such a tragedy, nonetheless we must *not* assume that transplant donation is what lends purpose to an abbreviated life.

However, the increasing strength of this specific argument—donation as therapy for bereaved parents—is a mirror of the spirit or Zeitgeist of the post modern age. Many ethical constructs in contemporary culture are the result of our 'therapeutic culture' whereby a 'sense of psychological well-being, not truth, is the controlling value'.<sup>45</sup>

A therapeutic model inhabits the public discourse of American culture and has determined that the only way to make the parents of dying anencephalic children find meaning is through a sense of well-being. This well-being emanates from the donation of their child's organ(s). Such a therapeutic and consequential ethic cannot be sustained theologically. It is forced in sustaining its validity to ignore the child's personhood and *imago Dei*.

## Conclusion

*It's taken decades to publicly adopt the new definition of death to include brain death. We are still trying to educate family members to donate organs of those who have literally died. Are we now going to ask society to approve the scything of organs from those who are soon-to-be dead, virtually dead, as good as dead? It is simply asking too much.*

Ellen Goodman<sup>46</sup>

*The yearly number of patients in the country actually benefitting from anencephalic kidneys, hearts, livers optimistically projects to zero, nine, and two respectively . . . . (and) ten years from now projects to at most 25, 12, and 7 . . . . Such present and future projections ought to be borne in mind . . . before we expend great effort in modifying diagnostic criteria for brain death, changing statutory definitions of death, or relaxing fundamental principles of transplantation ethics in order to obtain anencephalic organs.*<sup>47</sup>

It is wrong to utilize anencephalic neonates as organ donors. The whole brain definition of death—or a valid cardiac definition—is essential to the ethical conduct of transplant donation. A loss of respect for anencephalic life—a life tragic as it is—will effect others living in a neocortical existence. To allow these children to die peacefully is the only way in which we can reverence their tragic existence and respect their threatened personhood.

1. *JAMA* (1995); 273 (20): 1614–18. This article or position paper is referred to repeatedly in later sections of this paper by page only.

2. Ethical and Judicial Affairs. 'Anencephalic Infants as Organ Donors.' In the *Code of Medical Ethics: Reports, Volume I*. Chicago, Illinois. American Medical Association 1992: 49–52.

3. Council on Ethical and Judicial Affairs, American Medical Association. In the *Code of Medical Ethics: Current Opinions with Annotations*. (Chicago, Illinois. AMA 1994), 2: 162.

4. Within a similar time frame, another gerrymander of the boundary between dying–death has been proposed—non-heart

beating cadaver donor protocols. See Rutecki GW. 'Blurring Distinctions Between The Dying and the Dead. A Call for Discernment' in *Organ Donation. Ethics and Medicine* (1994), 10(3): 57–67.

5. *N Engl J Med*. 1990; 322(10): 669.

6. For one rendering of the debate of neocortical vs whole brain definitions of death see: Devettere RJ, 'Neocortical Death and Human Death', *Law, Medicine and Health Care*. (1990), 18: 1–2. See also R. Veatch, 'The Impending Collapse of the Whole Brain Definition of Death', *Hastings Center Report* (1993), 23(4): 18–24.

7. For example, 4–15% of live-born anencephalics have major cardiac anomalies. These may include hypoplastic left-heart syndrome or persistent truncus arteriosus both of which are severe enough to absolutely preclude the use of such a heart for transplantation. See op. cit.; *N Engl J Med* 1990. 'The Task Force'.

8. *N Engl J Med* (1989), 321: 344–50.

9. In the determination of pediatric brain death, the neurological evaluation (e.g. Modified Glasgow coma scale) is more definitive than laboratory testing (e.g. EEG or measures of cerebral blood flow). For example, only 80% of children who eventually qualify for whole brain death have a flat EEG at the initial recording. See Walters and Ashwal, 'Organ Prolongation in Anencephalic Infants: Ethical and Medical Issues.' *Hastings Center Report* (October/November 1988), pp. 24–26.

10. op. cit., J.W. Walters, S. Ashwal, (1988), p. 20.

11. D.A. Shewmon, A.M. Capron, W.F. Peacock, et al., 'The use of anencephalic infants as organ sources: A critique.' *JAMA* (1989), 261: 1773–1781.

12. R.K. Lawson, W.M. Bennett, R.A. Campbell, et al., 'Hyperacute Renal Allograft rejection in the Human Neonate.' *Invest Urol* (1973), 10: 444–449.

13. A. Kantrowitz, J.D. Haller, H. Joos, et al., 'Transplantation of the Heart in an Infant and an Adult.' *Am J Cardiol* (1968), 22: 782–790.

14. K. Iitaka, L.W. Martin, J.A. Cox, et al., 'Transplantation of Cadaver Kidneys from Anencephalic Donors.' *J Pediatr* (1978), 22: 216–220.

15. W.E. Goodwin, J.J. Kaufmann, M.M. Mimms, et al., 'Human Renal Transplantation. I. Clinical Experiences with Six Cases of Renal Homotransplantation.' *The J of Urol*. (1963), 89(1): 13–24.

16. op. cit.; K. Iitaka, L.W. Martin, J.A. Cox, et al., (1978), p. 217.

17. L.W. Martin, L.L. Gonzalez, C.D. West, et al. 'Homotransplantation of both kidneys from an anencephalic monster to a 17 pound boy with Eagle-Barrett syndrome.' *Surgery*. (1969), 66: 603–607. Despite the ethical conduct in the determination of death context, personhood is either conferred or withheld solely according to the perception of the nature of the infant. This anencephalic was not a child or a neonate but a 'monster.'

18. See explication of the 'titration of death' to produce a viable donor organ in B. Freeman, 'The Titration of Death: A New Sin.' *The Journal of Clinical Ethics* (Winter 1990), 275.

19. op. cit.; D.A. Shewmon, A.M. Capron, W.J. Peacock, et al., (1989), p. 1774.

20. op. cit.; J.W. Walters and S. Ashwal, (1988), pp. 22–24.

21. op. cit.; J.W. Walters, S. Ashwal, (1988), p. 23.

22. D.A. Shewmon, 'Anencephaly: Selected Medical Aspects'. *Hastings Center Report*. (October/November 1988), p. 16.

23. J.A. Freedman, 'Taking the Camel by the Nose: The Anencephalic as a Source for Pediatric Organ Transplants', *Columbia Law Review* (1990), 90: 917–978.

24. J.L. Peabody, J.R. Emery, S. Ashwal, 'Experience with Anencephalic Infants as Prospective Organ Donors', *N Engl J Med* (1990), 322: 669–674.

25. N. Mdes Cameron, 'Bioethics and the Challenge of the Post-Consensus Society', *Ethics and Medicine*. (1995), 11(1): 1.

26. Gilbert Meilaender, *Hastings Center Report* (April 1986), p. 23.

27. *Hastings Center Report*. 1986; April, p. 21–22.

28. One means of influencing whose ethics will apply to controversial research topics is the choice of a 'government bioethics commission' (Cohen BC, McCloskey EL. 'Private

- Bioethics Forums: Counterpoint to Government Bodies', *Kennedy Inst of Ethics J.* (1994), 4(2): 283-289.) This particular paper was in an issue dedicated to cloning research. Daniel Callahan also observed that the recent embryo research panel, determined that since there is no single criterion for personhood, ergo a 'pluralistic approach' to such research is needed (in a typically post-modern ethos where all truth is 'relative') (*Hastings Center Report* (January/February 1994), p. 39). He stated further 'in other words, the report seems to be saying, if your aim is to do research, then a 'pluralistic approach' will give you the leeway to do it but within reasonable limits.' Even better, Bernard Lo, a member of the panel, was proud to say that the panel made a 'concerted effort both to impose a single moral view in the deliberations' (*Hospital Ethics*. (November/December 1994), p. 5) When ethics is determined by a majority that avoids 'imposition of moral views', how does it remain ethics?
29. *Hospital Ethics*. (March April, 1995), p. 7.
30. B. Freedman, 'The Anencephalic Organ Donor: Affect, Analysis and Ethics', *Transpl Proc* (1988), 20(4): 57-63.
31. *ibid.*; p. 57.
32. The Multi-Society Task force on PVS. 'Medical Aspects of the Persistent Vegetative State', *N Engl J Med.* (1994), 330: 1499.
33. P.W. Armstrong, B.D. Colen, 'From Quinlan to Jobs: The Courts and the PVS Patient.' *Hastings Center Report*, (1988), 18:37-40.
34. H.C. Kinney, J. Lorein, A. Panigrahy, et al. 'Neuropathological Findings in the Brain of Karen Ann Quinlan: The Role of the Thalamus in the PVS'. *N Engl J Med.* (1994), 330: 1469-1475.
35. G.F. Gomez, *Regulating Death: Euthanasia and the Case of The Netherlands*. (The Free Press, NY. 1991), p. 45.
36. *op. cit.*; (1988), 15.
37. *op. cit.*
38. D.O' Mathuna, 'The Bible and Abortion: What of the "Image of God"?' in *Bioethics and the Future of Medicine: A Christian Appraisal*. 1995. Ed. J.F. Kilner, N. M de S Cameron, D.L. Schiedermaier. (Eerdmans Publishing Company, Paternoster Press). p. 208.
39. *ibid.*; p. 199-211.
40. O'Mathuna quotes D.J.A. Clines who makes a word study of the Hebrew *Tselem* (image) and *d'muth* (likeness) 'emphasizing not the physical resemblance, but that the image is a representative one and is to portray the character of the one imaged'. *ibid.*; p. 201-202.
41. *ibid.*; p. 202.
42. A. Verhey, 'Scripture and Medical Ethics: Ps. 51: 10a, The JARVIK VII and Ps. 50: 9', in *Religious Methods and Resources in Bioethics*, ed. P.F. Camenish (Kluwer Ac. Pub., 1994), p. 270.
43. *op. cit.*; p. 207.
44. Personhood Redux. *Hastings Center Report*. (1988); October/November, p. 31.
45. G.E. Veith Jr., *Postmodern Times: A Christian Guide to Contemporary Thought and Culture*. (Crossway Books, Wheaton, Ill. 1994), p. 213.
46. Ellen Goodman cited in Wilke and Andrusko, *op. cit.*, 1988, p. 33.
47. *op. cit.*; D.A. Shewmon, 1988, p. 16.

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## **The American Psychiatric Association's 'Guidelines Regarding Possible Conflict Between Psychiatrists' Religious Commitments and Psychiatric Practice': A Conceptual Critique**

**A.A. Howsepian, M.D.**

The American Psychiatric Association's (APA's) Committee on Religion and Psychiatry drafted its 'Guidelines Regarding Possible Conflict Between Psychiatrists' Religious Commitments and Psychiatric Practice' (hereafter, the Guidelines) in 1989. Both the APA Assembly and the Board of Trustees approved the Guidelines that same year. It was published in the American Psychiatric Association's *American Journal of Psychiatry* soon afterwards (April 1990). The Committee's statement is brief; but its brevity does not explain the paucity of subsequent psychiatric publications which interact with it, either in a positive or in a critical way.

The Guidelines is a significant professional statement on a topic of perennial interest. This interest extends to the more than 90% of theists among our patients (Gallup, 1981; Kroll and Sheehan, 1989) as well as to those 40-70% of psychiatrists who also endorse some variety of theism (American Psychiatric Association Task Force Report 10, 1975). In light of the widespread interest in religious matters among both psychiatrists and their patients, what explanation is there for the psychiatric community's apparent neglect of the Guidelines? My puzzlement is especially acute in view of the Guidelines' obvious shortcomings.



Consider the first sentence of the Guidelines: (1), 'Psychiatrists should maintain respect for their patients' beliefs.' (Assume that the beliefs in question are restricted to *religious* and other *ideological* beliefs, that the psychiatrists in question are *American* psychiatrists, and that the respect in question is *expressed* respect.) (1) is obviously meant to range over *all* religious and other ideological beliefs. But so understood it is clearly false. Consider, for example, a psychiatric patient who is also a devout Ku Klux Klansman and whose doxastic commitments include the ideologically motivated conviction that all Catholics and all Jews ought to be detained, relocated, and ultimately liquidated. According to (1), this patient's psychiatrist, were he to be made aware of his patient's racist religious beliefs, ought to express *respect* for such beliefs. But in what twisted sense ought psychiatrists to respect beliefs like *that*?

One could imagine the following riposte: Clearly, either the respect in question is not meant to be understood as being *expressed* respect or it is not the case that *all* religious and other ideological beliefs fall under this admonition's purview. But such a response misses the mark. As noted above, the obviously implied range of discourse is over *all* religious and other ideological beliefs, no matter how perverse. If some qualification *was* intended which would restrict the range of the religious and other ideological beliefs in question, we have yet to hear anything of it. (Unfortunately, the Committee tells us nothing about what qualifies a belief as being a *religious* or *ideological* belief. Are we to understand just *any* belief involving religious themes to be a 'religious belief' and just *any* political belief to be an 'ideological belief' or is there something more to it? For instance, do religious *delusions* count as religious beliefs?)

As far as the notion of *respect* is concerned, it is hard for me to imagine that what the Committee means is that instances of *insincere* or *feigned* respect expressed toward one's patients' religious beliefs would be appropriate in those cases in which a psychiatrist could not bring himself to generate a genuine *sentiment* of respect for some of his patients' religious beliefs. It would, that is, be surprising to find out that the committee is here advocating that psychiatrists ought to cultivate (inner) sentiments which do not conform to the shapes of their (outer) interpersonal relations.

It is even harder to imagine that the respect which the Committee is asking psychiatrists to maintain for their patients' religious beliefs is composed *merely* of unexpressed (inner) sentiments of respect. I take each item in the Guidelines to be intended to guide psychiatrists' *interactions* with their patients, not merely psychiatrists' inner lives.

The Guidelines go on to state that (2a) 'If an unexpected conflict arises in relation to such beliefs, it should be handled with a concern for the patient's vulnerability to the attitudes of the psychiatrist.' (Is the term 'unexpected' really necessary here?), and (2b) 'Empathy, for the patient's sensibilities and particular beliefs is essential.'

It strikes me as curious that in a document which is, in part, intended to mediate a rapprochement between

psychiatrist and their religious patients, (2a) is stated in a way that appears to betray the Committee's *anti-religious* bias as it relates to the therapeutic encounter. Although the Committee would like psychiatrists to endorse (2a), it appears that psychiatrists could not, in turn, plausibly expect the Committee to endorse the following variation on (2a): 'If a conflict arises in relation to beliefs about *psychotherapy*, it should be handled with a concern for the patient's vulnerability to the attitudes of the psychiatrist.' In this putatively *non-religious* context, the patient's vulnerability to the clinician's attitudes is often viewed as being *therapeutic*. Clinicians are often *encouraged* to exploit patient vulnerabilities to change (as they are exposed, for example, in the context of a positive transference) in accord with the therapeutic dictates of their theoretical endpoints. Thus, the depressed patient, undergoing cognitive-behavioural therapy is consistently challenged in her beliefs about herself and the world in a manner which facilitates both the abandonment of her distorted, maladaptive beliefs and the adoption of the therapist's allegedly more veridical and adaptive beliefs. Where is the 'concern' here for the patient's attitudinal vulnerabilities? Somehow, religious beliefs are viewed by the Committee as being improper objects of intentional change within the context of therapy whereas patients' vulnerabilities to changing certain *non-religious* attitudes are enthusiastically exploited. What justifies this curious bias?

(2b) asks psychiatrists to have empathy for their patient's religious *sensibilities* and *beliefs*. What precisely is the Committee asking psychiatrists to do here? Empathy is not, after all, properly directed toward the *attributes* of persons, but to *persons themselves*. Psychiatrists are to empathize with their patients, not with their patients' properties or their parts; they are to place themselves in their *patients'* shoes, to take on *their* points of view (as much as this is possible). They are not to place themselves in the shoes of their patients' *beliefs* or take the points of view of their patients' *sensibilities*, if only because beliefs and sensibilities have no points of view for psychiatrists (or anyone else) to take.

Suppose that this is, in fact, what the Committee is attempting to convey, i.e., suppose that what (2b) really means is (2b\*): Empathy for patients, whatever their sensibilities or particular beliefs, is essential. Now (2b\*) has the ring of truth, but *only if* having empathy for one's patients is *compatible* with harbouring sentiments of extreme disapprobation toward some of one's patients' deepest religious sensibilities and most cherished religious beliefs, for certainly *some* religious beliefs and sensibilities are *proper objects* of such disapprobation.

Sadly, it does not appear that the Committee would endorse such a claim of compatibility, for it goes on to state that (3) 'Interpretations that concern a patient's beliefs should be made in a context of empathic respect for their value and meaning to the patient.' Here the Committee is explicit that *empathy* for a given belief is to be tied to *respect* for that belief's value and meaning. But certainly there is no justification of which I am aware for directing 'empathic respect' toward the value

and meaning of a significant number of beliefs (religious or otherwise) embraced by our patients. I do not say that we ought not to treat human *persons* with respect, for human persons are beings with immense value who ought to be respected simply in virtue of the kinds of beings that they are. (I leave the notion of respect unanalyzed. Suffice it to say that, as I understand this notion, *respecting* person S is compatible both with expressing anger toward S and with expressing the sentiment that every belief of a certain kind held by S is either irrational, false, or pernicious. As far as I can tell, it is also quite conceivable that the 18th century Prussian philosopher Immanuel Kant was right in claiming that one's intentionally *killing* certain human persons—those who, for example, are known to have committed certain heinous crimes—is harmoniously compatible with one's respecting those persons.) But it certainly does not follow from any of this that we ought to respect all, or a certain proper subset, of another person's *beliefs*. Just as it is perfectly possible (some might say, obligatory) for persons to love one another but not to love everything others do or believe, so too one may respect another but not respect any things the other believes or does—including many *religious* things.

Likewise, we might, through the medium of empathic understanding, come to appreciate how our patients came to value certain traditions or come to hold certain religious beliefs. But why should we think that interpretations concerning some of these values or beliefs should, in *all* psychiatric contexts, be made with *respect* (in any plausible sense of that term)? Of course, much hangs on what precisely it *means* to respect a patient's beliefs. Even the maintaining of an ideal therapeutic *neutrality* toward patient's doxastic commitments does not itself guarantee that one has successfully generated an attitude of (unexpressed) *respect* toward such commitments.

Of course, *not having respect* for something is not synonymous with *disrespecting* it. One might, for example have very little, if any, respect for our current President without ever having communicated with him; but one could not disrespect him in this circumstance. Perhaps the Committee is asking psychiatrists not to disrespect their patients' beliefs. Certainly, ideal therapeutic neutrality is incompatible with *disrespecting* our patients or their beliefs. But equally certainly, not all proper psychiatric interactions are marked by ideal therapeutic neutrality. There is, in fact, good reason to believe that *no* psychiatric interaction is or can be ideally neutral. At any rate, it appears to me to be wholly appropriate in the course of some psychiatric interactions to expose, in no uncertain terms, the venality of some of our patients' most cherished beliefs—religious or otherwise—in the hope of eradicating them.

This is not to say that *all* religious beliefs ought to be targets for eradication. Far from it. I have become convinced that certain religious beliefs and practices (just as certain *non*-religious beliefs and practices) are indispensable catalysts for human flourishing. But certainly not all of them are.

It is at this point that a protest will arise: 'But who is to decide which of our patients' religious beliefs or

practices are proper targets for eradication, which are to be tolerated, and which are to be fostered as vehicles for human well-being?' To a first approximation, the answer is clear: *psychiatrists* (among other reflective persons) *are*, insofar as psychiatrists are reflective persons and insofar as questions regarding human well-being are paradigmatic psychiatric questions. Of course, not all psychiatrists will be able to deal with these issues judiciously, just as not all psychiatrists are judicious psychopharmacologists or judicious practitioners of psychoanalytic psychotherapy. Perhaps only *very few* psychiatrists will be able to deal with these issues judiciously; or perhaps (to me, this would come as a surprise) a significant number of psychiatrists will. Nobody, I dare say, knows. And given the Committee's recommendations, it is virtually guaranteed that no one *will* know. There is, in this domain as in any other, no substitute for careful reflection, vigorous dialogue, and sustained conceptual and empirical investigation. In contrast to such a call for reflection, investigation, and dialogue, the Committee has chosen, in the absence of any clear publicly accessible justification, to impose upon psychiatrists the set of rigid, poorly constructed generalizations found in the Guidelines.

The Committee goes on to state that (4a) 'Psychiatrists should not impose their own religious, anti-religious, or ideological systems of belief on their patients' (4b) '... nor should they substitute such beliefs or rituals for accepted diagnostic concepts or therapeutic practice.' Regarding (4a): *Why* ought psychiatrists not to impose such systems of belief on their patients? Psychiatrists appear to have been given license to impose *other* systems of belief on their patients. (See 2a above.) So why not ideological or (anti) religious ones? (To my mind, it is obvious that psychiatrists *regularly impose* some of their ideological beliefs on their patients in numerous psychiatric contexts. Was this not obvious to the Committee?)

What does it mean, according to the Committee, to *impose* one's beliefs on someone else, anyway? Am I, for example, imposing my beliefs concerning the Guidelines on anyone simply in virtue of having given them this essay to read at their leisure? If not, then might psychiatrists *not* be imposing their religious beliefs on their patients if they were quietly to hand their patients written 'personal statements of faith' to read at their leisure? (I don't know; I'm asking, for I don't know what the word 'imposition' is intended by the Committee to convey in this context.) In at least one pervasive psychiatric context we seem to impose conventional ideological beliefs on our patients all the time when, for example, we administer neuroleptics to patients in the hope of altering their delusional systems, or when we attempt to change the self-perceptions of depressed patients in the course of cognitive-behavioural or self psychotherapies. These, it seems, are paradigms of imposition (as that term is commonly used in ordinary discourse) yet the psychiatric profession allows, if not encourages, these practices.

Regarding (4b): Why are 'accepted diagnostic concepts' and '[accepted] therapeutic practices' sacrosanct to the Committee in this context? Could you imagine if

clozapine were serendipitously discovered and administered to patients by a lone 18th century researcher who, in virtue of this discovery, stopped treating his patients with cold baths and bouts in the spinning chair, but instead began treating them with clozapine? According to the Committee's view as embodied in the Guidelines (were this document current in the 18th century) the ideologically motivated treatment of patients with clozapine by this pioneering psychiatrist would have been deemed to be an unacceptable psychiatric practice. But certainly that would be absurd.

A similar problem plagues the Committee's stance concerning 'accepted diagnostic concepts'. Systems of American psychiatric nosology (as reflected, for example, in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* or *DSM*) change every few years. Why would anyone think that the *most recent DSM* is, therefore, the full repository of nosological wisdom in psychiatry? Imagine a psychiatrist in 1969 who had publicly stated that ego-syntonic homosexuality is not a mental disorder, no matter what the current *DSM* says, because his religious beliefs entail the view that 'homosexuality' is not a legitimate diagnostic entry in any proper taxonomy of psychopathology. According to the Committee's present position, this psychiatrist would have been in violation of precept (4b) of the Guidelines. I wonder how many members of the Committee would be alarmed by this particular violation of the principles laid down in the Guidelines. Probably very few.

Who are the ones setting this standard of acceptability anyway? The Committee? Even the compilers of the *DSM-IV* have found it prudent to make explicit in a 'Cautionary Statement' that 'The specified diagnostic criteria for each mental disorder are offered as guidelines for making diagnoses. . . They do not encompass, however, all the conditions for which people may be treated or that may be appropriate topics for research efforts.' (p. xxvii) A similar disclaimer is included in the *DSM-III-R*. Thus, the views expressed by the APA's task force in charge of drafting the *DSM-IV* and the *DSM-III-R* are, at least on the surface, at odds with the views of the APA Committee in charge of drafting the Guidelines.

One might cry foul at this juncture by pointing out that there is only the *appearance* of tension here. One might argue, for example, that the Guidelines and the *DSM* 'Cautionary Statement' are not really at odds because the scope of the term 'accepted diagnostic concepts' as understood by the Committee is meant to include certain 'accepted' *non-DSM* psychiatric diagnoses. One might claim, that is, that the term 'accepted' in this context, was not intended to mean 'an entry in the most recent *DSM*'. This is fair enough. But on what non-

arbitrary grounds are *religious* concepts excluded from playing prominent roles in the conceptualization of certain *non-DSM-IV* psychopathological 'conditions for which people may be treated'? None that I can see.

The Committee goes on to call a transgression of their Guidelines an 'antitherapeutic ethical violation'[,] But nowhere does the Committee provide *any justification* for thinking that transgressions of the Guidelines are invariably either antitherapeutic or unethical. Clearly simply in virtue of the Committee's stating that some particular practice is antitherapeutic or unethical doesn't make it so.

I conclude by proposing that the Guidelines be significantly reworked in light of its obvious shortcomings, in virtue of the gravity of those issues toward which it is directed, and because of the urgency with which guidance in this area is needed by the psychiatric community. The Committee's effort in this regard is especially troubling in light of the fact (i) that the *APA News* (August 6, 1993) has recently reported that an APA Ethics Committee has been asked to investigate the phenomenon of religious (specifically, *Christian*) psychiatry and (ii) that in response to a new Accreditation Council on Graduate Medical Education special requirement, 'the APA Committee on Religion and Psychiatry plans to propose a model training curriculum later this year'. (*APA News*, March 17, 1995, p. 9). Given the poor quality of the Guidelines, this projected APA investigation and model training programme gives us much about which we ought to be concerned.

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# Gatekeeper Ethics: The Primary Care Physician in the Era of Managed Care

*Don Buckley, M.D.*

No one will deny that third party payment systems in American medicine are currently undergoing drastic changes. Market forces, primarily employer driven, are leading to the introduction of a greater percentage of managed care plans such as Health Maintenance Organizations (HMOs) and Preferred Provider Organizations (PPOs) over traditional indemnity insurance. Americans continue to spend more money per capita on health care than any nation on earth—a huge \$884.2 billion in 1993 which is 13.9 percent of the GNP and the fastest growing slice of it. As our government and major employers have made abundantly clear over the past two years, they are growing weary of paying this ever increasing bill. With the stunning failure of national health care reform, only managed care strategies remain as viable options to reduce medical costs. Though highly touted by some, HMOs thus far have been able to record only modest cost savings of 6 to 7 percent.<sup>1</sup> Nevertheless, managed care is currently what the market wants and, as one HMO executive recently stated, 'The marketplace always wins.'<sup>2</sup>

In 1988, indemnity insurance accounted for 72.6 percent of the private health insurance market; by 1993, it had shrunk to 33.3 percent, leading some to predict its impending *death spiral*.<sup>3</sup> During the same period PPOs with discounted fee schedules and HMO enrolment have grown steadily. We have also experienced the birth of what some feel are more 'patient friendly' PPO plans which allow patients more freedom of medical service selection but at a greater personal cost.

## Compulsion to Managed Care

Doctors in many areas of the country have felt compelled to sign up with managed care plans or face losing a sizable portion of their patient base. A recent survey showed that three-quarters of private physicians were enrolled in at least one managed care plan in 1994.<sup>4</sup> Physicians are exhorted by leading medical journals to participate in such purported cost-cutting plans as our societal duty in the face of a *limited resource economy*.<sup>5</sup> However, there are significant voices of dissent. G. Gayle Stephens, arguably the chief proponent of family medicine theory and practice writes: 'I believe that the gatekeeper role is hopelessly conflicted, ethically unmanageable, clinically naive, professionally ungratifying, and historically unnatural for a family physician.'<sup>6</sup> He goes on to state: 'I cannot imagine that,

apart from defensive economic strategy, well-informed physicians or patients would choose a gatekeeper model of medical care on its non-economic merits.'<sup>7</sup> Indeed the economic necessity of such a system (at least in the private sector) is suspect when one examines the salaries of some of the leading Chief Executive Officers (CEOs) in the HMO industry. Are medical resources in the U.S. private sector truly limited when the top 10 CEOs of for-profit HMOs earn salaries of up to \$3.6 million annually?<sup>8</sup>

Let me say at this point that I do concede that there are limited public monies for health care (Medicare and Medicaid). I also concede the urgent need for better stewardship of private sector health dollars although I remain unconvinced of the need for some imposed mandatory rationing system.

Clinic and hospital administrators are becoming increasingly enamoured with capitated health plans such as HMOs, due to changes in the health care market. The past decade has shown an almost linear decline of gross collections to health care providers. The old fee-for-service system has been supplanted by a discounted fee-for-service system (PPOs) resulting in greatly diminished profit margins for clinics and hospitals. These discounted systems are thought by many to be only a transitional form of managed care. The evolutionary trend of managed care is toward capitated plans such as HMOs. Under capitated plans, physicians, clinics, and hospitals are paid a fixed amount of money to care for a defined patient population. Here the whole game plan of health care delivery is reversed. Under previous systems a physician was paid proportionally to the amount of service provided. A managed care consultant recently told a group of physicians, that the new system is 'Do more, get paid less'. He then paused to allow the corollary to sink in—'Do less, get paid more!' Herein lies the moral rub.

## Ethics Precede Economics

Some readers may be wondering, 'When are we going to stop talking about economics and start talking about ethics?' But that is the whole point. In the contemporary managed care debate it is often felt that *economics precedes ethics* (to borrow somewhat from Sartre). Indeed it appears that ethics is often only an afterthought designed merely to justify managed care strategies. Mary Devlin of the American Medical Association's

(AMA's) Council on Ethical and Judicial Affairs maintains that it remains to be seen 'whether the original pattern of medical ethics can be retained while undergoing modifications needed to meet the requirements of a changing technological, economic, and social environment'.<sup>9</sup>

It is somewhat frustrating to attempt to find writings on the philosophical, theoretical or psychological underpinnings of managed care. A Medline data base search of articles devoted solely to these issues was almost fruitless, so it appears that this is a fertile field of research for budding young Christian bioethicists. Nevertheless, on reviewing the currently available literature on managed care, it still seems possible to arrive at a rudimentary Gestalt of its underpinnings. In keeping with the spirit of our contemporary post-modern age these underpinnings are a somewhat eclectic blend that reflects the conflict inherent in managed care theory. The true blue evangelist of managed care typically begins the *sermon* by appealing to the social conscience of the physician in the face of a limited resource economy. Vague reference is made to the concept of distributive justice *à la* John Rawls. The sermon is sprinkled throughout with business management jargon—'capitation', 'case manager', 'clinical economist', 'health care providers/consumers', 'rationing', etc. The chief doctrine espoused is Utilitarianism—providing the greatest good to the greatest number of people—which is translated in managed care terms as more people provided with *adequate* access to medical services. Never mind the fact that such a philosophy has always proved more theoretical than practical but perhaps we could revivify Jeremy Bentham's mummified body and he could provide us with some sort of *managed care calculus* to guide us. As the managed care sermon draws to a close the evangelist pulls out a powerful psychological weapon to draw in the unconvinced physician—that of economic behaviourism. If the physician does not act to decrease overall health care consumption he/she will be punished economically with a lower take-home pay while the shrewd clinical economist is promised a bonus for her efforts. Remember, do less, get paid more!

David Sulmasy noted recently that America's current infatuation with managed care is anticipated to some degree in the well-known work of moral philosopher Alasdair MacIntyre entitled *After Virtue*.<sup>10</sup> MacIntyre describes the late twentieth century as a period of managerial revolution; but he goes on to decry the fact that this so called *managerial effectiveness* is nothing more than a *moral fiction*. MacIntyre opines, 'It [managerial effectiveness] is the name of a fictitious, but believed-in reality, appeal to which disguises certain other realities.'<sup>11</sup> What are these *certain other realities* that are being disguised? MacIntyre says that they are all that is *systematically unpredictable* in human affairs. As enumerated by Sulmasy, these include: 'the conceptual innovations, the unforeseen consequences of unmade individual decisions, the indefinite reflexivity, imperfect knowledge, and multiple simultaneous relationships that constitute our personal interactions, and the pure contingency that characterizes so much of our human history in the making.'<sup>12</sup> To put it quite simply,

life is too unpredictable to think that we can bureaucratically micro-manage it. Likewise, I contend that the practice of medicine is just as unpredictable. Somehow my patients never seem to fit those described in the available practice management guidelines.

A significant feature of America's managerial revolution in managed care is the current advancement of the concept of *managed death* (otherwise known as euthanasia and physician-assisted suicide). Certainly the adoption of such a term as *managed death* is simply a euphemism designed to lend an air of cool, swift professionalism to what we consider to be a callous disregard for human life. The increasing public debate over the concept of managed *death* occurring simultaneously with managed *care's* still young and impressionable policy formulation merits close moral scrutiny. I would call attention to the David Sulmasy's article 'Managed Care and Managed Death', found in the *Archives of Internal Medicine* (Vol. 155, January 23, 1995) for further reflection on this issue. In the section entitled, 'The Logic of Being a Burden' Sulmasy notes a *perilous line of argument* whereby these two movements could chillingly converge under the guise of cost containment.

The argument is: '(1) Too much money is being spent on health care, (2) certain patients are expensive to take care of (e.g., those with physical and mental disabilities and the elderly), (3) these patients appear to suffer a great deal, lead lives of diminished dignity, and are a burden to others, both emotionally and financially, (4) recognizing the diminished dignity, suffering, and burdens borne by these persons and those around them, their right to euthanasia or assisted suicide should be legally recognized, and (5) the happy side effect will be health care cost savings.'<sup>13</sup> Only time will tell if such logic comes to fruition despite our resistance.

The majority of primary care physicians I know approach capitated health care with a sense of ambivalence. We all favour eliminating unnecessary medical spending. We all favour better preventative health care and patient education. We all favour treating our patients at the most appropriate level of technological intensity. And we all care deeply for the economic plight of our country's health care establishment. But as physicians of the Christian-Hippocratic tradition, as physicians who follow the ethic of the Good Samaritan—we have got to take care of the patient on the table in front of us first. As Edmund Pellegrino has so passionately exhorted us in his ethical works, our primacy of obligation is to our patients—not to third party payers, and not even to society as a whole. Society itself will benefit when each of its individuals is treated with such primacy. Pellegrino says: 'It is important to realize that most of practical ethics consists in resolving conflicts of obligations. To resolve moral conflicts usually requires an ordering of obligations in accord with some governing principle. In the case of medicine, we do have an ordering principle, something not so clearly available in other states of life. That standard is the covenant of trust we enter every time we ask a patient, 'How can I help?'.<sup>14</sup> That is our ordering principle in medicine—the patient comes first.

Current managed care theory in subtle fashion calls into question the idea that we should give primacy to our individual patient's medical needs without simultaneously giving due consideration to the economic solvency of his health plan, be it private or government funded. Never mind that we as physicians never have nor will ever know how much money is available in the health care coffers. Gayle Stephens calls this the 'actuarial secret' of HMOs the 'hard core calculation of utilization of and expenditure that cannot be exceeded, a secret closely guarded and kept from physicians and subscribers alike.'<sup>15</sup>

The traditional relationship between physician and patient can be described as a covenant of trust in which physicians serve patients' medical needs with competence and beneficence. The physician acts exclusively for the benefit of the patient. Managed care or capitated health care adds a new element to this relationship—that of rationing. Rationing requires that a fixed sum of money cover all the medical needs of the population in question. It implies the possibility that an individual may be denied necessary and effective treatment if funds are felt to be insufficient or if resources are felt to be better utilized elsewhere in the plan. Physicians here are forced to act, as Marcia Angell describes, as 'double agents expected to decide whether the benefits of treatment to their patients are worth the costs to society'.<sup>16</sup> Such double agency poses a direct threat to the Hippocratic and Christian traditions of healing and erodes the trust that is vital in the physician-patient relationship. The patient is left to ask, 'Is my physician's advice based on what's good for the health plan/society or what's good for me?'

I argue that rationing is not an appropriate primary duty of the physician. At the same time I suggest that a physician is always obligated to act with thrift or economy. Such terms denote wise stewardship of available resources, elimination of waste, and the refusal to provide unnecessary or ineffective medical care. I think such notions are already implicit in the definition of physician competence.

### Moral Stress Tests

Needless to say, the primary care physician as gatekeeper (entry point into the health care system) faces numerous practical ethical dilemmas on a daily basis. Sulmasy refers to these ethical challenges as *moral stress tests* for physicians in the managed care era.<sup>17</sup> This is not to say that medical practice under fee-for-service plans exists or existed in a state of moral purity. We all know colleagues who have over-tested and over-treated for personal economic benefits. Ethical temptation is more intense under managed care, however, due to the omnipresent threat of economic punishment of the physician for alleged 'over-utilization of services'.

The following is a brief listing of some 'moral stress tests' for primary care physicians as gatekeepers:

1. *Physician-patient estrangement.* I have already alluded to the roots of this potential adversarial standoff. Gayle Stephens argues that even under the best of circumstances, 'gatekeeping has turned me and my

patients into a gang of wheedlers and sharpies, each trying to outfox the other for petty privileges and paltry savings'.<sup>18</sup>

2. *Stretching clinical competency.* Here the primary care clinician potentially compromises the patient's health by attempting care beyond her competency. This is a clear violation of the principle of beneficence.

3. *'Gaming' the system.* This involves distorting patient information in order to assist patients in the acquisition of medical services. We deceive ourselves when we resort to such end-justifies-the-means arguments.

4. *Skimping on preventative services.* Managed care prides itself on the provision of preventative health services such as immunizations, pap smears, and mammograms. With the frequent turnover of patients in HMOs, however, there exists the temptation to skimp on these services (especially immunizations) and let the patient's next primary physician provide them.

5. *Skimming of patient populations.* Under capitation a physician's inclination is to choose a younger and healthier patient population in order to conserve the capitation pool.

6. *'Churning' patients.* Medicaid patients have been victims of this practice before. Here the physician sees a large number of HMO patients with little time spent on any of them while allotting more individual time and attention to his fee-for-service patients. The HMO patients quickly realize they have become second-class citizens. A variation of this practice is to allot choice appointment times to the fee-for-service patients. Such a practice would discourage capitated patients from seeking medical care.

This list, although certainly not exhaustive, contains some of the many moral temptations primary care physicians face under capitated health care.

### Conclusion

So what can a primary care physician do when faced with the realities I have discussed? I believe it is clear that for many of us it will not be possible to 'opt out' of managed care and still provide for our families. As Christian physicians we must work for the reformation of managed care as it exists now in its formative stages. We must sit in on the appropriate committees as perpetual and vigorous advocates of patient care. We must serve as examples to our fellow physicians by delivering competent health care to all with economy. We should remain open to advice from clinical outcome studies or practice guidelines. Managed care insurers must be made accountable to patients and provide full disclosure of covered services and restrictions. Exorbitant profits of HMOs must be channelled back into patient care. And finally, we must assure those under our care that the physician-patient covenant of trust will remain inviolate.

1. Barbara Weiss, 'Managed Care: There's no stopping it now', *Medical Economics* 72 (March 13, 1995), p. 28.

2. *Ibid.*, p. 26.

3. *Ibid.*, p. 27.

4. *Ibid.*, p. 31.

5. Clifford J. Harris, 'Gatekeepers and Cost Containers in HMOs', (letter) *New England Journal of Medicine* 318 (June 23, 1988), p. 1698.
6. G. Gayle Stephens, 'An Opposing View', *The Journal of Family Practice* Vol 28, No. 6, p. 701.
7. *Ibid.*, p. 703.
8. Weiss, p. 34.
9. Mary M. Devlin, 'Ethics and the Health Care Revolution', *Quality Assurance and Utilization Review* 2 (February 1987), p. 13.
10. David Sulmasy, 'Managed Care and Managed Death', *Archives of Internal Medicine* 155 (January 23, 1995), p. 135.
11. *Ibid.*
12. *Ibid.*
13. *Ibid.*, p. 134.
14. Edmund D. Pellegrino, 'Words Can Hurt You: Some Reflections on the Metaphors of Managed Care', *JABFP* 7 (Nov.-Dec. 1994), p. 506.
15. Stephens, p. 703.
16. Marcia Angell, 'The Doctor as Double Agent', *Kennedy Institute of Ethics Journal* 3 (September 1993) pp. 279-80.
17. David Sulmasy, 'Physicians, Cost Control, and Ethics', *Annals of Internal Medicine* 116 (June 1, 1992), p. 922.
18. Stephens, p. 702.

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## **A Document Against So-called Embryo 'Reduction'**

***Centre of Bioethics, Catholic University of the Sacred Heart, Rome***

Over the last few years the scientific community has attempted to make certain operations appear to be 'normal'. These operations are performed by physicians but they are extremely questionable from an ethical point of view in that they involve the suppression of a human life. In other words there is an attempt to give these operations the characteristics of a medical procedure whereas actually there is nothing much medical about them at all.

This is the case of so-called embryo 'reduction', that is the selective termination of some embryos, sparing the others, in a multiple pregnancy usually due to medically assisted fertilization procedures.

In fact, as it is known, both hormone treatments for the induction of ovulation in the case of infertility, and assisted fertilization techniques (FIVET, GIFT, etc.) have led to a significant increase in multiple pregnancies and the associated maternal and/or foetal complications. Therefore, to prevent the inevitable negative consequences of multiple pregnancies the literature has begun to discuss embryo reduction, with the aim of improving the maternal-foetal prognosis, by reducing the number of embryos to two or three. The scientific societies of gynaecology and obstetrics have therefore made recommendations, consensus conferences have been organized and research programmes have been financed regarding the best methods for performing this operation, as though it were a question of an ordinary therapeutic operation.

It is clear however, that this technique has serious repercussions from a legal, ethical and moral point of view in that its compatibility with the law on abortion and the arguments adopted to justify it ethically are inadmissible.

Often in fact, the medical press describes the selective reduction of embryos as scientific progress which 'should make it possible today for the pregnant woman to avoid the trauma of an abortion', as though reduction were not itself the suppression of the life of some embryos, even though, one hopes, the others will continue to live.

We would therefore like to discuss the presumed therapeutic meaning of embryo reduction, and we consider that the research funds and researchers' energy would be better directed towards an improvement in medical hormonal treatment and the assisted fertilization protocols, rather than towards refining the techniques of embryo reduction.

### **The Medical Aspects of Embryo Reduction**

As mentioned above, this is an obstetrical operation which consists in terminating one or more embryos of a multi-foetal pregnancy (therefore reducing the number of embryos which have begun to develop) and encouraging the continuation of the pregnancy with the remaining embryos. However, the medical literature reports other 'indications' for embryo reduction, like the termination of one or more foetuses, even in a spontaneous pregnancy, in which the prenatal diagnosis has indicated the presence of congenital malformations and/or chromosomopathies; or even the termination of one or more foetuses if the woman says she is unable to look after all the new-born infants.

These other cases certainly represent borderline situations but in a recent case study carried out in the United States these 'indications' were 17% and 9% respectively of the embryo reductions performed.

Therefore it is clear that, on one hand, embryo reduction is connected to the increasing use of assisted fertilization techniques which has caused the greater incidence of multi-foetal pregnancies with a large number of embryos (four or more); on the other hand it is connected to the progress and technical and cultural background of prenatal diagnosis which has made it possible to obtain a more precise diagnosis of pathologies for which, unfortunately, there are not as yet any therapeutic perspectives. Therefore this technical development is the factor without which there would be no problem of foetal reduction.

The incidence of multi-foetal pregnancies with a large number of embryos (four or more) has increased over the last few years because of an uncontrolled and unscrupulous use of assisted reproduction techniques.

In fact, many physicians consider that introducing more than one embryo in the woman's uterus increases the possibility that at least one of them will implant itself and that the pregnancy will continue.

However, it often turns out that all the embryos introduced in the uterus implant themselves so some pregnancies occur with 7 or even more embryos.

With the increase in the number of embryos (in particular more than three), there is an increase in maternal-foetal complications, which are in direct proportion to the number of embryos present in the uterus. In particular, the percentage of preterm deliveries increases and a preterm infant risks serious metabolic and neurological sequelae. This is why a pregnancy with more than three embryos is considered an iatrogenic complication of the assisted reproduction techniques. The most often used techniques for terminating the extra embryos involve injecting a potassium chloride based solution or a saline solution, with a spinal needle guided by means of ultrasound, into the foetus' chest or heart. In this case, it is considered that the death of the foetus is due to the mechanical action of the needle combined with the increase in pressure in the chest resulting in cardiac arrest.

There is some data regarding the toxicity of potassium chloride in the embryos that continue living which demonstrates that the operation is not free of problems; the mean rate of 'spontaneous' miscarriages of the remaining embryos is, in fact, about 15% and ranges from 9 to 40%. However other complications connected to the operation technique have also been reported, like sepsis, metrorrhagia etc.; the possibility of psychological sequelae both in the mother and in the surviving children, as in the relatives, etc.

## **The Legal and Ethical Implications**

Several Ethics Committees from various countries and a few national laws have taken into consideration the ethical implications of embryo reduction and are trying to

prevent legally the factors that encourage this practice, like the introduction of more than three embryos in the uterus during assisted fertilization procedures. The law passed in Germany on the protection of embryos states that 'anyone who performs a transfer of more than three embryos into a woman during one cycle' will be imprisoned for up to three years or fined.

Other recent regulations on assisted fertilization operations also limit the number of embryos or oocytes to be transferred during a single treatment cycle to three, in order to lower the incidence of multiple pregnancies.

Similar indications have been provided by the French Comité Consultatif National d'Ethique. In 1991 this Committee pointed out that embryo reduction should not constitute the legalisation of the carelessness of the physician in performing assisted fertilization techniques. Finally, the Italian National Bioethics Committee has also pointed out that there are no medical indications for embryo reduction in triplet pregnancies.

From a purely legal point of view, there is also the problem of where this operation stands with respect to the legislation on abortion. At present in Italy the justification for the operation comes from the law on abortion, although actually the procedures required by the 194/78 Act are not followed. Since it is not an abortion but rather a question of terminating some foetuses and keeping other foetuses alive, it should be considered as 'embryonicide', as proposed by the Italian Commission for the reform of the criminal code.

In conclusion, we consider that the following ethical points must not be ignored:

- ⇒ *the direct, selected termination of healthy embryos in a multiple pregnancy justified by the fact that this is necessary in order to save the other embryos and/or the mother goes against the principle of the respect for human life;*
- ⇒ *the selective reduction of the malformed twin is considered a eugenic operation which is unacceptable on the basis of the respect due to every human being, whatever his degree of health. This operation also involves a concrete risk for the healthy twin;*
- ⇒ *the information given to the couple before the assisted fertilization operation has to include information regarding the risk of a multiple pregnancy;*
- ⇒ *in drawing up protocols and regulations for performing assisted fertilization techniques a more appropriate hormone treatment should be requested and/or a limitation of the number of embryos or oocytes transferred (two or three at the most), so there should be no need for a reduction operation. In the case of FIVET there are obviously still all the ethical objections regarding the modality of fertilization itself;*
- ⇒ *it is the duty of the physician who induces a multi-ovulation or who transfers more than three embryos into the uterus to take personally the responsibility for any consequences involved in a multiple pregnancy. On the other hand, if an obstetrician is faced with a woman with a multiple pregnancy, he has to*



*be able to express conscientious objections regarding the embryo reduction operation even though he still*

*has to assist the woman and all the fetuses of the multiple pregnancy.*

## Book Reviews

### **Ethical Aspects of Human Reproduction**

Edited by Claude Sureau and Françoise Shenfield, Published by Joun Libbey Eurotext, Paris, 1995, ISBN 2 7420 0086 0.

Ethical dilemmas surrounding obstetrics and gynaecology are legion and multiplying. The July 1994 meeting of the International Federation of Gynaecology and Obstetrics attempted to grapple with the issues and *Ethical Aspects of Human Reproduction* records the event.

The late twentieth century global mixing-pot of cultures now all too often leaves a practitioner with one set of personally held ethical values, giving treatment to a woman from another culture. On top of this, technology provides new opportunities that bring benefits as well as dangers. By their very nature many of the techniques are difficult to understand and professional medical teams struggle to give information in a way that is accessible to the potential recipients. As if this is not enough there is the thorny issue of who exactly is the patient—the woman or the fetus inside her?

B.M. Dickens' opening lecture summed-up the problem faced by the conference, and it was unfortunate, though predictable, that most speakers and delegates then sought to avoid the issue. The problem in a nutshell is this: how do you provide simple ethical frameworks in a post-modern society where what is acceptable to one is abhorrent to another? His solution was to suggest a fracturing of society, with each person signing-up to the medical care community that fits his/her particular ideology. On the whole, other delegates chose to give lip service to the notion that different cultures have different values, but then pursued their own particular argument as if there was no other way of addressing the issue.

Even so, the sections are thought-provoking. Regarding the fetus, the standard debate as to when personhood begins was held against the background of an obstetrician's need to remain within the law. For instance, should a physician seek a court order to carry out a caesarean section that he believes will benefit the fetus when the woman is refusing? Could he be sued for negligence by the fetus if he failed to act? Could he be sued for assault by the woman if he insisted on some action? With fetal medicine still poorly developed this is not an area of concern, but as fetal procedures become more advanced and successful, this area is going to become increasingly fraught.

When it came to discussing informed consent, things didn't get any easier. But is it really possible to give people all of the information they need to make a truly educated decision? At times it seems that the medical community is trying to absolve itself of the responsibility that comes from creating techniques simply by saying, 'It's your choice'. Is it ever possible to expect a member of the public who has never studied medicine, ethics or science to grapple with and understand the complex issues that surround so many discussions? Surely, many patients go to doctors because they want and expect answers, not questions.

The debate around the issue of using a fetus as a source of organs for donation always centres around when and why the organs are available. In adult donation the donor is always

declared brain-dead before the organs are removed—what is the equivalent test in a fetus where full brain function may never have been established? Delegates also raised the spectre of people deliberately conceiving a fetus in order to supply organs for the woman or some other members of the family. On top of this is the possibility of having women paid to conceive fetuses for organ donation—as expressed by Dr Fatalla, this would be another form of prostitution.

After a concerted block reviewing the ethical decisions around fetal medicine, the second half of the book looks at issues surrounding care for newborn babies, gamete donation and surrogacy, female circumcision, sex selection and research on pre-embryos. As Dr Alnot pointed out in his discussion of gamete donation the medical profession is not an innocent party in the social change that has accompanied many of these activities.

Like many conference reports this book has a tendency to be long-winded, although this is less of an issue if you are selective in reading the sections of specific interest to you.

PETE MOORE

### **Life At Risk: The Crises In Medical Ethics**

Richard D. Land and Louis A. Moore, editors  
Nashville: Broadman & Holman Publishers, 1995  
ISBN 0-8054-6265-1 paperback  
vi + 287 pp

The exciting and promising field of medical science has generated hope for disease-ridden millions while creating a new ethical challenge of major proportions for man in general and Christians in particular. The magnitude of the ethical challenge stems from the fact that it centres on the most basic issues known to man—matters relating to life and death. The prevailing naturalistic world view with its corollary relativistic ethics has resulted in a major shift in how western man views life and death (not in terms of their reality, but in terms of their meaning and significance). As a result, the intrinsic worth of life as defined by Christianity has been devalued (if not altogether denied), thus creating the illusion that medical science operates in a morally neutral environment. This comes at a time when the moral compass of western culture as a whole is becoming less and less responsive to the magnetic north of moral absolutes. Consequently, the declining influence of a moral consensus coupled with the burgeoning knowledge of medical science has created an ethical climate inimical to the Christian morality. The net result for culture is a growing bio-ethical crisis where life itself is at risk. Within this cultural milieu, the Christian is called by the risen Lord to be salt and light. To meet this challenge of bioethics, the Christian must be theologically grounded, culturally informed, intellectually honest and spiritually prepared.

For those desiring to meet this challenge, *Life at Risk: The Crises In Medical Ethics* is an invaluable resource. Far from being a religious diatribe, it presents current bioethical issues in an even-handed, well-modulated and understandable fashion, avoiding personal attacks and minimizing the use of technical terminology without sacrificing accuracy. Uniquely, it does all of this, while at the same time dedicating a healthy portion of space to developing a theologically-based response both for formal rebuttal and practical lifestyle agendas.

The editors, Richard Land and Louis Moore, have done a quintessential job in orchestrating a cadre of qualified Christian authors to present the Christian community with a diverse but unified response to the current bioethical concerns. Generated by the 26th Annual Seminar of the Southern Baptist Christian Life Commission, this book defines the issues, clarifies the questions and provides an insightful analysis and succinct overview of the crises in bioethics. The book is impressively punctuated with statements emphasizing the importance of one's theological-philosophical foundations as the starting point for both understanding and answering the issues in bioethics. It will not do your thinking for you, but it will prepare you to think Christianly and constructively about some of the very troubling bioethical issues of our time.

The book is divided into five sections: 'Crisis at the Beginning', 'Human Genetics', 'Crisis at the End of Life', 'Crisis for the People of Life' with the 'Conclusion and Summary' written by one of the editors, Richard Land. The nineteen well-written chapters aimed at enlightening Christians '... about the proper biblical response to the multiple medical-ethical issues today' (vi) hits its target squarely. This is not to say that the book single-handedly answers all the questions or deals with all the issues, but what it does do, it does well with a few minor exceptions.

The most disturbing notion appears in the first chapter titled 'Crisis Throughout Life' by James Draper. The main thrust of the chapter, which defines the crises, explains the scriptural view of life and gives suggestions for Christian action in meeting the present challenge, is very helpful. In fact, it prepares the reader for what is to follow. The point of concern, however, surfaces when Draper explains his understanding of the phrase 'image of God'. He quotes Robert Rakestraw saying, 'To be in the "image of God" means that we exist as the representatives of God on earth, with certain God-given and God-like qualities and capacities, so that we may experience vital relationships with God and others and so that we may exercise dominion over the earth. . .' (p 10). At first sight, this seems quite acceptable theologically, but as this idea is fleshed out, what is personally troubling is that this seems to get dangerously close to defining 'personness' in terms of function and potential. In fact, the quote ends by saying, 'The earthly life of a person thus begins at conception and ends when this ability or potential ceases' (p 11). If this is so, how does this impact on our understanding of 'personness', for example, in the case of PVS patients. Certainly they cannot 'experience a vital relationship with God and others'. At that point, both ability and potential have ceased, so are they no longer 'persons' or have I missed something in the definition?

The chapter, 'Fetal "Personhood"' written by Dianne Nutwell Irving is a stellar example of compelling argument. She presents the different positions for 'personhood', based upon embryological developmental stages and then systematically responds to each one. In a well researched and meticulously argued contribution, Dianne Irving demonstrates that by the standards of empirical data and scientific standards '... every human being is a human person from fertilization on' (p 44).

The fifth chapter, 'Southern Baptist Heritage of Life' by Timothy George, paints in bold colours the historical picture of the

leadership of the Southern Baptists, revealing what he calls a 'complicity and/or blindness' (p 84) in the moral issue of abortion. He charges that 'at the very heart of this ethical collapse was a profoundly theological failure of nerve' (p 84). This conclusion is not offered to berate Southern Baptists, but to serve as a serious reminder to all Christians of the central place theology must have in our lives if we are truly to live for God and speak meaningfully about the issues of life and death.

In terms of subjects addressed, I think the second section has a decided edge over the others. That evaluation obviously reflects a personal interest-bias, but that aside, undeniably the issue of gene therapy contains some of the most difficult and pressing ethical questions bound up in the larger bioethical discussions. Francis Collins', 'The Genome Project' succinctly outlines the essential facts and concerns relative to gene therapy. Recognizing both the risks and benefits of gene therapy, he wisely comments, 'We certainly cannot hold those people [those with CF] hostage to concern about potential misuses. However, we have to take the responsibility to be sure those misuses do not occur' (p 113). This is followed by Ben Mitchell's enlightening chapter titled, 'Genetic Promise and Problems' which provides a reality check for genetics while offering helpful insights and 'prudential judgements' concerning 'prenatal screening, genetic discrimination, workplace screening and monitoring. . .' (p 115).

Kurt Wise's thought-provoking chapter, 'It Matters Where You Start' addresses the much neglected (but most important) subject of how Christians should understand the relationship of genetic manifestation of the pre-fall conditions with that of the post-fall conditions. Explaining the difference in conditions, he writes, '... it can be argued that God created a significant amount of genetic information which was unexpressed at the time [this is of original creation]. It is very likely, for example, the pain sensation, the capacity for carnivory, floral thorns and toxins, as well as complicated mechanisms for survival under conditions of competition were pre-programmed for expression at the time of the fall. It is likely that this is just a small part of the latent information placed within genetic systems' (138-139). This is one of those chapters where you sense the impulse to underline every sentence. The book is worth the price for this chapter alone.

Rounding out section two is Thomas Elkins' 'The End of the Autonomy Road'. When the prevailing idea, even among many Christians, is health on demand as a personal right and that physical suffering must be eliminated at all costs, Thomas Elkins skilfully shows another way of looking at suffering and death. This is a very personally challenging and compassionate treatment of the subject with almost the flavour of a treatise on a theology of suffering. Appropriately, section three picks up on and expands the discussion of issues concerning suffering and dying. It challenges the church to accept her responsibility to minister compassionately in that context. While the chapters in section four are very beneficial in their own right, one senses a certain loss of continuity with the flow of the previous three sections. Nonetheless, all nineteen chapters, in their own right and as a contribution to the whole, make a significant contribution to understanding and responding to the moral crisis in bioethics.

Richard Land captures the urgency and passion expressed in each chapter when he summarizes, 'If we fail to insist that our society be one in which it is always wrong to do certain things to a human being, then we are bound to live in a society in which virtually anything can, and will, be done to human beings' (p 287). This is not mere religious rhetoric, this articulates the inevitable trajectory of bioethics without the impact of the Christian influence. Those who will invest time to read the book will be better prepared to be a part of that Christian

influence as well as being personally enriched. The only regret I have is that I did not read *Life At Risk: The Crises In Medical Ethics* sooner.

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### **Readings in Christian Ethics, Volume 1: Theory and Method**

Edited by David K. Clark and Robert V. Rakestraw  
Grand Rapids, MI: Baker Books, 1994  
ISBN 0-8010-2581-8 paperback  
328 pp. \$17.99

Concerned that 'sloppy ethical thinking' (p. 9) is rampant among Protestant Christians because of a neglect of foundational ethical matters, Clark and Rakestraw set out in *Readings in Christian Ethics, Volume 1: Theory and Method* to offer a correction. This first volume in a two-volume set addresses, as the subtitle asserts, theories and methodologies of ethical thinking and practice within a distinctly evangelical Christian trajectory. The second volume, *Issues and Applications* (set for release in July 1996), takes-up specific ethical issues.

The truth of the editors' assertion is clearly evident in the ethical debates which rage in American society. One needs only to watch certain television 'talk' shows or read the comments of certain Christian spokespersons in the print media to understand that few Christians have a firm grasp of basic ethical theory. Nonetheless, many evangelicals rush into the public policy field, certain of their convictions, without considering the proper foundations of ethics.

The ill-founded nature of Christian thinking in ethical matters can be traced back to the training ground for pastors in universities and seminaries which are failing to teach students the basics of moral theory and application.

In seeking to draw together writings on ethical theory, the editors make clear that not all selections are written from an evangelical Christian perspective. Nonetheless, the editors assert that this volume is unique in that their 'selection of topics and general approach . . . is driven by the concerns that evangelical believers consider to be central. We have chosen issues, views, and persons who are of interest to evangelicals' (p. 10). The uniqueness of this work, according to the editors, is that while other anthologies of Christian ethics have been published, *Readings in Christian Ethics* seeks to represent distinctly evangelical thinking. Additionally, although noteworthy works have been offered by evangelical writers in the field of ethics, each of these carries with it a particular viewpoint which fails to take account of contrary ethical theory within the evangelical world. Thus, the editors sought a 'balanced continuum of views or several aspects of a problem' (pp. 10-11) in choosing the readings.

In addition to the evangelical orientation of the editors and their purpose, the work is 'dominantly theological,' (p. 10), rather than strictly philosophical or exclusively biblical.

*Readings in Christian Ethics* is targeted toward the student at the beginning of a course in ethics and, perhaps, the pastor in the field in need of a refresher in basic Christian ethics. In light of this, the readings are not burdensome and represent an introduction to the major issues at stake in ethical theory. Topics addressed include: the nature of ethics, grounding moral norms, moral dilemmas, moral situations and cultural contexts, the use of the Bible in ethical judgments, love and justice, virtue and character, and the process of decision-making. Leading names in Christian ethics are among the contributors to this volume: Lisa Sowle Cahill, John Frame, Norman Geisler, Stanley Hauerwas, Daniel Maguire, Stephen Charles Mott, Oliver O'Donovan, Lewis Smedes, and Helmut Thielicke. The

editors also draw from interdisciplinary fields authors who have contributed to ethical thinking. These persons include: Gordon Fee, Walter Kaiser, Alister McGrath, J.P. Moreland, and J.I. Packer.

Although the book is intended for the beginner in ethics, this writer wonders if Clark and Rakestraw err on the side of offering not enough material for the reader, rather than too much. Perhaps the editors, in an effort to reach as broad an audience as possible, intend to leave the particularly motivated college or seminary student wanting more. For such persons, that will be the case.

Clark and Rakestraw offer a quite well organized work. Each chapter is introduced by a brief essay which synthesizes the major topics which are addressed in the writings for the chapter. As the editors introduce new key terms of ethical theory each is defined and highlighted by bold print. These terms are collected at the end of each chapter in a glossary which allows ready reference for the student who may need assistance in grappling with the term in the reading of that chapter. All of the highlighted terms are collected at the end of the book in a handy glossary which new students will need to turn to in their studies.

Another helpful feature of this volume is the 'For Further Reflection,' section concluding each chapter. In addition to the glossary, the editors also include two thought-provoking case studies which will challenge the reader to grapple in concrete ways with the topics which he/she has just read. An annotated bibliography is also included. Here the editors enumerate major books, chapters of books, and journal articles which treat the subject matters of the chapter. Included are selections which the editors believe are important and will enhance the student's understanding of the literature of the field. Thus, the selections come from across the theological and philosophical spectrums, some of which challenge the evangelical presuppositions of the editors. The annotated bibliography will be quite helpful for the new student in ethics.

All the features of this work's organization—the introductory essays, selected writings, case studies, glossaries, and annotated bibliographies—make for an ideal text book for courses which introduce Christian ethics.

*Readings in Christian Ethics, Volume 1: Theory and Method* is a helpful and needed contribution to the literature of this critical field. The editors' desire to offer a distinctly evangelical Christian work developing theories and methods of ethical thinking is commendable and desperately needed. Professors and other teachers will find the volume a highly usable text which will enhance their efforts at introducing basic ethical theory for the new student.

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### **Human Fertilisation and Embryology Pre-conceived Ideas—A Christian Perspective of IVF and Embryology**

Edited by: Saint Andrew Press, Edinburgh, 1996; 95pp., £5.95  
Submitted and accepted by the General Assembly of the Church of Scotland May 1996

The report commissioned by the Church of Scotland's Board of Social Responsibility represents an excellent and informative discussion concerning the problems of childlessness and the most recent developments in the field of assisted conception.

The very competent members of the study group, who produced the report after almost two years of work, confront the relevant problems, while acknowledging some of the medical

and theological difficulties in an understanding and compassionate manner.

The introduction examines an overview of the medical and social problems. The report then reviews with much depth and clarity the government's position on embryo research and storage, the cost of treatment and the established legal framework.

The subsequent theological discussion represents the backbone of the study, offering a very rational and thorough development concerning the status of the embryo, which lies at the heart of the debate surrounding reproductive medicine. The three possibilities presented are that the embryo has: no moral status at all; a degree of moral status that may be outweighed by other moral factors; an entitlement to protection as a human being from the time of fertilisation onwards.

The study group is in support of the third view, opposing, on the grounds of intrusion by third or fourth parties into marriage, assisted reproduction using the gametes of donors together with surrogacy and sex-selection (with the exception of sex-linked genetic diseases). On this last point, however, a more detailed theological discussion concerning the important questions of sex-selection for personal preference by future pre-conception methods would have been of interest.

The report is instructive, worth reading and has been mentioned by many General Assembly commissioners, who officially accepted it, as being of outstanding quality.

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Editor European Journal of Genetics in Society

### **The Troubled Helix: Social and Psychological Implications of the New Human Genetics**

Edited by: Theresa Marteau and Martin Richards  
Cambridge University Press, Cambridge, UK, 1996. ISBN 0-521-46288-6. xviii + 359pp. £35.00 (US \$64.95), hardback.

In 1959, a leader article in the *New York Times*, quoted by Deborah Thom and Mary Jennings on page 230 of *The Troubled Helix*, described human genetics as '... an enormous territory, awaiting exploitation of the human chromosome map as the first prize, if the early promise is only half-fulfilled'. To put the leader article in context, it was written only six years after the publication of Watson and Crick's papers on the structure of DNA. Recombinant DNA technology had not yet been invented (1973 marks the birth of genetic engineering) and the formal start of the Human Genome Project was 31 years into the future. The article from which the quotation is taken was describing cytological rather than molecular techniques for studying chromosomes. Yet how prophetic those words have proved to be. The development of modern molecular biology, much of it based on our ability to manipulate and study genes using recombinant DNA techniques, coupled with major technical advances in cytogenetics, has led to an explosion of research on genes. For human genes this research has, since 1990, been co-ordinated through the Human Genome Project.

Human genetics is indeed proving to be an enormous territory but, just who is exploiting it, who is winning the prize? Certainly the 'new human genetics' is very exciting for biological scientists and medical practitioners. Moved by such excitement it is easy to forget the wider implications of this research. However, there are other players in the game. In October 1996, Tom Wilkie wrote in *The Guardian*: 'As our genetic inheritance is unravelled to reveal more about the diseases we are likely to sustain, the insurance industry has started to campaign for greater access to our most intimate secrets . . . Now . . . the insurance companies are asking for . . . access to our DNA. They want to know what genes we have

inherited from our parents and, therefore, when we are likely to die.

For the past five years, British geneticists have been trying, in vain, to persuade the insurance companies that they need not pry into people's genetic inheritance. Insurers, for their part, fear that people who know from a genetic test that they are likely to develop a fatal disease in later life will pile on the life insurance . . . without declaring the test result on the application form.'

In these two quotations from newspapers, separated by 37 years, we begin to get a taste of what *The Troubled Helix* is all about. We can no longer ignore the social context of human genetic research, even if those of us who are scientists or medical practitioners would like to think that the results of research are value-free. Who is to have access to the results of genetic research? How and why will individuals, organizations or indeed 'society' 'exploit the territory'? And what about those directly affected by genetic disease, patients, carriers and their families? Are their needs to be squeezed between the interests of the medico-scientific community and those of powerful pressure groups or organizations with their own agenda or purpose?

*The Troubled Helix*, edited by Theresa Marteau and Martin Richards, is, according to the publishers' description on the dust jacket, '... the first book to attempt to explore and survey these issues from such a wide variety of perspectives, from personal accounts of individuals coping with the threat of genetic disease, from the viewpoint of clinicians and scientists and from those concerned with psychological, social, legal and ethical aspects.' Do the editors succeed in this attempt? I can answer this question in three words: *Read this book!* It is a must for anyone with an interest in human genetics and, especially for those who are used to dealing only with the 'purely' medico-scientific aspects, it will be a real eye-opener. Part I, *Personal Stories*, consists, as the title implies, of personal accounts written by people who have faced up to the reality or possibility of genetic disease, followed by a comment on those accounts from a leading clinical geneticist, Peter Harper. These accounts form a memorable and sometimes disturbing opening to the book and show how little we really know about the way in which genetic information affects the lives of 'real' people. This kind of material should be compulsory reading for anyone training for a career in medicine or nursing.

The remaining chapters deal with the wider aspects of human genetic research and its applications in their clinical context (Chapter 2-8) and their social context (Chapters 9-17). All of these chapters are informative and thought-provoking. However, I should say that the book does not make for easy bed-time reading. It deals with serious issues in a serious and professional manner. There are, inevitably in a multi-author volume, stylistic differences between chapters which lead to differences in readability. For readers who are used to the terminology of science and medicine, the vocabulary, language (and the underlying thought-processes) of social scientists are at first difficult to unpack. However, even though it is *not* on the whole to *easy* to read, *The Troubled Helix* is *rewarding* to read: it is worth making the effort.

I also need to say that many readers of this journal will not agree with or be in sympathy with everything that they read in *The Troubled Helix*. Indeed, there is even some disagreement between different contributors to the book! In several places, different authors come perilously close to stating that the results of scientific research are a social construct. While I accept that some of the agenda for scientific research and many of the applications of the results of scientific research may be social constructs, I do not accept that objectively collected data from properly controlled experiments, observations or surveys are a social construct. Clearly science needs

to defend itself strongly against the influences of post-modernism.

In dealing with conflicts of ideas, I must give some specific attention to Meg Stacey's chapter, 'The new genetics: a feminist view'. Human genetics raises many issues for women, for example as mothers, carers, carriers (especially of sex-linked illness) and, as described by Martin Richards in Chapter 12, as 'genetic housekeepers' for families. It is absolutely right that these issues should be discussed by a woman writer, free from masculine prejudice. However, Meg Stacey's chapter is spoilt by her making statements which the data patently do not support. Now, I am aware that, as a male, criticizing a feminist writer, I am on a 'hiding to nothing': to borrow a phrase from another woman 'He would say that, wouldn't he'. Nevertheless, I am bound to say that the idea that Barbara McClintock's Nobel Prize award was delayed because mainstream male scientists did not understand her work is somewhat of a distortion of the truth. Neither do I accept that science (and particularly biological science) is run to a masculine agenda, nor do I recognize the social structure and gender balance that Stacey describes as characteristic of the scientific community.

Perhaps she should visit a modern medical or biological research institute to see what they are really like. Finally, I want to take issue with her re-statement of the idea that discrimination against women can be ascribed to the Judaeo-Christian inheritance. This view, propagated by the eco-feminist movement and by sociologists such as Hilary Rose, is as prejudiced an interpretation of the data as some of the attitudes which Stacey seeks to demolish, and should be seen as such.

Although I have dwelt at some length on points to which I reacted negatively, I certainly do not want to leave our readers with a negative view of *The Troubled Helix*. So let me state again: *Read this book*; you will find the time, effort (and money, if you buy your own copy) well spent.

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