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# ETHICS MEDICINE

# An International Christian Perspective on Bioethics

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## From Agneta Sutton Comment: A Family Year?

Insofar as the word 'family' still has anything to do with kinship and marital relations, the start of 1994, *The Year of the Family*, can hardly be described as auspicious.

A British woman aged 59 gave birth to twins after receiving IVF treatment (in Italy), using donated ova and her husband's sperm; an African woman, also availing herself of ovum donation (at another clinic in Rome), gave birth to a white baby: and, finally, there has been talk in the United Kingdom of techniques using aborted female fetuses as ovum donors.

All three procedures entail the use of third party gametes, which means that the carrying mothers are not the genetic mothers of the child they carry. This may well cause psychological problems. It is easy to see that children so conceived may feel confused about their own kinship identity. Also, they may have difficulty in facing the reality of having been produced in a test-tube or petri dish in the laboratory.

'The third technique mentioned, moreover, involves making dead females into mothers, showing scant respect for either the dead or the living, born or unborn. This kind of technique could also be applied using the ovaries of born but dead females. Both situations would entail taking immature ova from dead bodies and allowing them to mature under laboratory conditions before fertilising them in vitro and implanting the embryo(s) in a recipient female. '

The practice of gametal donation, no doubt a fruit of the sexual ethics of the liberal sixties, can only be described as an extreme form of adultery, performed anonymously. The child is not a gift received in the loving embrace of its parents but a product of the cold and calculated actions of scientists using spare parts from a third party to help an infertile couple. The donor, relinquishing all responsibility for the child-to-be, effectively forsakes her child before it is born or even conceived. By so doing not only she violates the natural order but she undermines the trust children hitherto always have had in their kinship relationship with their gestational mother and grandmother.

The third technique mentioned, moreover, involves making dead females into mothers, showing scant respect for either the dead or the living, born or unborn. This kind of technique could also be applied using the ovaries of born but dead females. Both situations would entail taking immature ova from dead bodies and allowing them to mature under laboratory conditions before fertilizing them *in vitro* and implanting the embryo(s) in a recipient female. Alternatively, tissue from fetal ovaries could be grafted onto non-functioning adult ovaries. In either case, it would mean treating dead female human beings, girl fetuses or young girls and women, as merely disposable and spare material.

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It would also make a farce of motherhood. Not only would it allow women to become mothers after their death but, in the case of the dead fetuses, the possibilities are stranger still. Never before have biological mothers not reached puberty; never before has it been possible to become a mother without having been born! Those who researched into these possibilities never questioned the wisdom of nature or providence.

It is hard to imagine the feelings of the child or young person who finds out that his or her genetic mother was a dead woman, or worse, an aborted fetus. No-one has a right to a child at all costs. Certain ways of procreating are clearly contrary to the dignity of man, woman and child.

What is at issue is parental motives and social attitudes. Parents who think of children as something to which they have a right in the same way as they have a right to buy a car, or who choose babies to specifications, thinking more of their own satisfaction than of the welfare of the child-to-be, treat children – however unconsciously – as consumer goods or designer ware. But children are not commodities and anything that threatens so to reduce them will harm them and, in the end, us all.

## From C. Ben Mitchell **Comment:** Genetic Engineering – Bane or Blessing?

We are in the midst of an amazing biological revolution. Medical technologies once thought to be only science fiction have now become science fact. In the past, genetic manipulation was possible only through careful processes of breeding and cross-breeding plants and animals. Today, however, the manipulation of genes or 'genetic engineering' is possible not only for plants and animals but for humans as well.

Just because we *can* engineer humans, however, does not mean we *should* do so. Questions about what it is possible to do scientifically must be answered by those who are actively engaged in scientific research. Questions about what we should or should not do ethically must be answered by each of us. The ethics of genetic engineering is, in many ways, far more critical and demanding than the science of genetics. As evangelical Christians we must bring to bear all the tools at our disposal – science, biblical studies, hermeneutics, systematic theology, etc. – to the task of grappling with the ethical issues that arise from the new genetics.

The expansion of scientific information and the multitude of treatment modalities presently available demand our utmost concern. The potential benefits of genetic therapies are enormous. The potential for evil uses of genetic technology is equally mind-boggling.

#### The Big Science Project

All of us are aware of the power of our inherited genes. Eye colour, hair colour, and other physical characteristics are linked to our genes. Genetic factors have also been linked to a host of major health problems and birth defects. Conditions such as cystic fibrosis, Duchenne's muscular dystrophy, Down's syndrome, Huntington's chorea, Alzheimer's disease, diabetes, cancer, and perhaps some forms of mental illness, may each be traced genetically. To date, little or nothing can be done to treat, let alone cure, these diseases. But through a major science project, funded by U.S. taxpayer dollars, we may someday be able to offer treatments to help the hundreds of thousands of persons who suffer from these illnesses.

In 1990 the National Institutes of Health (NIH) and the Department of Energy (DOE) officially began a jointlysponsored initiative known as the Human Genome Project (HGP). The HGP is a massive, fifteen-year project that has as one of its goals to identify the sequence of the 3 billion base pairs of DNA that together carry the complete human genetic blueprint. This genetic blueprint is known as a 'genome'.

'The information generated by the human genome project is expected to be the source book for biomedical

science in the 21st century and will be of immense benefit to the field of medicine. It will help us to understand and eventually treat many of the more than 4000 genetic diseases that afflict mankind, as well as the many multifactorial diseases in which genetic disposition plays an important role.'<sup>1</sup>

The HGP, authorized by Congress in 1989, is divided into three five-year segments. The first third of the project seeks to (1) map and sequence the human genome, (2) map and sequence the DNA of model organisms like the fruit fly, (3) collect and distribute available data, (4) examine the ethical, legal, and social issues of the project, (5) train researchers, and (6) develop and transfer genetic technologies for the world-wide effort.<sup>2</sup> The budget for the HGP is over \$250 million per year, adjusted annually for inflation, or over \$3 billion. This is big science.

For the first time in a major government-funded science project, 3 percent of the first five years' budget has been set aside to study the ethical, legal, and social implications (ELSI) of the technology. The ELSI component of the project is thought to be critical because of the tremendous social and ethical implications of studying and manipulating human genetic material. The ELSI working group, a committee of scientists, ethicists, insurance professionals, and others, has said: 'Any scientific endeavour of this magnitude must be developed in concert with a plan to ensure that the public has access to the benefits in improved health care, which should be the result of the research. It is also imperative to protect individuals and society from possible hazards which may be a consequence of our improved ability to detect and predict hereditary illness. The use of genetic information, for good or ill, has long been an issue in our society. But the quantity and complexity of genetic information that should become available requires that special precautions be taken.'3

The committee on the ethical, legal, and social implications of the project has correctly identified the fact that the immensity of this initiative carries with it responsibilities of gargantuan proportions. It is imperative that each of us understands as much as possible about the implications of the HGP and seriously reflects on what the Bible informs us about the ethics of such an undertaking.

The HGP's accomplishments are already very promising. The genes have already been isolated for a number of devastating illnesses, including, amyotrophic lateral sclerosis (Lou Gehrig's disease), cystic fibrosis, Duchenne's muscular dystrophy, Fragile X syndrome, Huntington's disease, neurofibromatosis, retinoblastoma, retinitis pigmentosa, and Wilm's tumour.<sup>4</sup> Announcements of the discovery of genes for other diseases are being made almost daily. Once the disease genes are identified, efforts can be made to find treatments or even cures for these diseases. Several genetic illnesses are already treatable through gene therapy.

The hope of being able to offer treatments and cures for over 4,000 genetically-linked illnesses is absolutely wonderful. The relief of human suffering and the prospect of restoring health to those persons who are debilitated and die from these diseases is, all things being equal, sufficient to endorse the project. Indeed, we should applaud and encourage scientists in their war against genetic illnesses.

#### **Proceed With Caution**

Is there a down side to the HGP? Are there precautions which should be taken? Should we scrutinize the technology or let it proceed unexamined? As with every technology there are benefits and burdens, goods and evils. Sadly, the history of genetic experimentation and the use of genetic information is strewn with the wreckage of abuse. At the turn of the 20th-century in America, social reformers called 'eugenicists' began a programme to rid our nation of so-called 'genetic defectives'.

'Eugenics' is a term 'coined in 1883 by the English scientist Francis Galton, a cousin of Charles Darwin'.<sup>5</sup> Galton saw eugenics as 'the "science" of improving human stock by giving "the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable" '.<sup>6</sup>

The American eugenicists, borrowing from Galton, pushed a social movement they hoped would rid the world of 'hereditary defectives' such as 'the feebleminded' and 'criminal'. At the Kansas Free Fair in 1929, an exhibit placard asked, 'How long are we Americans to be so careful for the pedigree of our pigs and chickens and cattle – and then leave the ancestry of our children to chance or to "blind" sentiment?'<sup>7</sup> The impact of the eugenics movement led to a number of horrific efforts in 'social hygiene'.

Charles Davenport, one of the founders of the American eugenics movement, defined eugenics as 'the science of the improvement of the human race by better breeding'. 'Heredity,' said Davenport, 'stands as the one great hope of the human race, its savior from imbecility, poverty, disease, immorality.'<sup>8</sup> Davenport pushed for so-called racial hygiene and worked to halt sexual reproduction between Americans and European and African immigrants, including Jews. In an effort to prevent American genetic stock from 'deteriorating,' Davenport and other eugenicists supported statutes restricting immigration.

Sterilization was another method of 'protecting' Americans from deleterious genes. By 1917 at least seventeen states had passed laws which made possible the mandatory sterilization of prison inmates who had been sentenced for crimes such as drug addiction, sexual offences, and who suffered from epilepsy. Included in most legislation were statutes permitting the sterilization and castration of the insane, deviant, and 'idiots in state institutions'.<sup>9</sup> It had been determined that the best means of preventing further corruption of the gene pool was to prevent those thought to be suffering from 'bad genes' from reproducing. Justice Oliver Wendell Holmes put it most illuminatingly in the infamous court case *Buck v. Bell* when he said: 'Three generations of imbeciles is enough.'<sup>10</sup> The decision of the court was that the sterilization of a 'mental defective' was within the police power of the state and did not constitute cruel or unusual punishment.

Eugenics lost popularity in the United States when it became apparent that human rights were being violated and human dignity assaulted through this kind of genetic engineering. Across the Atlantic, however, under national socialism in Hitler's Germany, the American experiment was taken ten steps further and became even more grotesque. 'German racial hygienists throughout the Weimar period expressed their envy of American achievements in this area, warning that unless the Germans made progress in this field, America would become the world's racial leader.'<sup>11</sup>

In 1923, Fritz Lenz, a German physician and advocate of sterilization, severely criticized his own countrymen for their hesitancy to adopt mandatory sterilization laws like those in the United States. He held up the American eugenics movement as a model for what ought to be done in Germany.<sup>12</sup> Thus was born one of the most notorious human tragedies of the century. An estimated 400,000 people were sterilized in Germany under the 'Law for the Prevention of Genetically Diseased Offspring' which was passed in 1934.<sup>13</sup> According to Robert Jay Lifton, 'Only in Germany was sterilization a forerunner of mass murder.'<sup>14</sup> That is, the sterilization programme gave credence to the notion which justified the massive euthanasia programme to follow; namely, that the 'hereditarily sick' were living a 'life unworthy of life' (*lebesunwertes Leben*).

While no one is arguing that the Human Genome Project is an extension of the Nazi atrocity, or of the American eugenics movement for that matter, unless the lessons of the past are heeded, we may indeed repeat them in the future. Human nature certainly has not changed since the turn of the century. The history of the abuse of genetic information and technology must not be permitted to devolve into a future of similar abuse.

Because we have a well-documented history and because the HGP is a 'big science' project involving many thousands of researchers around the globe, we can approach the project with cautious optimism. We therefore may be hopeful that the new genetics will result in the cure of thousands of diseases, but we must be careful not to violate the sanctity of human life along the way.

#### Where Is God In Human Genetics?

What does the Bible say about genetic engineering? While the writers of the Old and New Testaments did not envision a scientific project like the HGP, the omniscient God who inspired them certainly foreknew and gave humans the capacities for such a knowledge. All truth belongs to God and is ultimately given to us for his glory and for our good. There are, no doubt, both good uses and evil uses of the knowledge God reveals or enables us to discover, and it is our responsibility as stewards of this knowledge to seek to use it in ways that will glorify God and bring good to humanity.

Are there precepts, principles, or examples in Scripture that should shape Christian ethics with respect to genetic issues? Since we do not find the words *gene*, *genetics*, or *genome* in a concordance of the Bible, what are some of the scriptural principles which ought to inform our thinking about the Human Genome Project?

First, we must begin where the Bible begins, at creation. Human beings, like all of the universe, are the result of the creative activity of a personal God. 'In the beginning God created the heavens and the earth,' declares Genesis 1:1. The doctrine of creation is the foundation of the Christian theistic worldview. Christians may not agree about or fully understand all of the particulars, but we begin with the presupposition that the universe, including human life, is not the result of random events, the luck of the draw, or blind chance, but the purposive action of an omnipotent God.

Second, the Genesis account reveals that Adam and Eve, and all their progeny, were created in the image and likeness of God (Genesis 1:27). The human genome is, therefore, not only biologically unique, but spiritually (or metaphysically) unique. Human life has been invested by God with sacredness and has intrinsic value. Just as there are some ways of treating human life that are clearly unethical and immoral, some ways of treating the most basic biological building blocks of human life are unethical and immoral.

Third, the Scriptures declare that when Adam and Eve sinned in the garden of Eden, something tragic happened to the whole created order (Genesis 3:17-21; Romans 6:12). Though theologians characterize differently the results of the fall, it is obvious to anyone who is observant that this is not the best of all possible worlds. Sin has brought with it disease and death. Not only that, but the fact that human beings themselves are sinners means we often find ways to use good things for evil purposes.

Since disease is ultimately the result of the corruption of the world through sin, it is critical that we understand that genetics will not be a new messiah to redeem us from all bodily or mental ills. That is not to say, however, that we ought not to use genetic technology for the purposes of curing human disease where possible. The genome project is not, in and of itself, open to the charge of 'playing God' any more than other medical therapies. Whenever we take advantage of medical therapies or interventions (even one so common as the flu shot) we are using technology as an intervention against human disease.

There is, though, a curious reductionism that sees every human ill – physical, mental, or spiritual – as curable through genetics. Reducing the human predicament to 'bad genes' is tantamount to making the new genetics another utopian vision.<sup>15</sup> Paradise exists in 'another world' and awaits only those who trust in Jesus Christ as Saviour and Lord.

Fourth, the sorts of things we are already able to accomplish through genetics is simply phenomenal. But genetic technology can be used as a potent weapon, as a means of eliminating the 'unwanted' or 'non-useful' or persons who are living 'lives not worth living'. Genetic information may be used as a method of high-tech discrimination against persons based on their genomic characteristics. For instance, in the 1970s mandatory sickle-cell screening among African-American children became a method of discriminating against black children because they were merely carriers of the sickle-cell trait. Screening is currently being used in some cases for gender discrimination. Parents are using genetic information for sex-selection. If they determine they are going to have a girl baby and they wanted a boy, they may abort the baby and try again.

Fifth, and more optimistically, we must acknowledge that all of God's creation, especially us humans, are 'fearfully and wonderfully made' (Psalm 139:14). Efforts to understand better the human body, the disease process, and the ways to fight those diseases should, all things being equal, be celebrated and encouraged. Discovering more about the profound complexity of the human body, mind, soul, and spirit, points to the reality of the Creator and gives believers more cause to praise and worship him intelligently. That our great God has permitted us to discover ways to relieve physical human suffering, save lives, and cure diseases is certainly a manifestation of his grace and mercy.

Every good and perfect gift comes from God (James 1:17). That fact makes it imperative that we not misuse or squander the gifts he gives, including the gift of genetic technology.

Finally, we must face squarely the limits of the new genetics and not think more highly of it than it deserves. Genetics will not ultimately save us from death and the grave. Human beings have an 'illness' that permeates us more completely and is unquantifiably more deadly than any genetic disease. Our predisposition to sin is a result of who we are as fallen creatures. If left 'untreated' that falleness will result in an eternity without hope and without God. The remedy for our sin is new life in Jesus Christ. He alone is Messiah. He alone is the Great Physician. Ultimately, in heaven, we will be cured of every disease, even our bent toward sinning. *Soli Deo Gloria!* 

#### **Ethical Issues In Genetic Engineering**

Realistically, the Human Genome Project probably does not raise many new ethical issues. Centuries of medicine and research have surfaced already most of the dilemmas which face the project. The new genetics do, however, amplify and make more critical issues which earlier were thought of as exotic or extraordinarily rare. And the social power of genetic information is even more dangerous than in the past.

Though the ethical issues in human genome research are myriad, we will focus on only three: prenatal screening and abortion, privacy, and discrimination.

#### Prenatal Screening and Abortion

Presently, there are two major kinds of genetic screening

tests. On the one hand, prenatal screening, the most common application of genetic screening technology, aims at the early recognition of individuals who are affected by a genetic anomaly. Prenatal testing is done for a host of genetic illnesses such as Down's syndrome and neural tube defects like spina bifida.

On the other hand, carrier testing is done in order to identify individuals who are at risk of transmitting genetic diseases to their offspring. Screening for Tay-Sachs disease and sickle-cell anemia are classic examples of this form of genetic screening. Prospective parents who have a high probability of passing a genetic disease to their children may choose not to conceive children who will be at risk for such an illness.

Once the children are conceived, however, if the developing child is diagnosed *in utero* to have a genetic illness, parents will have only one of three possible choices; (1) to bring the baby to term despite the illness, (2) attempt a presently experimental treatment *in utero* (which is possible only in an extremely limited number of cases), and (3) choose to abort the baby because of his or her genetic disease.

As Nancy Wexler, a geneticist and member of the ELSI committee has said, we must 'keep in mind that more often than not, diagnostic information will become available well before any ability to act on it therapeutically'.<sup>16</sup> In other words, through genetic screening, parents will be enabled to predict whether their children will be affected by a deleterious gene, but will be impotent to do anything about it except to carry the baby to term or abort him or her. In many cases, genetic counsellors may encourage abortion, 'due to the anguish of carrying a fetus with a severe or lethal genetic disease'.<sup>17</sup>

We do not wish to trivialize or underestimate the anguish involved in having a child with a radical deformity or lethal genetic disease. Christian compassion demands that we display utmost concern for, and minister to parents of, children who are devastated by such an event. At the same time, we should not condone or support technologies which encourage abortion, except to save the life of the mother.<sup>18</sup>

For many evangelical Christians, and most Southern Baptists, the issue of abortion has been at the forefront of concern for two decades. Since 1973 the number of abortions in America has consistently increased. Since the passage of *Roe v. Wade* more than 30 million legal abortions have been performed. Southern Baptists are on record for their over decade-long opposition to abortion, except to save the life of the mother. Information gained by genetic testing will increase the number of elective abortions unless parents are adequately informed and choose not to abort. 'Until effective treatments become available, such tests offer little more than scientific guidance to inform the decision of parents who are willing to consider abortion to prevent the birth of a child who could be gravely ill.'<sup>19</sup>

As one sociologist has warned: 'Clearly, it is a just and meaningful desire to prevent fatal and debilitating diseases. Yet in pursuing this goal, we pay unobserved costs. In eliminating individuals with unwanted diseases, we also create a mind-set that justifies the process of human selection. We thus move into the questionable arena of human worth, and to some degree eugenic thought. We forego the idea of therapeutic change (i.e., dietary change or other forms of treatment) and opt instead for elimination. Individuals are seen as flawed. It is easier and more desirable to prevent their existence than to work for their survival.<sup>20</sup>

We submit that only a 'sanctity of human life' ethic will prevent our society from tumbling down the slippery slope into an even greater holocaust of abortion and eugenics. Genetic screening for diseases for which there are no treatments or cures will, no doubt, lead to a significant increase in the number of abortions performed in the United States. Furthermore, genetic screening for sex selection purposes is an affront to the sanctity of all human life and is a peculiarly grotesque form of gender discrimination.

We essentially agree with Christian ethicists and biologists at Calvin College who have said, 'Where there is a safe and accurate test for a condition and where the test is related to available and effective treatment, we celebrate this new power to diagnose newborns, children and adults. Where such conditions are not met, we are more cautious than celebratory, and we are particularly concerned about the sort of mentality that would routinely screen for such conditions for which there are neither accurate tests nor effective therapy.'<sup>21</sup>

We urge that, until we know more about the ethical, psychological, and social impact of prenatal and carrier screening, such screening for genetic diseases for which there are no treatments or cures be prohibited or highly regulated.

#### Confidentiality

One's genetic information is the most personal and highly sensitive information one could possess. We can be separately identified from an unlimited number of persons through a DNA fingerprint. Our genetic information enables us and others to know, among other things, our predisposition to certain diseases. Our family heritage may be determined through genetic tests. In short, our genetic information is extraordinarily comprehensive.

Who has a right to know one's personal genetic information? Who wants to know? Certainly, you and your immediate family might want to know if you have a predisposition to a genetic disease. But, do insurance carriers have a right to know? Would a genetic anomaly be classified as a 'pre-existing condition' and thus lead to the cancellation of your insurance coverage for a disease you might acquire? Some entire families have been refused health insurance because one member of the family had a genetic disorder (such as Tourette's syndrome).

As the HGP progresses, large data banks of genetic information will be stored. The government is already screening members of the Armed Forces and convicted sex felons. In these cases information is being kept for identification purposes. What about information gathered

Ben Mitchell

on other persons? Will insurance companies, prospective employers, and government agencies have access to that information without asking permission or gaining consent? How might that information be used?

We cannot predict today what we will be able to detect or know in twenty years about an individual through genetic tests. As tests become more accurate and we are able to interpret the data more fully, it is impossible to discern what might be discovered in the year 2010 from a blood or tissue sample taken today. These facts have led some states to pass genetic privacy legislation, which aims to protect individuals against the misuse of that information.

Persons who are having genetic tests should (1) inquire as to the nature of the test (what are you being tested for?), (2) be allowed to consent or not consent to the tests, and (3) be permitted to demand that the results be destroyed if they so choose. Only then can genetic privacy be protected.

The Genetics, Religion, and Ethics Project of the Institute of Religion and Baylor College of Medicine in Houston, Texas, issued a 'Summary Reflection Statement' concerning the Human Genome Project. Part of that statement says, 'Religious values mandate the defense of personal privacy, integrity of the family, and good social relations. Therefore, they support policies and methods of securing consent to have access to genetic information obtained through screening. Moreover, the use of confidential information must be carefully circumscribed to avoid embarrassment, social stigmatization, disruption of marital and familial relations, and economic discrimination. Care should be taken to avoid or prevent the unjust uses of an individual's genetic data in respect to securing and holding employment, insurance, and health care.'<sup>22</sup>

#### Discrimination

The uses of genetic information for the purposes of discrimination have already been alluded to. The American eugenics movement, the Nazi experience, and the sickle-cell public policy disaster are potent testimonies to ways by which genetic information can be used to discriminate against certain groups in a society.

Even though Southern Baptists as a denomination have not yet spoken specifically to the issue of genetic screening, it is relatively simple to translate our abhorrence of racism to an abhorrence of all forms of stigmatization and discrimination against individuals based on their genotype. The new genetics offers the potential, if abused, of using high-technology medicine as a weapon of discrimination. Individuals who were predisposed to Huntington's disease have been unable to secure jobs. In 1988, China passed legislation prohibiting the marriage of mentally retarded persons unless they were sterilized. Nobel laureate Linus Pauling 'suggested that there should be tattooed on the forehead of every young person a symbol showing possession of the sickle-cell gene or whatever other similar gene, such as the gene for phenylketonuria [PKU], that has been found to possess in a single dose. If this were done, two young people carrying the same seriously defective gene in single dose would recognize

this situation at first sight, and would refrain from falling in love with one another.  $^{\prime 23}$ 

In light of past abuses of genetic information, Pauling's suggestion no longer seems out of the realm of possibility. Think of the implications for discriminating against individuals who might be more highly susceptible to illnesses like colon cancer, diabetes, or muscular dystrophy. It may well be the case that they will never come down with the disorder, or may be able to prevent its occurrence through changes in diet or life-style, yet their genetic profile marks them for life. Persons with disabilities are particularly interested in how the information gained through the Human Genome Project might be used, especially as that information might be used in a discriminatory way.

Again, the Institute of Religion's 'Summary Reflection Statement' is apropos: 'A religiously based consensus on the full and equal dignity of all human persons is often contradicted in practice by discriminatory prejudice of one group against another. Ethnic and racial diversities among human beings are due in large part to genetic factors which must never be interpreted as indices of personal or social worth. Neither should the presence of physical or mental disabilities, whether or not they are due to genetic inheritance, detract from one's personal or social value.'<sup>24</sup>

#### Conclusion

It is too early to tell whether the information discovered through the Human Genome Project will catapult us into a modern Eden or Jurassic Park. Sadly, we may not know until after the fact. We are optimistic about the results of the project because of the potentials for healing and the relief of human suffering. At the same time, we are realistic in our view of the propensity of human beings to use good things for evil purposes. Christians call this propensity the sin nature. This predisposition to sin is clearly part and parcel of every human being. We must, therefore, guard against the abuse of genetic information for the purposes of abortion, the violation of privacy, and for discrimination.

The psalmist declares that we are 'fearfully and wonderfully made' (Psalm 139:14). To the extent that the genetic engineering enables us to celebrate that fact, we can endorse it. But to the extent to which genetic technology is used to devalue the sacredness of human life, or as a means of discriminating against individuals, we must reject it. Furthermore, we should resist premature legislation which could jeopardize informed public debate on the merits or hazards of genetic technology.

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## H. Jochemsen, Ede, The Netherlands Report

Transplantation of Fetal Tissue: A medical and ethical assessment, with special attention for the treatment of patients with Parkinson's Disease

#### I. Tissue transplants as a treatment for Parkinson's Disease: a medical assessment of some results of animal studies and clinical studies

Already from the early seventies on, medical researchers have experimented on animals to see if certain tissue transplants to the brain would improve neurological disorders. Transplantation of adrenal medulla, for instance, which is capable of producing catecholamine neurotrans-mitters, did not bring about a lasting improvement in animals with artificially induced Parkinson-like disorders. The results with transplants of fetal substantia nigra appeared to be better.

Since the second half of the eighties, clinical tests have been done with transplants of fetal brain tissue - available from miscarriages or abortions - to patients with Parkinson's Disease. Initially, some relatively positive results were reported, but further analysis showed no lasting improvement in the long run. So far the best results were obtained by the transplantation of bilateral fetal substantia nigra in both the nucleus caudata and putarrien of the receiving patient. The exact reason for the improvement remains uncertain, however. Also unclear is whether the transplanted tissue causes improvement only temporarily or whether it also inhibits the progress of the disease. Due to the lack of clarity about the medical benefits, and also because of the uncertainty as to possible long-term risks, the large-scale clinical implementation of this transplantation technique is still nowhere nearly justified.

Other research suggests new and better methods for the treatment of patients with Parkinson's Disease. A few promising prospects are: certain new medications, the use of cells which – by generic modification – are capable of excreting dopamine and are implanted in the substantia nigra of patients, and the use of dopamine-producing cells in thin polymer capsules.

## II. The use of fetal tissue as a treatment of patients: a Christian ethical assessment

Several ethical issues are related to the use of tissue obtained from aborted fetuses for the treatment of patients. Here, only some of the most important can be hinted at. Based on a Christian view of life, our assessment of these issues assumes the following ethical positions. In the first place it is believed that the life of each human being begins at conception and therefore is inviolable from that moment on. Secondly, an ethical judgement of a certain action must take into account the social context of human action, as well as its social consequences in the long run.

The use of tissue obtained from aborted fetuses is usually morally defended by the following reasoning. Abortion is legal and so the fetal tissue becomes available legally. There need not to be objections to the use of this tissue, as long as this use is separated from the decision of the woman to have an abortion and from the performance of the abortion. Consequently, in several proposals for regulations, this separation is one of the most important conditions under which the use of fetal tissue may be allowed (see e.g. the recommendations of the Dutch Health Council, the Report of the Polkinghorne committee). However, a close scrutiny of the way in which fetal issue is actually obtained leads to the conclusion that it is practically impossible to enforce such a separation between abortion and transplantation. In order to obtain fetal tissue suitable for transplantation, the aborting physician needs to know about the transplantation and the transplanting physician needs to know about the abortion.

In those recommendations, another proposed condition is the mother's consent for the use of the fetal tissue. This consent, by the way, makes the complete separation between abortion and the use of fetal tissue even more difficult. But it can also be defended, further, that by having the abortion the mother can no longer be supposed to act or give consent on behalf of the fetus and in its interests. Thus the removal of the fetal tissue occurs without a morally justified consent.

The condition that tissue may be removed from a living but nonviable fetus only after death has been ascertained beyond doubt, is disputed in the literature. The tests to establish total brain death are not always judged necessary before tissue is harvested. Sometimes the size of the aborted fetus does not permit those tests. The long term consequences of the eventual abandonment of the condition of total brain death in the context of fetal tissue transplantation are hard to assess. It might form a precedent for the enlargement of brain death criteria so as to be able to increase the number of possible organ donors (e.g. anencephalic babies, PV5 patients).

There is a real danger that the existing international trade in aborted fetuses will lead to pregnancies with completely instru- mental purposes arising from financial motives. The search for better treatment of patients with serious illnesses deserves general support. However, in view of the serious ethical objections against the use of tissue of aborted fetuses, and of the danger of an increasing instrumental use of the human fetus, the development of promising alternatives to fetal trans- plantation is much to be preferred.

It is the duty of the government to protect the lives of human beings in all stages and ages. Considering the various medical and technical developments concerning the beginning of human life, a comprehensive and fully protecting legislation is called for in order to prevent the dehumanizing of medicine and society by dubious medical treatments such as the transplantation of fetal tissue.

A summary of: H. Jochemsen (ed.), *Transplantatie van foetaal weefsel*, the 9th Scientific Report of the Prof. dr. G. A. Lindeboom Institute, in Ede, The Netherlands. Chapter I was written by T. van Laar and F. Visscher, neurologists, and chapter II by E. J. Westerman, theologian. Although the report itself is in Dutch, its overview of mainly international literature may be of interest to non-Dutch readers.

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# The Status of the Embryo from a Christian Point of View

Summary: The Christian point of view about the embryo is paradoxical, because it is not a matter for faith. Christian principles appeal for the use of reason. But scientific reason cannot pronounce itself upon the ontological status of the embryo. So the Christian has to become a philosopher. However, philosophical reason needs the experience of the recognition of the 'morethan-neighbour', which is a Christian experience.

The Christian point of view about the embryo is paradoxical, for it has to be confined neither to faith, nor Christian observance, nor even to Christianity itself. Otherwise, it will be relativized, then ruled out.

Indeed, we cannot defend and honour faith if we divorce it from reason. From the moment where faith without reason is urged against reason without faith, faith is no longer faith and reason is no longer reason. Because such a faith can no longer claim to be an adherence to God's word, it therefore becomes simple belief, to which man adheres. As to reason, the past atheistic reason of the Enlightenment's philosophy has been swept away by scientific reason.

The result has been disastrous. On the one hand, there is strong and pure scientific reason, holding an exclusive and monopolistic position: on the other, there is the entire irrational world of feelings, opinions, desires and fantasies. That's the 'hard' against the 'soft'. And the Christian point of view, then, necessarily seems like a subjective opinion, among and against many others.

But is that really a matter of faith? No, it doesn't seem to be, for there isn't anything written in the Scriptures about the status of the embryo. Besides, we can notice serious conflicts between Church Fathers and theologians, some saying that the embryo is immediately animated (Gregory of Nyssos, Maximus the Confessor), and others saying that it is not (Thomas Aquinas). Is the Christian point of view to be only one of a Church, *i.e.* a lobby like another one, strongly marked by antiquated Italian or Polish – according to the ruling Pope's origin – mentalities?

Our reply is that Scripture's silence, in fact, marks the importance of using reason and exercising our responsibility. Even if Christian people have sometimes been wrong on that point, we do know that we must not search the Scriptures for a speech about scientific cosmology, or biology, or embryology. Revelation gives us only the essential truths for salvation, truths that natural reason is not able to obtain by deduction. All the rest devolves upon us.

From a catholic point of view, the encyclical letter *Donum vitae* does not proceed in another way: it states a fundamental and proper Christian principle ('The gift of life is given by God, the Father and Creator, to man'), in order to enlighten our thought, without putting a stop to our thinking. It appeals to our use of reason, in the conditions under which history places us. The Church is acting here as if it were 'expert in humanity', 'to propound the moral doctrines which fit the person's dignity and its entire calling'. But there is only one rational morality which applies to everyone, as St Paul says in *Romans* about the natural conscience of pagans.

#### The Deadend Of Science

There is a great temptation to ask science to choose between opinions and beliefs which neutralize one

H. Jochemsen

another. Science has given us so much knowledge about the biological reality of the embryo that it is indeed very difficult for us to ask the right question. That question is not 'What does science *tell* us about the embryo?' but 'What *can* science *legitimately* tell us about the status of the embryo?' Because, although science has become the prettiest girl in the world, it will never do better than the prettiest girl in the world, who can give only what she has. Now, what it is able to give is limited to the conditions which make science science, conditions which are also to be understood as limits. Thus the life known by science is the objective life, the objectivated life, the phenomenal life, and it is not the thinking life, the subject-life which is acting in science itself out of reach of science for it is this life which makes science possible.

Whether we favour the genetic or embryological approach, science will tell us either that as soon as the genetic programme is constituted, the chips are down; or it will tell us that the embryo becomes an embryo, and then a foetus only when it passes through the stages of its development. No problem so far: it is normal for the biological development which proceeds in time, to proceed by successive stages of a process. But the problem appears when we ask science to pronounce upon the status of the embryo, which obliges it to change its register, and leave the phenomenal order for the ontological.

If we insist on this impossible somersault, we can only produce sophisms. For instance, to focus on one or other stage of the development of the embryo as if on a fixed point, means the same as Zenon's pretence to prove that an arrow would never reach its target, for it always had half of the distance to cover. Again, to limit the assertion of the humanity to the objective existence of any physiological condition, is doing as phrenology, what Hegel laughed at for saying: the mind is dependent on the brain, the brain is dependent on the form of the skull, so the mind is a bone.

Here we can clearly see the fault: the biological conditions of human life are necessary, but it is impossible to determine its being from its conditions of existence. It is impossible for any biological condition to be the cause of being, for the being is not the result of any cause, but it is what forms causes and effects, which are ontologically subordinated to the being itself.

If science intends to force the gate, it goes beyond its limits and is no more science: it is scientism. Scientism states firmly that there is only one reality, only one rationality, only one possible speech – 'science'. For scientism, science knows the whole reality, so what is unknowable by science is nothing. Therefore we instantaneously notice that scientism is not actually science: either science is science, and it is not everying, or science pretends to be everything, and it is no longer science. What is it then? It is not even philosophy, for it takes the place of philosophy. It is therefore an ideology.

In that case, science becomes a ventriloquist: its scientific lips allow someone else's talk to flow out: the talk of action. Thus, the progress of biology and biotechnologies reveals to us what had been kept hidden for so long, the fact that science is not first pure and disinterested knowledge (*theoria*), but a superior mode for the action of mankind (*praxis*), by which it has a hold over the world. It is now said that the discourse of science is of a *performative* type. That is to say, scientific knowledge is also a power. Actually, science is not used to discover the status of the embryo – but to justify what man wants to do with the embryo – usually, to dispose of the embryo as we fancy.

#### From The Biological Phenomena To The Human Phenomena

Of course, all scientists are not proponents of scientism. Some of them are Christians. For them, as for many Christian people today, it is a temptation to use science in order to strengthen their confiction that the embryo has to be respected like any human being. Science itself leaps to no such conclusion; the scientest himself can leap, because his reason is methodologically divided and limited, and not substantially.

Now, if genetics really proves the existence of an individual genetically programmed from his beginning, an individual who belongs without any doubt to the human species, we must first reduce the person to his genes ('I am my genes'). Humanity becomes an object of biological science. Such talk, with the best intentions in the world, is materialism and scientism. Furthermore, the problem of twins thus becomes insoluble, because the same genetic programme produces two individuals.

We can certainly consider that the existence of such an individual is a necessary and sufficient sign of the existence of a human being. A biological human individual who was not of mankind has never been seen, nor a man's body which was not human. But two objections ought here to be noted: 1) the sign is exaggerated, for science only gives us an individual organism and not a body, for there is no body without a soul which makes the body what it is; 2) this result is not obtained by knowledge but by recognition – first recognition in a personal experience of the meeting of the other, then in a thought. Science cannot produce a humanity judgment, or a no-humanity judgment, only scientific judgment. The closed door of the humanity of the embryo cannot be opened by the biological key.

Two kinds of phenomena need to be recognized: if the biological phenomenon is really the object of science, then the human phenomenon can only be the object of phenomenology. But is phenomenology of the embryo possible?

#### Christianity And Philosophy: The Meeting

If well understood, science plays an important part: it has brought the embryo out of the unknown and out of the mystery in which the imagination could elaborate in total irrationality, or in which false knowledge could disturb the thinking (which happened to Thomas Aquinas because of Aristotelian biology). But in order not to reduce the being to the phenomenon, we need to think in philo-

sophical terms. As a matter of fact, philosophy speaks of the complete human being and not only the biological organism. Only this philosophy can say something about the being as it is, without reducing it either to its ways of being or its conditions. It goes from totality to its parts, from the actuality to the potentiality. It first seizes and sets the being in the constituent unity of body and soul (the body is what makes the proper existential reality of twins, who yet have the same genetic programme), it apprehends the body before the organism and the organism before its programme. Such a philosophy leaves to science to search the modalities and laws of the development of the being. But only philosophy can avoid judging the *physis* by the pattern of the *techné*: a half-built car is not yet a car, but a developing living being is a being. A living being owns its principle inside itself, it generates itself in its own being, from itself; but a technical object has its principle out of itself, is produced and known from the outside.

Thus, philosophical rationality is the only type of rationality which makes possible the development of Christian speech about the embryo. Christianity is certainly not philosophy: although both of them eventually state the same content (or substance) of truth, the form of this truth is not the same, because philosophy must reproduce by the use of natural reason what Christianity proposes to do by revelation and tradition, or it must develop what it does not reveal but what happens to be logically involved in its principles. To speak the truth, that is not new: without the Judeo-Christian religious revolution, philosophy would not have given us the concept of a natural Nature (taking away its sacred aura), nor would it have developed the concept of a singular and free human person.

Although there is no Christian revelation about the status of the embryo, Christianity thus opens up the path to the philosophical reflection which, otherwise, runs the risk of withdrawing into a purely ethical position (Kant's way), concerning respect, without daring to go further.

Christianity compels us to change our question. The question whether we can theoretically prove that the embryo is a human being is wrongly propounded. The first good question is: 'Who is the embryo to us?' The lawyer who questioned Christ did not ask him 'What is a man?' or 'Is this living being a man?', but 'Who is my neighbour?' He knew very well that one's neighbour has to be loved, as we all know that every human being is to be respected. The difficulty, for him as for us, is to know who the neighbour is, or who the person to respect is. The teaching of Christ in the Good Samaritan parable, is in fact that we do not find our neighbour in the person we have already recognized, but that we start with the neighbour – with the wounded stranger who happens to be here – to recognize the person in him.

Now, the embryo pushes the experience of the neighbour to the limit: it is a close being, so close that it is hard to distinguish it clearly, in the beginning, from the body of the mother who bears it; but it is already another, which can also be considered as a stranger, the enemy that is to be denied if one's being is to be protected. From the moment at which it is most dependent, the embryo is also already an 'ego' - that is what the 'gift of life' means. It is true that the embryo does not yet present a human face, as a foetus does. But its presence, which does not show itself through its appearance, flows over the present moment, for it engulfs the future being which it will become, if we let it be. That is why our current respect for the present, and even the basic embryo, links its future to the past which was ours when we were embryos. We must love our neighbour as ourselves: one loves oneself as an embryo. The embryo, the closest of the neighbours, the 'more-than-neighbour', compels me to act morally towards a future already ontologically present, but not yet phenomenally. Being the most insufficient and the weakest of all neighbours, the embryo compels me to 'answer' for him, in solidarity. Does it have to be considered as a person? Without any personality, without any face, locked among the silent and the secret, it would rather be an 'anti-person'. But the experience of the morethan-neighbour compensates for the deficiency of my experience, it destroys the walls erected against respecting the embryo as a person. That is the true phenomenological experience.

The whole problem is therefore one of our behaviour. The embryo is the weakest part of the human chain, and it tends to be considered as something to be used to preserve our interests. But because a chain has got only the strength of the weakest of its links, man is worth what the embryo is worth to him.

This paper was read at the 1993 Budapest Conference in Bioethics.

### **MEDICINE AND THE BIBLE** Bernard Palmer (Editor)

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## Gregory W. Rutecki, M.D., Medical College, Northwest Ohio

# Blurring Distinctions between the Dying and the Dead: A Call for Discernment in Organ Donation

In 1953 when Hume reported his dismal experience with nine unsuccessful kidney transplants, could he or anyone else have been prescient enough to predict 1990's state of the art transplantation? Not only were 16,000 solid organ transplants performed in 1991 with long term graft and patient survival, but many authorities presently consider transplantation the 'ultimate and by far most successful treatment of end stage single organ failure' available.1 However, any tendency towards hyperbole disguises a sobering reality - contemporary transplantation has become a victim of its own remarkable success. In March, 1993, 30,000 patients in need remained on waiting lists for transplant organs in the United States alone. Six to seven of these 30,000 patients die each day during their fatal wait for organs which are never donated (especially liver and heart).<sup>2</sup> Proposed remedies for the paucity of donor organs have included aggressive public education concerning need and presumed consent of those without donor preference at death. A more recent and exceedingly more controversial proposal to increase organ supply is retrieval from so called non-heart beating cadaver donors (NHBCD). The most facile way to define a NHBCD involves two empiric descriptions: one of death itself and one of contrast between the two definitions of death in current use.

For literally thousands of years, empiric delineation of death relied on an absence of cardiorespiratory function. Though this particular definition of death had occasional shortcomings,<sup>3</sup> it continues to correlate with an irreversible loss of heart and lung function consistent with the absence of life. This is the 'oldest' definition of death; updated for our present purposes it would be consistent with death in some NHBCD.<sup>4</sup>

Access to modern technology, however – especially ventilatory and aortic balloon pump support – has greatly altered our understanding of death. Indeed, as we will see in much greater detail later, brain death is a 'newer' definition of death (since the late 1960's) and defines death despite the presence of a beating heart and functional lungs (a potential heart-beating cadaver donor or HBCD). Contemporary need for donor organs has also updated the 'older' NHBCD criteria consistent with access to modern technology. The new category of NHBCD includes terminal patients who do not qualify for brain death. Initially these patients have a functioning cadiorespiratory system though such function may require technologic support. At some time prior to the pronouncement of death, NHBCD are removed from ventilatory or circulatory support in the operating room; cardiorespiratory function then deteriorates and eventually ceases. Organ retrieval begins after an appropriate interval between the cessation of heart beat (NHBCD) and the actual pronouncement of death. The 'interval' in question cannot be so long that it causes ischemic organ injury in the donor on the one hand, but not so short either that the donor is dying and not dead.

Unfortunately, exact definition of the interval is variable. If the recently deceased receives cold preservation, the interval may be stretched to one hour; without cold preservation, it probably should not exceed fifteen minutes.

At this point, the potential impact of NHBCD protocols on the supply of donor organs should be summarized. In the Netherlands, use of NHBCD has increased the supply of donor organs by 21% or 32-41 kidneys per million population per year.<sup>5</sup> In the United States, the University of Pittsburgh NHBCD protocal foresees an increase of 20-25% potential donor organs.6 Appraisal of the impact of such a protocol on transplantation, however, must proceed cautiously. Consideration should be given to both the predicted technique related success and the inherent ethical dilemmas. NHBCD protocols necessitate yet another update in the definition of death for a new generation of donor. Perspective on any such protocol or the predicted results thereof should not occur in a cultural or historical vacuum. Therefore, an abbreviated history of transplantation as technique is required followed by a history of transplantation ethics. Both have experienced drastic changes spanning a period of forty years (1953–1993).

#### The History Of Transplantation as Technique

Hume's disappointing results with renal transplantation in the early 50's was followed by the first success in kidney transplantation in the same decade – grafting between identical twins followed by a two decade survival.<sup>7</sup> Aside from the technical success, this result highlighted the importance of tissue histocompatibility in graft longevity. The 1960's followed and were literally an explosion of 'firsts' which established transplantation as technology's newest prodigy. The imuranprednisone combination confirmed the importance of immune suppression in graft survival and was rapidly followed by the first liver transplant (poor survival), the first transplantation textbook, the first 'successful' liver transplant (3 months survival), and finally the first heart transplant in 1966 by Christian Barnard.<sup>8</sup>

The 1970's may be described as the period of plateau or growth arrest in transplantation. Vigorous use of immune suppression in that decade led to opportunistic infections and as a result both patient and graft survival with cadaveric transplantation were disappointing. However, major discoveries in the 1980's were pivotal in the success transplant enjoys today. The 70's plateau in immune suppression was finally breached by the discovery and implementation of benefits from cyclosporine that continue to accrue through the early 90's. Transplant organ viability was improved by the technique of insitu cooling of organs to decrease warm ischemia time and by the discovery of the University of Wisconsin solution for organ preservation in 1987. Monoclonal antibodies (OKT<sub>3</sub>) and antilymphocyte globulin found a role by impacting adverse immune mechanisms leading to graft rejection. More recently, FK 506 may benefit liver transplantation with further safety and efficacy in immune suppression. These basic science and clinical discoveries have been applied with unparalleled success to the transplantation of kidneys and single organs such as heart, liver and pancreas. However, clinical transplantation and its two patients (donor and recipient) cannot be extricated from an accompanying ethical matrix. Young practitioners and students of this discipline should recognize the fact that the success of transplantation as technique was an impetus for a 'new' definition of death that evolved in the 70's and has remained until today.

#### A History of Transplantation Ethics And The Cadaver Donor: A Pivotal Role For The Definition Of Death

Viable transplant organs are obtained from one of three sources: living related donors (LRD), HBCD and NHBCD.<sup>9</sup> Each donor type has impacted a different period of transplantation and further study of this phenomenon provides a perspective of each era's view the definition of death.

The first period was that of the 'first generation NHBCD' (1936–1968). In 1936, Voronoy retrieved a kidney from a NHBCD (dead six hours) and performed primitive (donor B positive to recipient O positive) and unsuccessful kidney transplant.<sup>10</sup> Apart from the naivete in histocompatibility, this transplant reveals an essential observation related to NHBCD. It is critical that the interim between the death of the NHBCD and organ retrieval be as short as possible to limit the warm ischemia time of cadaver donor organs. The earlier one diagnoses death accurately, the more likely that organ viability will be preserved. Hume's nine renal transplants were all also obtained from NHBCD in the earliest era of transplant (1951–1953).

The second period of donation was that of LRD. Despite unique ethical considerations for this particular type of donor (primum non nocere), the benefits of tissue matching became more apparent (1954–1968). However,

the availability of LRD then and now is the major limitation of this donor type.

The third period of donation sets the most germane precedent for this discussion (HBCD 1968). It more than any other attempts to articulate a thoughtful definition of death for cadaver donors, requiring serious review and further consideration.

This period actually began in 1964, when a male donor in Sweden with a massive intracerebral bleed fulfilled brain death criteria – absence of both neocortical and brain stem function. This occurred a few years prior to publication and legal recognition of such a 'new' definition of death (1968).<sup>11</sup> The two involved physicians (Ekestrom and Frykholm) were disciplined for perceived ethical shortcomings and almost lost their medical licenses. In 1966, both Starzl (liver) and Barnard (heart) had two potential donor patients who most likely qualified as 'brain dead'. These patients were disconnected from their ventilators and their hearts eventually stopped beating. This in essence made each HBCD into a NHBCD in an attempt to obviate legal and public repercussions prior to a legitimized 'new' definition of death.<sup>12</sup>

A watershed for both transplantation and ethics was reached in 1968 with the publication of Harvard neurologic criteria for death.<sup>13</sup> The Harvard ad hoc committee communicated two salient reasons for a 'new' definition of death based on 'brain death' criteria. First, 'improved methods of resuscitation and support of individuals whose brains were damaged irreversibly permitted their hearts to continue beating at great emotional and financial cost'. Though this was a valid observation based on a subset of patients who were surviving in 'limbo' from advances in life support technology, their second reason is more incisive for our purpose. 'It was difficult to obtain organs for transplant using the traditional definition of death' (cardiorespiratory cessation or NHBCD).

Though the decision to define death by whole brain criteria was not uniformly supported and may have reflected some pressure from the transplant community, empiric observation has borne out that HBCD are dead and not dying.<sup>14</sup>. Though one may argue that consequentialism (increased supply of organs) played a significant role in the final decision of the Harvard Committee, the medical, legal and popular community generally agreed with the ethical construct of this particular definition of death based on irreversibility.

Our contemporary period, troubled again by a shortage of organs, has attempted an update in the definition of death through utilization of a new breed of NHBCD. In so doing the fourth era of the donor in transplantation ethics in the United States has begun. The University of Pittsburgh has recently implemented a unique protocol to retrieve organs from NHBCD's.<sup>15</sup> The Netherlands, Latvia, Spain and Japan have already implemented NHBCD protocols.<sup>16</sup>

An extensive ethical appraisal of the use of NHBCD's at the University of Pittsburgh was recently undertaken.<sup>17</sup> That review presented a spectrum of opinions emanating from pluralistic world view perspectives and a review based on a Christian world view of medicine in the context of the Hippocratic tradition has been lacking. To

accomplish this I would like to summarize the NHBCD protocol and then study it further from three related perspectives: 1. The definition of death in the protocol and the critical distinction between the dying and the dead; 2. the physician's role in NHBCD protocols in the context of the Hippocratic tradition and its proscription of euthanasia; 3. The Christian community's responsibilities in the care of the dying.

#### A Summary Of 'The University Of Pittsburgh Medical Center Policy And Procedure Manual For The Management Of Terminally Ill Patients Who May Become Organ Donors After Death' (NHBCD)<sup>15</sup>

I have divided the protocol into six areas of consideration: the methods used to reach 'foregoing of life support therapy' in the individual patients in question; the ethics of decision making and consent regarding eventual transplant donation for NHBCD; care of terminally ill patients after the 'forego' decision; consideration of intention through the principle of double effect; the serious question raised in NHBCD of euthanasia-titration of death; and finally the technique and timing of the organ retrieval itself.

By way of a more general introduction to the protocol, a preliminary discussion of certain key concepts is required. In summary, the protocol identifies terminal patients who are not brain dead. After such identification, a decision to donate organs is made without coercion. The patient is taken to the operating room and disconnected from support (ventilator or balloon pump) and agreed upon empiric criteria are used to define death. As a result, much of the ethical construct of the protocol rests on the presumed proof that the patients involved are 'irreversible' at the time of death; irreversibility defined as the absence of potential autoresuscitation. Since this contention is arguable, even use of 'cadaver' in NHBCD may be premature and 'begs the question'. Nonetheless, we will proceed with a more specific delineation.

In regards to the foregoing of life support, the policy relies on previous guidelines of foregoing life sustaining treatment in effect at the University of Pittsburgh Hospital. Effort is made to correctly identify patients who are terminal and 'on life sustaining treatment' in whom withdrawal of that is likely to result in death within a few hours. The policy further clarifies this issue in that life sustaining treatment is defined as a respirator or intraaortic balloon pump which the patient requires for survival. This identification precedes any consideration of potential organ donation.

Decisions regarding informed consent for organ donation – which involve either the patient or patient surrogate – are protected by the following guidelines. The decision to withdraw mechanical support is made separately from and prior to any discussion of organ donation. Consideration of organ donation occurs only after a decision that the patient is 'comfort measures only' has been made by

patient, surrogate, or family and physician. Patients deemed incompetent and without surrogates are not considered for organ donation. If questions remain, ethics consultation is mandated to clarify appropriate procedures. Finally, physicians involved in the process have no clinical responsibilities on the transplant service and do not receive funding related to transplantation.

The protocol and its guidelines for care such of terminally ill patients are as follows. 'Primary responsibility to optimize the patient's (donor) care' is the goal of the healthcare professionals. Medications are used for the indication of patient comfort only. As such, the dose of these medications is carefully 'titrated' for the purpose of comfort. Implied is the fact that no medications are used to either hasten the dying process or which lead to a cadaver better suited for transplant. This fact is repeated for emphasis in regard to patient need for medication later in the same protocol.18 The issue of physician involvement – particularly in the use of pain medications - is discussed in the protocol in the context of the 'principle of double effect'. Primary intention is identified as 'assuring patient comfort' though it is recognized that secondary or unintentional effects of medications may hasten death in the potential donor.

Normative principles regarding euthanasia are also addressed. 'No (policy's emphasis) interventions are to be justified only to be effective in preserving a more usable transplant or in regulating the time of death' (A-5). Protection of the donor from potential 'hastening of death' is provided in the following way: the physician certifying death is not involved either in the procurement of organs or in the care of any of the transplant recipients.

Finally, the act of organ retrieval occurs 'after the patient is declared dead'. Death is certified in accordance with existing Pennsylvania law and the physician certifying death deemed independent of the 'process' (transplantation) as mentioned in the preceding paragraph. The empiric definition of death is cardiopulmonary (NHBCD) and defined as 'the irreversible cessation of cardiopulmonary function' after disconnection of life support. This is further specified as, 'recognized (sic) by persistent cessation of functions during appropriate periods of observation'. This period(s) is then defined as two minutes of ventricular fibrillation, electrical asystole, or of electricalmechanical dissociation.

Since choice of the two minute duration is germane to our discussion, the process that led to this interval should be reviewed.

#### The History Of Transplantation as Technique

The ad hoc committee desired a time for the definition of death in NHBCD that guaranteed autoresuscitation would not occur. Review of the reasoning and empiric constructs involved is illuminating. 'Based upon the *little scientific evidence available*, a group of intensivists with clinical and research expertise in resuscitation selected two minutes as the duration of pulselessness required for determining death; i.e., the duration after which the likelihood of autoresuscitation is *vanishingly small* (author's emphasis)'.<sup>19</sup>

As will be developed in more detail later, the protocol's identification of terminal patients is responsible and safeguarded. Though other safeguards are provided to ensure that the decision making process remains independent of the consequence of transplant organs, it would be most difficult in an institution so intimately associated with transplantation to completely separate this bias from any physician on staff.<sup>20</sup> My major concerns, however, relate to the definition of death in the protocol, lingering questions on euthanasia – titration of death, and the application of the principle of double effect to the protocol.

#### Definition(s) Of Death And The Necessity For An Unambiguous Distinction Between The Dead And The Dying

'We do not want to apply a double ethical standard: one for the unconscious patient with a head injury who is not being considered as a possible donor and another for the same kind of person who is.' There would be a double ethical standard – and perhaps two moments of death – if in discussing the nature of the procedures for stating death or in applying these procedures in individual cases, the need for borrowed organs led to agreement upon procedures for stating death that for this purpose hastened pronouncements of death.<sup>21</sup> Ramsey.

An enterprise to construct an ethical boundary between the dying and the dead in the context of organ donation begins by necessity with empiric observations. Updates in the definition of death are pervious to empiric constructs since the trenchant observations of Ramsey and Hauerwas.<sup>22</sup> They espouse a philosophy that places the concept of death in the realm of theology, but relegates the definition of death to the medical, empiric domain. Historically this is consistent with the present statutory and popular understanding of death. For our purposes, consistent definitions of death are critical since the cadaver transplant enterprise has relied on the dead donor rule: persons *must* be dead before their organs are retrieved.

Even though an apparent separation exists between the concept and definition of death in the dialogue at hand, the theologian-moralist is not prohibited from proposing certain guidelines and caveats which should ethically limit the boundaries of such a definition. The first of these is both ontologic and empiric in confronting an essential fact: a person dying is still a person living until the time when death supervenes.<sup>23</sup> This observation ensures that dying person retains his/her inviolable claim on the same protection, dignity and care accorded all living humans. This distinction disallows any 'policy creep' which would blur the boundaries between life and death. A second unbreachable caveat is that a definition of death must not be altered for the purpose of transplant donation. The meaning of death for a given individual should not be determined in light of someone else's need.<sup>24</sup> Any consequentialism which includes benefit for the organ recipient – especially when that benefit leads to a change in the designation of death for the donor – must be rejected. Finally, another guideline must be proposed to protect against a more recent variant and inconsistency in a 'dual' definition of death. In the development of this last guideline, I will discuss and question whether the empiric requirement of irreversibility for the definition of death is altered for terminal as opposed to non-terminal patients based on expectation of unsuccessful or successful resuscitation respectively.

Based on this introduction, I would like to engage the definition of death in the Pittsburgh NHBCD protocol for organ donors vis a vis accepted empiric definitions of death based on irreversibility in patients who are not considered either donors or terminal.

Certification of death in the University of Pittsburgh protocol described previously, is repeated:<sup>14</sup> the diagnosis of death is made by 'traditional' cardiopulmonary criteria and any one of the following electrocardiographic criteria will be sufficient for such certification in the potential donor – two minutes of ventricular fibrillation, two minutes of electrical asystole or two minutes of electromechanical dissociation. The protocol describes each of these two minute cardiopulmonary criteria for death as 'irreversible' (A–6).

In contrast, 'Guidelines For Cardiopulmonary Resuscitation and Emergency Cardiac Care were recently published in the Journal of the American Medical Association.<sup>25</sup> These guidelines reveal a significant variance between reversibility criteria in non-terminal cardiac arrest patients when such criteria are juxtaposed with those of the University of Pittsburgh NHBCD protocol for terminal patients. The guidelines state specifically, 'no specific duration of time predicts unsuccessful resuscitation'.26 The debate in the 'guidelines' concerning the duration of circulatory and ventilatory absence relating to the eventual efficacy of life support (the criterion of reversibility) begins at thirty minutes.<sup>27</sup> CPR prior to the interval of 30 minutes is described as unique in the ability to reverse 'clinical death'.28 It is necessary to stop at this juncture and answer some pertinent questions. My preceding juxtaposition of the protocol and guidelines occurs despite the obvious fact that NHBCD patients are 'morituri' in contradistinction to guideline patients who have the potential and apparent desire to be resuscitated. Reliance on this significant difference between the two groups translates into two potential mitigating factors for the two minute criterion in the NHBCD protocol: resuscitative efforts will not be applied to NHBCD and such patients or their surrogates are requesting removal of ventilator or cirulatory support with death as the immediate, expected outcome. In order to address these potential mitigations, a unifying philosophy must be developed in an attempt to explicate this striking disparity in the empiric determination of the time of death.

The empiric requirement of irreversibility as an absolute criterion of death has literally stood the test of time. It was an essential criterion for the duration of the cardiopulmonary determination of death and has retained its essential character with the use of brain death criteria. It

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provides the highest level of certainty that the person in question is dead (irreversible) and not just dying. Arrival at this level of certainty must occur independently of both eventual transplant donation and diagnosis or expected outcome preceding death. I would ascribe a goal that may be more arguable, namely that the concept of irreversibility should not be altered in application to terminal, no resuscitate patients vis a vis non-terminal vigorously resuscitated patients. Irreversibility as a criterion for the definition of death is a necessary standard which prohibits a 'dual' definition of death - one for patients who are viewed as resuscible and one for terminal patients which can lead only to confusion and a tendency towards an ever earlier definition of death in terminal patients. This tendency will inexorably lead to a potential for speeding along the terminal process of dying. This may become more acute when the process occurs in someone who is deemed a potential transplant donor. If irreversibility is considered a universal criterion in the definition of death, rather than relative to a patient's particular situation, these potential dangers will be avoided.

Since 'little scientific' evidence is available to pronounce a strict time limit between heart dysfunction, lack of autoresuscitation, and a definition of death, should we not choose a lengthy time interval (approximating five minutes) rather than the short one used in this protocol? The NHBCD protocol of ROBI4 seems to allow a less ambiguous distinction between the dying and the dead donor. If an increase in the duration of the two minute criterion was developed to bring guidelines and protocol irreversibility definitions more in line, cold perfusion could be utilized to limit warm ischemia and thus preserve organs for potential donation. Any remaining potential or question of reversibility should continue to be construed as a criterion for 'dying' and not allow a creep to a new definition of death. With the two minute duration, some of the patients with ventricular fibrillation would at least 'reverse' to a stable rhythm with a simple thump to the chest. Empiric observation will not accept this as irreversibility.

Another intriguing argument which may support the protocols 'new' definition of death would lead to a restructuring of the aforementioned traditional dead donor rule. This would contend that the entire retrieval process in NHBCDs, 'violates no interest'.<sup>29</sup> This idea would be stated thusly: 'Are there some patients (NHBCD) whose quality of life is so unacceptable and whose death is so imminent that we may take their organs before they die' (or at least during the blurred margins of dying/death)? The wedge effect of this particular argument (anencephalics or living patients in whom further medical care would be construed as futile then become potential donors) and the potential slippery slope<sup>30</sup> lead to a negation of this argument's placement of the dying in the group of 'life not worth living'.

The short time criterion for the definition of cardiopulmonary death in the Pittsburgh NHBCD protocol creates a dangerous ambiguity between the dying and the dead. Any further shortening of this time, which becomes a viable possibility, would be construed as vivisection. The observation that the patient in question is a 'do not resuscitate' and therefore different does not mitigate the impact of the duration choice. The determination of 'irreversibility' should be universal in order to protect each individual patient from an early pronouncement of death and from a continuing 'policy creep' that would redefine death for the purpose of an increase in organ donors. If warm ischemia time is the greatest impediment to organ survivability, the time chosen for the definition of death should be increased with the inclusion of 'cold perfusion' to preserve organ viability. Any identification of NHBCD patients as 'violates no interest' is an unacceptable mitigation using 'almost dead' as equivalent to 'life not worth living'. On empiric grounds, the only acceptable definition of death is one that provides near universal certainty that no reversibility remains regardless of expected outcome.

#### The Hippocratic Tradition Vis A Vis The Concept Of 'Titration of Donor Death' in NHBCD

Titration of death is . . . to express the undertaking of causing or permitting death to occur within carefully delimited parameters. It is, I think, a new form of sin . . . it is primarily concerned with producing a cadaver that is usable in some manner; and titration of death per se has only incidental concern with the dying process.<sup>31</sup>

'It should be emphasized that we recommend the patient be declared dead before any effort is made to take him off a respirator, if he is then on a respirator. This declaration should not be delayed until he has been taken off the respiratory and all artificially stimulated signs have ceased. The reason for this recommendation is that in our judgement it will provide a greater degree of legal protection to those involved. Otherwise, the physicians would be turning off the respirator on a person who is, under the present strict, technical application of law, still alive.' (Harvard, Ad Hoc Committee 1968, a time when the Hippocratic Oath was still dominant in medical practice).

In the context of the Hippocratic oath and tradition, a physician is proscribed from the activities of euthanasia and assisted suicide. Though language in the euthanasia debate is confusing, imprecise and affected by intention, certain significant issues arise nonetheless. Such issues impact the University of Pittsburgh NHBCD protocol and therefore warrant further consideration.

The American Medical Association's Council on Ethical and Judicial Affairs makes the following statement. 'A physician may . . . omit treatment to permit a terminally ill patient to die when death is imminent. However, the physician should not intentionally cause death . . .'.<sup>32</sup> Prima facie review of the Pittsburgh NHBCD protocol seems to place it within the confines of this intention – especially since the patients in question are terminal. However, on further review, it appears that when the intention in question is one of nonintervention to specifically produce a cadaver of a certain kind, it becomes apparent that there is an intention to ultimately contrive the death of the donor.

To illustrate this point, Benjamin Freedman uses the term 'titration of death' as a description of causing, contriving, or permitting death to occur within special, delimited parameters that primarily seek the consequence of a cadaver that is usable in some manner.<sup>33</sup> He postulated this specific terminology after a discussion with a colleague concerning the use of foetal tissue for transplant in Parkinson's disease. A clinician-researcher asked him for his ethical opinion about the morality of modifying abortion standards solely to increase the supply of usable, harvested foetal tissue from the abortion process. These modifications or the actual 'titration of the death' took into account the following: timing of abortion based on gestational age by ultrasound, foetal location, conscious reduction in suction force used during the vacuum aspiration process and alternations in the vaccum cannula's diameter - all to the end of sustantially increasing the supply of foetal tissue. Freedman further implied that this conscious 'titration' also occurs when ventilatory support of dying anencephalic infants is prescribed with the intention of eventually protecting and using anencephalic organs for transplantation. He views this entire process of titration as 'the manipulation of a dying person as an object, treating death as an ally rather than an adversary,' and finally notes that 'titration partakes in a central way of euthanasia - i.e. acting for the purpose of death'.34

One cannot avoid application of his reasoning to the University of Pittsburgh management of the dying process in NHBCD - especially as the management relates to the manipulation of warm ischemia time and contrived removal of the donor from life support. If one accepts my preceding criticism of the two minute duration as the shortest time to be chosen for a definition of death, this would be consistent with a policy to limit warm ischemia time as a primary goal of the protocol. The protocol's specific denial of leading to a cadaver that is better suited for transplant purposes is not in concert with an orchestrated removal of the donor from life support in the operating room with a surgical team at the ready for organ retrieval. Lastly, there is no question that the protocol's particular 'titration of death' has only incidental concern for the donor's dying process. I expect that the designers of the Pittsburgh NHBCD protocol might offer other mitigating circumstances to attentuate the moral and ethical dilemmas of such presumed titration. They may justify 'letting die' in NHBCD based on the appraisal that their patients are 'doomed to die very shortly in any case' with extreme necessity existing for the recipient of transplant organs. Devine would adjudicate this mitigation in what he calls 'Rawls like terms: the one who is killed (or let die) in such cases is not worse off than if he/she would not have been killed' (or let die).<sup>35</sup> As a result, the recipient in need benefits immeasurably from the 'letting die'. This theory of 'extreme necessity' however cannot really obviate the observation that it is wrong to contrive the course of the dying process in any way solely for the dying to dead patient's organs.

The result of such contrivance in timing of the definition of death or timing of life support discontinuation not only identifies a post Hippocratic tradition but threatens both institutional responsibility and patterns of mutual trust required for the practice of medicine. Margaret Mead observed that the impact and longevity of the Hippocratic oath related to an essential fact – the oath was the first to separate 'white' (healing) from the 'black' (killing) medicine which was de rigueur in the pre-Hippocratic shaman.<sup>36</sup> Physician and hospital involvement and contrivance in the dying process of NHBCD is diametrically opposed to Hippocratic philosophy and its separation of white from black medicine. The helplessness of the dying patient, the breach of trust necessary in the physician – donor relationship – skewed in favour of a presumed physicianrecipient greater good – may impact organ donations adversely.<sup>37</sup>

To pursue the context of the titration of death further and its possible mitigation by extreme necessity, it is interesting to review Childress' comments about the Pittsburgh NHBCD protocol relative to the distinctions between 'killing' and 'letting die'.38 He reviews this aspect of the protocol within the matrix of double effect. He addresses the intention of double effect through the use of pain medications prior to the actual terminal event.<sup>39</sup> However, he later addresses the terminal event in NHBCD in the language of 'killing - letting die'. He notes that it is 'difficult to make a plausible case that the intention of death is not part of the decision to withdraw life sustaining treatment from a patient when that withdrawal is likely to result in death in a few moments'.40 He notes further the particular end result, 'glosses over fundamental, conceptual and normative problems'.41 But he states on the same page that the Pittsburgh NHBCD protocol authorizes activities 'not inconsistent with dominant practices where there are no efforts to procure organs'. This seems false when one considers the context of the previous discussion on the timing of the definition of death and the timing and location of the removal of life support.

In conclusion, Childress relies heavily on the fourth aspect of the principle of double effect to mitigate the 'killing-letting die' argument i.e. proportionality. However, the principle of proportionality as he applies it suggests that the retrieval of a few organs now (good effect) might result in less organ donation later because of the eventual public institutional mistrust (bad effect).42 It may be more accurate, however, to apply the principle of proportionality not with a utilitarian calculus from NHBCD to the public at large but rather to the disproportion of dignity accorded the individual donor vis a vis the individual recipient. This individual proportionality is weighted heavily towards the bad effect (disrespect for the dying; manipulation definition of death) and not the good effect (more organs). This disproportion in the principle of double effect, especially as it pertains to the donor, negates the perceived good of the process entirely.

#### On 'Care' And The Dying

'Because Christians never let anyone die alone!' A leader in the then Soviet Union when asked why active persecution could not repress Christianity.<sup>43</sup>

'Death is not only a crisis of the flesh. It is . . . a crisis of community. Death will also reveal starkly and unmistakably something about the communities in which a dying person lives'.<sup>44</sup> William May.

The University of Pittsburgh protocol leaves me with some unsettling feelings as well as unanswered questions in response to the dying in the context of transplantation. In fact, these feelings and questions may be extrapolated to the dying in more general situations. This leads to an engagement of the issue as to how to treat the dying so that we may learn something about the 'community in which the dying person lives'.

We will begin with certain assumptions necessary to our discussion. The medical identification of someone as 'dying' implies certain characteristics. First, as developed earlier in our discussion, this is a person who retains membership in the living community. Second, this is a person who now accesses medicine qua medicine in its responsibility to care rather than cure. And finally, this is a person who requires a specific type and quality of such care because of the discomfort, loneliness and solitude concomitant with dying. It would do us well at this juncture to develop further a concept of care in both descriptive and prescriptive terms that may be specifically applied by the Christian community. Hauerwas, Ramsey and May have each addressed such description of and prescription for the dying.

Hauerwas admits to the ambiguities and inadequacies of the word 'care' especially in reference to the word's essential meaning to medicine as moral enterprise.<sup>45</sup> In fact, I found his expansion of this semantic concept analogous to C. S. Lewis' expansion of 'love' as a multifaceted jewel that loses essential meaning in reductionism to English.<sup>46</sup> Hauerwas expands further that care is context dependent and must be specified in relation to roles and institutions.<sup>47</sup> Care in medicine must qualify in its definition that it is directed with special attention to someone because that someone is in particular need.

Ramsey also addressed care in the context of medicine48 and argued that care is the 'source of all particular obligations and one's court of final appeal for deciding the features of actions and practices that makes what we do right or wrong in any context' (author's emphasis). This leads to his contention that directives to cure are suspended and replaced by directions to care defined as comfort and dignity for the dying. Compassion as an essential part of care demands that the physician be so disposed that his every action and word will be rooted in respect for the person he is serving. Hauerwas later observes, specific to the context of transplantation, that care carries a basic deontologic commitment that cannot be overridden by teleological ones.<sup>49</sup> He quotes Ramsey in a following sentence that the primary task of caring for the dying is to reconcile the welfare of the individual with the welfare of mankind when both must be served.

These descriptive aspects of care and associated definitions further developed may offer some prescriptions addressed to care of the dying. Ramsey correctly identifies the sting of dying as solitude, discomfort, loneliness and need for compassion.<sup>50</sup> He exhorts us to be with the dying, to comfort them and assure them that we will not desert them. As a community the 'means' by which we can express or present faithfulness to the dying during dying acknowledges solidarity in mortality due the dying from us who also bear flesh.<sup>51</sup> Care for the dying is a moral medicine imperative for faithfulness.<sup>52</sup> Finally, Ramsey says the one dying should not be deserted, not pushed from the community which specially owes them (the dying) love and care.<sup>53</sup>

A context of prescriptive caring can occur within the hospital, the home or the hospice setting. In fact, Hauerwas has reminded us that the hospital was a 'house of hospitality' which did not abandon the dying.<sup>54</sup> If we isolate the dying, we have betrayed the essential purpose of medicine and distorted both our community and ourselves. May agrees wholeheartedly with this community support during the separation of death.<sup>55</sup>

It seems to me that this commitment and care to the dying is overridden by teleologic and technologic ends in the University of Pittsburgh NHBCD transplant protocol. The operating room is a stark and lonely place to die, the regimented 'stop watch' two minute asystole and the absence of community presence prior to the retrieval of organs stands in disturbing contrast to Hauerwas and Ramsey's definition of medical 'care' for the dying. The protocol does not seem to reconcile the welfare of the individual (donor) with the welfare of mankind.

Contemporary compassion and care for the dying is being provided by two diametrically opposed approaches in Europe. The contrast of a voluntary euthanasia programme in Holland vis a vis active hospice care in Great Britain<sup>56</sup> provides two markedly disparate attitudes toward the dying. The hospice programme provides care to the dying via the relief of pain with no attempt to hasten the dying process. In contradistinction, the programme in Holland is characterized by a hastening of the dying to death process. These are the only two potential responses of the medical profession to the dying. Any protocol that contrives or hastens the dying process, in the context of transplantation or otherwise, bears resemblance to the Dutch rather than the British response. The 'wedge' created with a lack of emphasis on care, substituting rather some consequential result (death or organ donation), does not bode well as a community response to the dying. In fact, as William May observed, such responses tell us something about the community in which people die. The witness of the Christian community must increase through a hospice presence to convince people of a positive moral alternative to 'letting die' in solitude or eventually euthanasia. Any programme that is involved in a contrivance of the dying to death process is a dangerous medical addition to a pluralistic society that presently lacks a consensus towards the dying.

<sup>1.</sup> Devita, M. A., Snyder, J. V., and Grenvik, A. 1993. History of organ donation by patients with cardiac death. Kennedy Institute of Ethics Journal 3 (2): 123.

<sup>2.</sup> Ibid., p. 123–124.

<sup>3.</sup> Alexander, M. 1980. The rigid embrace of the narrow house: premature burial and the signs of death. Hastings Centre Report, June, p. 25–31. An excellent historic study of the potential pitfalls of the cardiopulmonary definition of death prior to monitors. A bit of the genre of the 'Fall of the House of Usher' by Edgar Allan Poe.

4. The Regional Organ Bank of Illinois (ROBI) presently uses just such an 'older' definition of death for HNBCD. Recently deceased patients are perfused with cold preservation solution and organs retrieved up to one hour later. UNOS. 1992. UNOS Update 8 (6): 15.

5. Koostra, G., Wijnen, R., van Hooff, J. P., and Van der Linden, C. S. 1991. Twenty percent more kidneys through a non-heart beating programme. Transplantation Proc. 23: 910-911.

6. Nathan, H. 1992. Impact of processing organs from NHBCD. Conference on the ethical, psychosocial and public policy implications of procuring organs from NHBCD. 9–11 October, Pittsburgh, PA.

7. Merrill, J. P., Murray, J. E., Harrison, J. H., et al. 1956. Successful homotranplantation of a human kidney between identical twins. JAMA 160: 277-282.

8. Starzl, T. E. 1990. The development of clinical renal transplantation. Am J. Kid Dis. 16: 548-556. In the opening paragraph of this paper, Dr. Starzl states, 'Any two people can travel the same road and see different things. Thus others discussing the history of renal transplantation might have noted different landmarks.' Dr. Starzl's 'road' is medicine as technique and thus he never mentions any transplant history or a different 'road' if you will, in DeVita, M. A., Snyder, J. V., and Grenvik, A.'s paper 1993. Ibid. p. 113-129.

9. Since this paper's focus is on the definition of death for humans and the related ethical problems, xenografts will not be discussed.

10. Ibid., Starzl. 1990, p. 548.

11. Ibid., DeVita, Snyder, Grenvik. 1993, p. 117.

12. Ibid., p. 118. 13. Ad Hoc Committee of the Harvard Medical School to examine the

definition of brain death. 1968. JAMA 205: 337-340.

14. Despite the recorded lengthy survival in persistent vegetative state (neocortical death), simultaneous neocortical and vegetative brain death is inconsistent with survival beyond days to at most week(s). Despite ventilator and other support, brain death will uniformly and quickly lead to deterioration of cardio-respiratory function.

15. University of Pittsburgh Medical Center Policy and Procedure Manual. Subject: management of terminally ill patients who may become organ donors after death. Kennedy Institute of Ethics Journal 1993. 3 (2): A-1-A-15.

16. Ibid., DeVita, Snyder, Grenvik. 1993, p. 123.

17. Kennedy Institute of Ethics Journal 1993. 3 (2): 103-A-15.

18. Ibid., Protocol University of Pittsburgh NHBCD. P. A-8, A-10 and A-12

19. DeVita, M. A., and Snyder, J. V. 1993. Development of the University of Pittsburgh Medical Center policy for the care of terminally ill patients who may become organ donors after death following the removal of life support. Kennedy Institute of Ethics Journal 3 (2): 139. 20. For, R. C. 'An ignoble form of cannibalism' Reflections on the Pittsburgh protocol for procuring organs from non-heart beating cadavers. 1993. Kennedy Institute of Ethics Journal 3 (2): 237-238.

On the average, a transplant is performed every 12 hours at the University of Pittsburgh Affiliated Hospitals and more types of transplant are done at Pittsburgh than at any other location in the world. Could one divorce medical staff members on the University of Pittsburgh staff from bias related to transplantation?

21. Ramsey, P. 1970. The Patient as Person. New Haven, Yale University Press. p. 106.

22. Ramsey, P. 1970. Ibid., 59-112 (Chapter 2). Hauerwas, S. 1986. Suffering Presence. University of Notre Dame Press. p. 87-99.

23. Ibid., Ramsey, P. 1970. p. 75.

24. Ibid., Ramsey, P. 1970. p. 73, 101-112 and Hauerwas. 1986. p. 90. 25. Guidelines for cardiopulmonary resuscitation and emergency cardiac care. 1992. JAMA 268: 2172-2302. 26. Ibid., p. 2285.

27. Ibid., p. 2285.

28. Ibid., p. 2282.

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#### TERMINAL CHOICES Euthanasia, Suicide and the Right to Die Robert N. Wennberg

The author asks searching questions about what it means to trust the providence of God in our own act of dying; whether suicide is always wrong; when it may be right for a patient to refuse treatment; what is meant by terminal illness. ISBN 0 85364 508 6 • x + 246 pp. • £10.99 net

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# **Book Reviews**

### Euthanasia and other Medical Decisions Concerning the End of Life

P. J. van der Maas et al.

Elsevier, Amsterdam, London, 1992, 262 pp., hardback \$160.50

'This book is the complete translation into English of the socalled Remmelink Report', an examination of the practice of euthanasia in The Netherlands in 1990 whose results caused such a stir when they first appeared in September 1991.

A very thorough study was performed by experts in public health and social medicine at Erasmus University, Rotterdam in collaboration with the Central Bureau of Statistics in The Hague. The investigation was in three parts: a series of interviews with physicians asking them to look back over patients with whose deaths they had been involved, a comprehensive death certificate study, and a forward-looking six month study with a representative group of the physicians. 95% of the 128,786 deaths in the Netherlands in 1990 were covered and there have been no significant criticisms of the methods.

In terms of the published statistics, the results can be trusted; it is the interpretation of these figures and their significance that have caused controversy. Only a few of the findings can possibly be quoted in this review.

'54% of all Dutch doctors were discovered to have assisted suicide or performed euthanasia' (in the Dutch sense of the active termination of the life of a patient by a doctor at the request of the patient), and only 4% stated that they would never perform euthanasia or refer a patient for it. Looked at another way, 96% of all Dutch doctors are prepared to be instrumental in euthanasia cases.

The Report does not ask any of the sorts of questions that readers of this journal would like to ask, but there are some teasing insights – for example, 40% of the doctors thought that good care would make euthanasia unnecessary, but there is no comment as to why they could not offer that care themselves. 43% belonged to a religious group or were 'linked to a specific philosophy of life', but these beliefs were only 'important' with regard to euthanasia in less than half of those who held them (18% of the total). We read elsewhere that working in an 'institution of a particular religious persuasion' had no effect on behaviour . . .

Van der Maas et al collated their three studies to come up with reliable estimates of how often euthanasia was performed in Holland in 1990. By their statistics, euthanasia (as defined above) accounted for 1.8% of all deaths in Holland (2,300), assisted suicide for 0.3% (400 cases), and most worrying of all, life terminating acts without explicit request' accounted for another 0.8% of all deaths (more than 1,000 cases).

I believe that all these killings were wrong, but it is the last category which must be emphasized. There may have been some vague discussion with the patient earlier on in some of these cases, or some consultation with other care givers, but the existence of even one case of euthanasia which is not voluntary proves the reality of the 'slippery slope'. If patient autonomy is used as an argument in favour of voluntary euthanasia, this last category does not illustrate autonomy but medical paternalism of the very worst kind!

When the first extracts of the Remmelink Report appeared in English, in *The Lancet* in September 1991, this category was not even mentioned in the abstract! That perhaps typifies the Dutch problem – it is not that they don't print the statistics, but that

they don't or can't see the significance of them. Because of this example of gross abuse, and because of the evidence here and elsewhere that 'guidelines' are not followed and do not work, any enthusiast for patient autonomy should not support euthanasia, but reject it!

It is possible to arrive legitimately at worse conclusions still from the statistics. In public debate with the Voluntary Euthanasia Society and others, I tend to stay with the figures quoted above as they clearly prove the point about the slippery slope, and I do not want to waste precious 'soundbites', but if for example we examine the doctors' *intentions* we find that Dutch doctors in 1990 had an 'explicit' or 'secondary' intention to shorten life by using large doses of painkilling drugs in another 8,100 cases, and similarly to shorten life by withholding or withdrawing treatments in a yet further 7,875. I have deliberately not mentioned the figures in these categories where shortening of life was *forseen* but not *intended*, as these will probably be in that grey area which includes 'good medical practice'.

It is obvious then that the published statistics (and there are many more in the numerous tables) confirm the widespread practice of euthanasia and the widespread abuse of the so-called 'guidelines'. The figures are frightening, but almost more frightening is the tone of this Report. Academic language should of course be unemotional and neutral, but as indicated earlier, the authors fail to ask the right questions, or are dismissive of the implications of their findings.

As one of many such examples, in a discussion of 'life terminating acts without explicit request' we read two short sentences: 'Also in a small number of cases life was shortened by more than half a year. Apparently these patients were not in the terminal phase of their illness.' This is surely a masterpiece of understatement!

The authors are to be commended for their thorough study, and the Dutch medical profession is to be commended for its openness in responding (anonymously). However, the conclusions must cause the world medical community very serious concern, and we must learn the lessons from this Report. It shows clearly that euthanasia cannot be policed, the injustices demonstrated go some way towards explaining why euthanasia is fundamentally wrong, and we know that when good palliative care is practised, euthanasia is always unnecessary. We never need to kill the patient to kill the symptoms. We can do much better than all this.

London

ANDREW FERGUSSON

Man & Mouse: Animals in Medical Research William Paton

Oxford, xiv + 288 pp., 1993, £7.99

If 'dogs are inferior, cats are superior – pigs is equal', what are man and mouse?

Sir William Paton should be eminently qualified to address every aspect of medical research involving animals. Emeritus Professor of Pharmacology at Oxford, Emeritus Fellow of Balliol College, noted historian of medicine and science, prominent member of numerous learned Societies, Sir William is himself credited with invaluable discoveries due to the same laboratory procedures he defends.

In this New Edition of 'Man & Mouse', which first appeared in 1984, Paton also presents, confronts, and refutes many of the arguments against the laboratory 'breeding', 'feeding' and 'consumption' of animals. As *per capita* statistics, you and I will devour during our lifetime 8 cows, 36 sheep, as many pigs, and 550 chickens. Science, during that same period, will 'consume' 5 mice for the two of us, and another 5 for the sake of *other* animals.

Whatever one's own view – and most debaters peer warily above their trench – Paton strides a no-man's-land where rational communications are rare, and few indeed have raised a white flag. He who does so must be forgiven his uniform and rank.

Paton's important contribution to a scarce literature should be to hand for all combatants – and observers – in the animal welfare warfare. 'Man & Mouse' deserves selling-out, and wearing out, in this paperback edition.

The book's structure is convenient. Contents includes chapter sub-titles, and all are repeated as sub-headings in the text. The Introduction is by the author, and doubles as the first of 12 chapters. Every chapter ends with a Summary; enumerated and with further remarks. Charts and tables – about 40 of them and readily 'readable' – are strategically positioned in precise contexts. A deliberately informal element, by which chapters are intended to suggest the next, succeeds well; though, in what amounts to an excellent reference-work, one enjoys reading ahead, reading again, and reading-by-Index.

The following is not a defence of 'vivisection'; the term does not feature in the Index of 'Man & Mouse'; except by way of 'antivivisectionists – arguments of – insensitivity of – literature – societies' and 'see also boiling water'. But, it is the introduction of anaesthetics and other advances that Paton insists has shifted the ground of the debate. So, if 70% of laboratory procedures are conducted under anaesthesia, and 70% of operations were performed into this century without it, perhaps 'vivisection' is indeed an inadequate – if not antiquated – term.

Immediately facing the Introduction to 'Man & Mouse' is a carefully-chosen verse; 'Ghosts', by Bob Andes. Its last lines are: 'One should choose ghosts/Like friends./Carefully.' So, let us consider – carefully – the following quotation from Paton's Summary of 'The Ethical Questions'. 'The term "animal rights" should be replaced, with no loss, and perhaps some gain, by such a phrase as "the moral worth of animal life", if the language of animal welfare is not good enough.' The opinion of a scientist? And JP. And clergyman's son.

The covers advertize Sir William as 'compassionate'. Reading between them with some care, one discovers the author is profoundly so. Paton's biblical exegesis is remarkable. His concern for law-enforcement of relevant Acts of Parliament, amendments, codes and official guide-lines is committed – and far from uncritical. This is a scientist who might wish that we knew good and evil not 'as gods' – which, also, we do – but, as God. This is a man who devoted his life to the betterment of man and animal alike by experimental research in the laboratory, and who has sincerely practised 'Reverence for Life'.

The Lamb misused, breeds publick Strife; And yet forgives the Butcher's Knife.

– William Blake

London

DONALD SMITH

Putting the Soul Back in Medicine: Reflections on Compassion and Ethics

David Schiedermayer, M.D.

Baker Book House, Grand Rapids, 1994, 192 pp., \$9.99

The editor of *Ethics and Medicine* has sometimes lamented that there is not a sufficiently rich literature on the theology of medicine. While this brief volume does not attempt to elucidate such a theology, the reflections of Christian internist David Schiedermayer remind us that the theology of medicine, if it is to be useful, must be informed by the exigencies of clinical practice.

Schiedermayer, who practises medicine at the County Hospital in Milwaukee, Wisconsin and teaches a course in medical ethics for chaplains and graduate students at Trinity Evangelical Divinity School, has given readers eighteen chapters addressing a host of issues in the clinical practice of medicine. He even makes house calls.

The chapters of the volume are divided into four parts: Caring for the Body, Mind, and Soul; Comforting the Sick; Facing Death's Mystery; and Overcoming the World. Several of the chapters have appeared in other journals and demonstrate the author's familiarity with medicine, ethics, and the humanities.

Part One is largely devoted to phenomenological issues. Dr. Schiedermayer models the observant and compassionate care of patients. 'When you make house calls, an old Wisconsin doc once told me, you should somehow find your way back to the kitchen. The kitchen is where you learn about a patient's personality and interests and religion . . . Dress modestly. Carry a black bag if you have one, a stethoscope if you don't. When you examine the patient, if dignity permits, have a family member present. Always look at the patient's hands and ask about his or her bowels. Talk to both the patient and the family members' (p. 28). Schiedermayer offers more than diagnostic tips in these chapters, he explains how attention to the patient and her environment make the physician-patient relationship less sterile and cold. After all, as Schiedermayer says, 'Physicians need to see beyond physicians' "rights" to informed consent, and beyond physicians' "duty" to inform their patients to what is essentially a Christian imperative: Honor thy patient. Honor thy patient by talking to him or her as a person, as Jesus talked to people he encountered' (p. 43).

Part Two takes up issues such as the sometimes strained physician-clergy relationship and the place of high technology medicine in treating modern day Jobs. 'Hospitals are places of pain and suffering, and intensive care units distill human agony. They are the places where we would find a modern Job – a patient with a life-threatening disease who is febrile and possibly septic. In the modern ICU patients are frightened and overwhelmed by the severity of their illness and the inescapable presence of high technology. Their 'dignity is driven away as by the wind': hospital workers regulate patients' bowels and bladders and examine, feed, wash, and turn them. But it is also in the ICU that they, like Job, might survive their near fatal illness' (p. 69).

In this section, the good doctor helps readers fathom why physicians always face the temptation toward cynicism; why the practice of medicine sometimes tempts doctors to exhibit more than clinical distance. Doctors 'are supposed to embrace the sick and offer compassionate hands to the dying while they practice their art. But their own flesh recoils at the thought of disease and contagion. They do not want to be fellow sufferers; they want to cure the wound so they don't have to look at it any longer' (p. 79). Schiedermayer challenges Christian physicians to emulate the good Samaritan, not the priest and Levite who passed by the wounded man on the roadside (Luke 10:30–37).

Part Three introduces readers to cases in which cardiopul-

Book Reviews

monary resuscitation and mechanical ventilation seem futile. Death seems inevitable. Schiedermayer has a deep respect for the sanctity of human life, yet, as he points out there are times when medical treatment causes harm to dying patients and should be foregone. Chapter eleven, 'In the Valley of the Shadow' explores the Nancy Cruzan case and presents the arguments for and against tube feeding for PVS patients. While this discussion is useful, the good doctor does not resolve the issues for us. In fact, he maintains, along with other members of the Christian Medical and Dental Society's (CMDS) ethics committee, that the withdrawal of nutrition and hydration for patients in an irreversible coma or in a persistent vegetative state remains an open question. Schiedermayer says that the CMDS statement on Withholding or Withdrawal of Nutrition and Hydration 'did not specifically address the situation of patients like Nancy Cruzan' (p. 115). That may be the case. Nonetheless the statement is fairly clear: 'Because we believe there should be a basic convenant between all of us who care for those who are incapacitated, we are committed to the provision of food and water to those who cannot feed themselves.' Moreover, the CMDS statement points out that there may be exceptional cases in which 'tube feeding may actually result in increased patient suffering during the dying process." It seems to this reviewer that in those cases withholding or withdrawal of nutrition and hydration is clearly appropriate. Physicians are under obligation 'to do no harm'. At the same time, for patients who can tolerate feeding through a nasogastric tube, feeding seems morally appropriate (unless a competent patient refuses). We are not, it seems to me, obligated to perform surgically invasive procedures (such as gastrostomy or TPN) on PVS patients in order to feed and hydrate them. Simple tube feeding (through the nose into the stomach), when the patient can tolerate it, is hardly invasive, however, and presents no clear harm to the patient. In fact, supportive care, including simple nutrition and hydration, represents a minimal obligation to comatose or PVS patients.

Part Four examines interesting issues surrounding the meaning of 'profession' and remuneration for physicians. Especially for physicians who question whether they should take promotional items from pharmaceutical companies (pens, pads, stethoscopes, flashlights, weekend junkets to exotic locals), chapter 15, 'Medical Economics and the Free-Lunch Syndrome' will be useful. Schiedermayer concludes, 'Let's stop accepting payola. We know there's no such thing as a free lunch. Let's do better than Esau, who sold what was his for a bowl of good soup. We have knowledge which can help our patients; we have skills and training which enable us to act in their best interests. We should refuse any gift which would distract us from this role or jeopardize our professional integrity' (p. 156). 'Letters from the Twenty-first Century' (chapter 17) is a series of imaginary letters between Dr. Luke and his young nephew, Timothy. This correspondence focuses on HIV/AIDS and is one of the highlights of the book.

Putting the Soul Back in Medicine is a welcome volume. Though it is somewhat uneven, the book provides a glimpse into the heart and mind of a physician who is deeply devoted to God, the Scriptures, and his patients. Christian healthcare workers will resonate with the book. Lay persons who delve into its pages will be less cynical about doctors. Medical students will find a great deal of encouragement in their quest to serve their patients as they serve the Great Physician.

Nashville, Tennessee

C. BEN MITCHELL

How We Die

Sherwin B. Nuland Alfred A. Knopf, New York, 1994, ISBN 0 679 41461 4

'I have written this book to demythologize the process of dying.' With these words, Yale University surgeon and medical historian Sherwin Nuland introduces his in-depth account of the nitty-gritty details of dying. As a literary work, Nuland has carefully crafted the book to attract a general reading audience unattuned to medical terminology and somewhat understandably averse to careful consideration of his subject matter. The author notes that there are few reliable accounts of the ways in which we die. 'Poets, essayists, chroniclers, wags, and wise men write often about death but have rarely seen it. Physicians and nurses who see it often, rarely write about it.' Nuland, who as a surgeon and family member has witnessed death on many occasions, attempts to break this traditional silence with this work. His skills as a medical observer and chronicler are quite evident throughout the ensuing chapters as he leads the reader through quite graphic accounts of death from causes such as AIDS, myocardial infarction, cancer, stroke, murder and suicide.

The author laments the fact that the concepts of *ars moriendi* (the art of dying), the 'good death', and 'death with dignity' are increasingly mythic in today's society due in great part to our current medical delivery system. He maintains that only by direct confrontation with the true facts of dying can we rid ourselves of the fear of dying. These facts he proceeds to portray with startling realism, such as when he describes holding a heart in his bare hands ('like a wet, jellylike bagful of hyperactive worms') during an emergency open-chest attempt. He later explains why drowning victims always sink headfirst at death. The reviewer will spare further details at this point.

The thoughtful reader with an eye toward transcendence may be somewhat disappointed with Nuland's source of hope at death. For the most part, the work is an exercise in reductive naturalism, where death is seen by the author as 'a state of permanent unconsciousness . . . in which there is simply nothing.' A few paragraphs are devoted to the concepts of God and the existence of an afterlife with the hope that lies therein, although Nuland notes that such options are decreasingly considered by dying postmoderns. He does note that 'it is not for medical personnel or skeptics to question the faith of another, particularly when that other is facing eternity.' Nuland's personal source of hope at death lies in a wish to be free from suffering, abandonment, and futile attempts to prolong a terminal condition. At the same time, he notes that the idealized serene deathbed scene is rarely the norm.

Disciples of the Hippocratic tradition will be disappointed with the author's muting, at times, of the primacy of preserving life. This can be seen in his timely handling of the subjects of suicide and euthanasia. While condemning Derek Humphrey's book, Final Exit, as an 'ill-advised cookbook of death', he simultaneously commends the Hemlock Society author's method of suicide utilizing sleeping pills and a plastic bag for asphyxiation. He also has nothing but praise for the 'rational suicide' methodology of Dr Timothy Quill, which he feels 'may prove to be a reference point on the compass of medical ethics.' The author notes the 'sensitivity' of the Dutch Reformed Church's recent policy condoning euthanasia and its use of the euphemistic term 'self-deathing' over the usual term 'self-murder'. While admitting that actively taking one's own life is 'almost always' the wrong thing to do, Nuland appears to call upon family physicians to at least consider their terminal patient's request for suicide assistance. He writes that such assistance has been 'a muted practice that has existed since Aesculapius was in swaddling clothes'.

To his credit, Nuland chastises his fellow physicians for their

occasional insensitivity to and psychological abandonment of the terminally ill. He calls upon his profession to admit its limitations and to be totally honest with patients facing inevitable death. He also calls for a more personal approach to medicine and suggests increasing the number of primary care physicians to help accomplish this ideal.

In conclusion, if one is looking for an explicit account of various modes of dying, then this book is definitely an option. For ethical advice in the Hippocratic tradition, however, the reader should look elsewhere.

Pensacola, Florida

DON W. BUCKLEY, M.D.

#### A Matter of Principles? Ferment in U.S. Bioethics

Edited by Edwin R. DuBose, Ronald P. Hamel, and Laurence O'Connell

Trinity Press International, Valley Forge, PA 1994. ISBN 1-56338-081

The dominant school of thought in American bioethics is principlism. Principlism's chief *apologia* is found in the text, *Principles of Biomedical Ethics* (now in its fourth edition) by Tom Beauchamp (Kennedy Institute of Ethics, Georgetown University) and James Childress (University of Virginia). This school of thought has had an overwhelming impact upon the ethics education of physicians, nurses, and other health professionals as well as influencing government decision-making concerning research on human subjects (including embryos and fetuses) and animals. Other prominent bioethicists who are principlists include Robert Veatch, LeRoy Walters, Ruth Faden (Beauchamp's wife), and Patricia King, all of whom are connected in some capacity with Georgetown University's Kennedy Institute for Ethics.

Although some principlists disagree precisely on exactly the number of principles one should employ in bioethical deliberation, Beauchamp and Childress offer four: autonomy, beneficience, nonmaleficience, and justice. Beauchamp and Childress maintain that these principles can be derived from virtually every metaphysical worldview and ethical theory (i.e., utilitarianism and deontological ethics), which means that metaphysical questions about the ontological grounding of these four principles are simply not that important. Questions about how a health professional applies these principles and determines their hierarchy of importance are dictated by the particular case to which one is applying them.

Members of the principlist clique are found on important National Institutes for Health ethics committees and wield considerable influence on the conclusions of these committees and the types of restrictions and regulations which the White House and/or Congress will allow. These bioethicists frequently appear before congressional committees as 'ethics experts'.

Although other views are permitted an appearance, principlism is the core creed proffered annually in June at the 'Intensive Course in Bioethics' offered since the mid-1970s by the Kennedy Institute. This one-week course—which consists of approximately six hours per day of lectures and small discussion group meetings, as well as 800 pages of reading—is the chief way by which many health professionals, lawyers, and professors become acquainted with bioethics (or they become acquainted elsewhere through the writing of the Kennedy Institute's faculty, whose textbooks are used generously throughout U.S. medical schools, graduate schools, and law schools). In 1993, about 120 people attended. To many hospital and health facility administrators, completing this course 'qualifies' one as a bioethicist. In sum, principlism is the intellectual foundation of a wellconnected bioethics education industry. Professional prestige, government appointments, congressional invitations, publications in respected journals, and contracts with major textbook and monograph publishers are sometimes linked to a principlist pedigree.

Such explains the importance of this new volume, *A Matter* of *Principles? Ferment in U.S. Bioethics*, a collection of 19 essays (including forward, introduction, and afterward) which offers a critique of principlism. A book from the Park Ridge Center for the Study of Health, Faith, and Ethics, this volume begins with a forward by Albert Jonsen and an introduction by the editors.

The book is divided into four parts: (1) Principlism in U.S. Biomedical Ethics, (2) Principlism and Its Critics, (3) Currents in U.S. Biomedical Ethics, and (4) Horizons in U.S. Biomedical Ethics. Part one contains fascinating history of American bioethics ('The Entry of U.S. Bioethics into the 1990s: A Sociological Analysis' by Renee C. Fox) as well as a reflective presentation of principlism by one of its chief architects, James Childress ('Principles-Oriented Bioethics: An Analysis and Assessment from Within').

Part two—'Principlism and Its Critics'—contains six critiques of principlism from different social perspectives: Western European ('Principlism: A Western European Appraisal' by Henk ten Have), Theravada Buddhist ('Community and Compassion: A Theravada Buddhist Look at Principlism' by Pinit Ratanakul), liberation theology ('Bioethics in a Liberationist Key' by Marcio Fabri dos Anjos), African-American ('European-American Ethos and Principlism: An African-American Challenge' by Cheryl J. Sanders), feminist ('A Feminist Critique of Biomedical Principlism' by Christine E. Gudorf), and religious ('Principlism and Religion: The Law and the Prophets' by Courtney S. Campbell).

Although each of the articles in part two, in greater or lesser degree, makes some important contribution toward a serious critique of principlism, some lack significant intellectual rigor. In fact, some of the authors make controversial (and sometimes, philosophically naive) claims while providing no substantiation or argument for these claims. Take for example the following statement by Christine E. Gudorf: 'To insist on a hierarchical ranking of values or principles is to insist on the priority of one social group's perspective over all others. The refusal to rank values and principles makes feminist bioethics more open to the particularities of the situation than many other types of principlism' (p. 173).

Gudorf provides no argument for this assertion. She simply assumes its truth and moves on. But a more fatal ailment infects this claim: it is self-refuting. That is to say, Gudorf is claiming that hierarchicalism—the view that some perspective is better than others—is wrong. But this would mean that her perspective (that hierarchicalism is wrong) is better than the perspective that hierarchicalism is right. Consequently, Gudorf's denial of hierarchicalism presupposes it. Her claim thus is self-refuting, and therefore, nonsense. It is unfortunate that we cannot dismiss this as an academic aberration, for many of the popular intellectual movements in the United States (which come under the term 'political correctness') make similar school-boy (I mean, school-child) errors.

Conspicuously missing from part two is any criticism of principlism from an evangelical Christian perspective. While selecting critics of principlism the editors evidently were set on getting representatives from movements which for the most part attract intellectuals (e.g., liberation theology, feminism, and multiculturalism) rather than those to which ordinary patients can relate. In fact, however, a physician is more likely to encounter a patient who is a Baptist than she will a feminist deconstructionist.

Part three—'Currents in U.S. Biomedical Ethics'—takes a look at some contemporary trends in bioethics that seek to supplement, and possibly eclipse, the principlist approach: phenomenology ('Experience and Moral Life: A Phenomenological Approach to Bioethics' by Richard M. Zaner), hermeneutics ('Toward a Hermeneutical Bioethics' by Drew Leder), moral story-telling ('Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation, and Validation in the Practice of the Ethicist' by Rita Charon), virtue ethics ('Character and the Moral Life: A Virtue Approach to Biomedical Ethics' by James F. Drane), and casuistry ('Casuistry and Clinical Ethics' by Stephen Toulmin).

Relative to the contributions in part two, the selections in part three are much more intellectually engaging. Although they are all very good and important contributions to the literature, the essays by Zaner, Charon, and Drane stand out as exceptional.

This text's fourth part—'Horizons in U.S. Biomedical Ethics' —contains three essays authored by representatives of the three disciplines which most interact with bioethics and from which most bioethicists come: philosophy ('Rejecting Principlism, Affirming Principles: A Philosopher Reflects on the Present Ferment in U.S. Bioethics' by Larry R. Churchill), medicine ('Clinical Medicine and Biomedical Ethics' by Christine K. Cassel), and theology ('Beyond Principlism is Not Enough: A Theologian Reflects on the Real Challenge for U.S. Biomedical Ethics' by Richard A. McCormick).

Of the three essays in this part (which are all very good), Cassel's is the most informative, since she critiques principlism from a clinical perspective and provides readers with some insights into the mind of the physician who is faced with making a troubling ethical decision. She argues that although principlism has provided physicians and other health professionals with a vocabulary by which to discuss difficult ethical issues, 'It hasn't really worked' (p. 337).

Although there is much in this book which is critically important in any critique of principlism, there are two areas with which this book does not deal and which receive short shrift in the American bioethics community: (1) the metaphysical status of moral claims, and (2) what constitutes 'expertise' in bioethics. The first is of particular concern to theistic bioethicists who maintain that moral claims have ontological status and that a purely secular set of bioethical principles does not and, therefore, is not morally binding upon human persons. Theistic philosopher J. P. Moreland, who is a bioethicist for PersonaCare Nursing Homes in the U.S., confronts this issue in two of his books: *Scaling the Secular City* (Baker, 1987) and *Does God Exist*? (Prometheus, 1993). But what Moreland has done is a rarity in bioethics literature these days. Also, the resolution of certain issues such as abortion, fetal tissue research, embryo experimentation, and physician-assisted suicide depends on what it means to be a human person and what constitutes actions morally appropriate or inappropriate for such a being to engage in. These are metaphysical questions which must be answered *prior to* an appeal to 'principles.' Anything short of that is question-begging.

As I noted earlier, Beauchamp and Childress dismiss the relevancy of metaphysics to the bioethical enterprise. but how one can talk about bioethical principles and their application to human persons with no concern for the existence of these principles or what exaclty is the nature of a human person is, to say the least, philosophically disturbing. Metaphysical agnosticism has never been and never will be a sufficient justification for an elaborate and sophisticated theory of ethics.

With the exception of philosopher Diane Irving (see her article in *Life and Learning: Proceedings of the Second University Faculty for Life Conference*, ed. Joseph Koterski [Washington, D.C.: University Faculty for Life, 1993]), there has been virtually nothing said about the second area of concern: what makes one a bioethics expert. As Irving points out, since so many people are claiming to be bioethicists, and many of these have shown an incompetence in both biology and the history of philosophy and ethics, how do we separate the sheep from the goats, so to speak? Since the issues on which bioethicists deliberate are issues of life and death, having a profound affect upon the nature of the medical profession and education, as well as the lives of vulnerable people, the question of bioethical expertise in dire need of being addressed.

Despite its shortcomings, A Matter of Principles? is an important contribution to the ongoing bioethics debate in the United States. I highly recommend it for courses in bieothics which employ the principlist approach and whose instructors are looking for alternative perspectives to present to their students.

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