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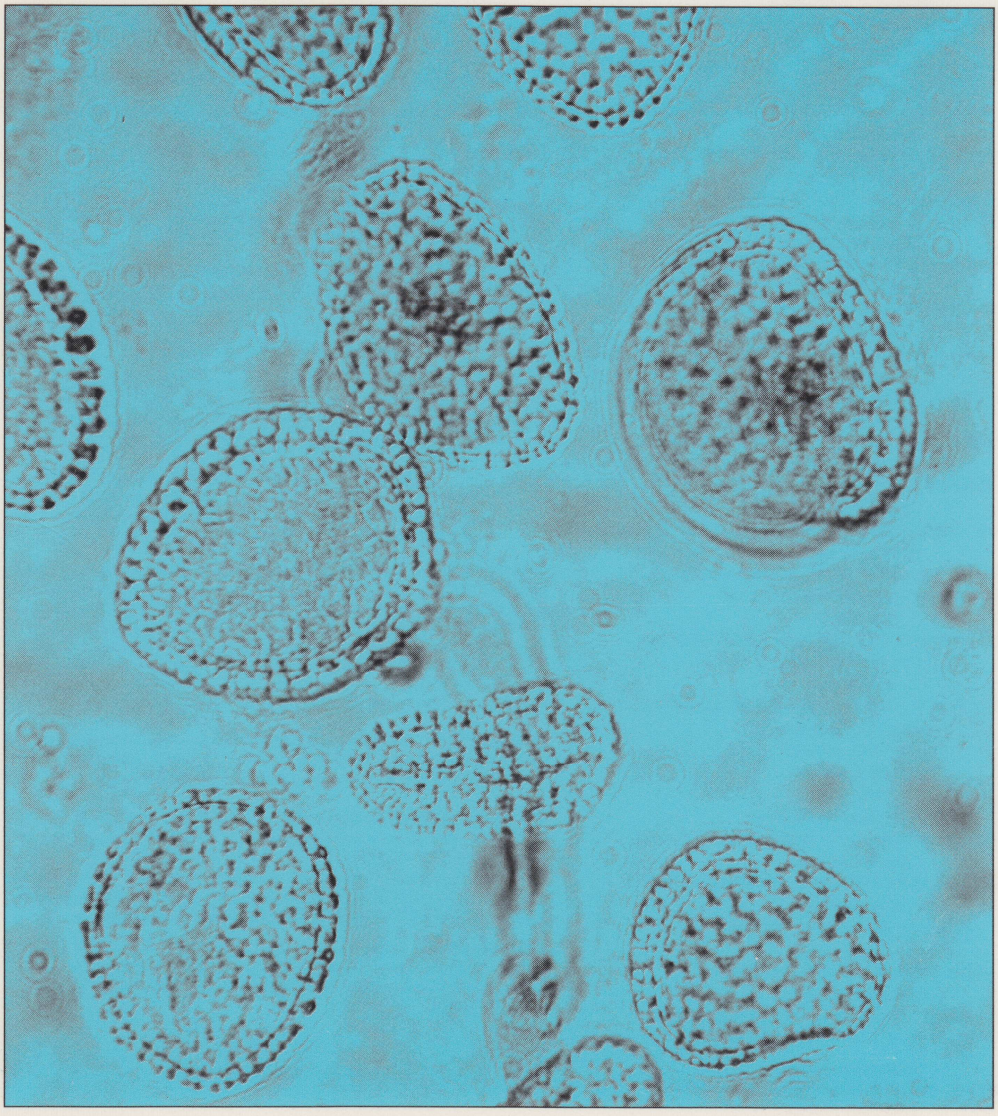
Ethics & Medicine

An International Journal of Bioethics



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EDITORIAL

CLONING NEWSPEAK

NIGEL M. DE S. CAMERON, JENNIFER LAHL

Something remarkable took place in Congress in February, as left and right joined forces to pass a ban on human cloning by a large majority. Support for the bill by Reps. David Weldon, R-Florida, and Bart Stupak, D-Michigan, came from anti-abortion conservatives, liberal pro-choice Democrats such as Rep. David Wu of Oregon, and even the House's one independent, pro-choice socialist Bernard Sanders of Vermont. Sanders did not just vote for the bill: He served as a co-sponsor and made a floor speech in its favor. This was not business as usual.

The vote was the culmination of a process in which anti-abortionists joined hands with Judy Norsigian (feminist guru and editor of the women's health book *Our Bodies, Ourselves*) and Brent Blackwelder (president of Friends of the Earth), as well as mainline religious groups such as the pro-choice United Methodist Church. A new cause is emerging, and it is beginning to unite the two centers of conscience in American culture, on the right and the left.

The dispute in Congress and the country is simple to state. Most people agree that we do not want the birth of cloned babies. Yet, the biotech industry wants freedom to manufacture and destroy a very large number of cloned human embryos. Most people do not agree. Many of them believe that the embryo should be protected as nascent human life. Many believe that the only effective way to prevent the birth of cloned babies is to stop the manufacture of cloned embryos. There are also major concerns about the abuse of women in the harvesting of the eggs that will be needed for embryo cloning (in huge numbers, according to the biotech industry). These reasons have brought together unusual allies from the anti-abortion, feminist, and environmental communities.

Cloning marks the first great debate of the "biotech century." How it is resolved in public policy will set the tone for decades of debate, as the Pandora's Box of bioscience is opened wide. That's why the biotech industry, brashly led by its trade group BIO (http://www.bio.org), is so determined to prevent controls on the manufacture of human embryos. And it has led some biotech industries to resort to sinister and dishonest language games in an attempt to alter public perceptions.

First, they tried to use the word "therapeutic" to counter the negatives of "cloning"—hence, "therapeutic cloning," contrasted with "reproductive cloning," as if all cloning were not inherently reproductive (a cloned embryo is indistinguishable from an embryo resulting from fertilization). But this ploy failed; the American public was not sufficiently malleable. So they have decided to change the language altogether and abandon "therapeutic cloning."

That is why Stanford, in the public relations fiasco announcing its new center for cloning research, actually denied that it would be cloning human embryos at all. And it is why the latest congressional bill aimed at protecting the biotech industry's right to build embryo farms for experiments has the audacity to redefine "human cloning" as the implantation of the cloned embryo. Yet, we

are told, in the bill's language, that it is not really a question of a "cloned embryo" at all. It is an "unfertilized blastocyst." That phrase is scientific nonsense: You do not fertilize a blastocyst, you fertilize an egg. But it is also dangerous: The whole point about cloning is that it makes real embryos without needing to "fertilize" eggs.

Since Dolly the sheep was cloned, we have all been re-reading Aldous Huxley's *Brave New World*. Now that we are facing George Orwell's "newspeak," it's time to turn to *1984*. E&M

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GUEST COMMENTARY

HIGH-TECH MEDICINE AND THE PHYSICIAN-PATIENT RELATIONSHIP

ERZSÉBET KAPOCSI, MD

Modern medicine has its foundations in natural science and technology. It holds the complete control over the human body as its ideal. Its achievements are fascinating, and its perspectives are boundless. The evolution of what we may call techno-medicine did not start in recent days, but rather it has just reached the level at which it is capable of opening whole new dimensions of medical thinking and a new spectrum of possible actions to be taken—as opposed to orthodox medicine.[1] In the older days, a physician had to rely on the five senses and a few simple devices to form a diagnosis, whereas today there are hundreds of biochemical tests, ECG, EEG, various types of X-rays, ultrasounds, CTs, and PETs at his disposal. He may measure all quantifiable parameters and can then summarize and store his results in computer databases. After having set up a scientifically precise diagnosis, he can pick out the optimal available therapy and suggest it to the patient. If an invasive method or surgical operation is required, laparoscopes, endoscopes, computerized microscopes, laser technology, and even robot-surgeons are there to aid the medical team. Terminally ill body parts can be replaced with transplants or artificial implants (heart valves, pacemakers, joints, bones, etc.). Hereditary diseases, genetic abnormalities can be screened with prenatal tests. There are specialized technological methods and special devices to deal with specific problems, from kidney dialysis to artificial insemination and cosmetic surgery. In an acute crisis the patients, from infants to the elderly, can be placed in intensive care units, where machines constantly monitor all vital body functions, and artificial respiration, as well as nutrition, is provided as needed.

The patients who are referred to the hospital or clinic with symptoms of an uncertain background find themselves in a mammoth medical plant. They are transferred from one department to the next, where they are examined with all sorts of instruments and devices they know nothing about, and they meet various doctors and technicians they have never met, and will probably never see again, if they are lucky enough. During these short examinations, lasting maybe from five minutes to half an hour, they are hardly talked to, and receive no feedback as to their results. They feel lost and alienated, and the anxiety caused by the sickness itself is compounded by a fear of the unknown technical apparatus.[2]

High-tech medicine is the level of medicine where the use of modern technical instruments and devices is not considered an exceptional occasion, but a part of the everyday routine. It results in a change of quality as opposed to traditional medical practice, both in diagnostics and in the field of therapy. Techno-medicine became a part of everyday practice by the end of the 20th century. Understanding of this particular type of medicine begins not with the patient or the doctor, but with comprehension of the technology involved. He who wishes to understand modern medicine should know its instruments.[3]

Ethics & Medicine, 19:2 (2003):69-74.

Tools, Instruments, Technology

Medical tools are exact, precise, and able to provide much useful information in a very short time. With their help it becomes possible to minimize stress, pain, and time spent hospitalized. These wonders of technological achievement never tire, and are devoid of any margin for subjective error. The technical arsenal of modern medicine possesses a built-in knowledge, primarily not medical, but of natural science, engineering, and information technology.[4] This means these devices were designed or modified to suit the needs of human medicine. Their advanced state of development doesn't in itself guarantee their success in practice, for the medical knowledge of the users—technicians and doctors—is also required. The machine only becomes a tool to help in diagnosis and the patients' convalescence when it is in the hands of the skilled doctor. In itself it "behaves" like other machines do—it wears out, breaks down, and is subject to the technological race, since newer and better versions may appear on the market. Furthermore, most of these devices are outrageously expensive; therefore they have to be maximally utilized to make their use profitable. These factors raise a number of ethical questions. Does the existence of these tools substantiate their use? In other words, do they have to be used at all times just because they are available? Should all technology be used in a heroic struggle to the bitter end, even in situations that are hopeless from the beginning? How many tests should a physician run before setting up a diagnosis? (There are always more parameters to measure.) Is it in the best interest of the patient that the doctor picks still more tests to carry out? Or is it in their own defense (defensive medicine), or maybe just to hide their inability to decide? Does the demand to make the use of the instruments profitable determine the number of tests that are carried out? Exceptional and rare equipment also pose the question of allocation or distribution.

These issues warn physicians that technology itself is blind, and that the technically possible cannot be separated from the fundamental principles of medical ethics: "help" and "cause no harm". Doctors have to precisely determine the need, aim, and limit of medical intervention.[5] Another fact to consider is however accurate and reliable these instruments are, there is always a degree of risk involved in their use.

High-tech medicine involves some further dangers. On one hand there is the rather real danger of over-glorifying the significance of these technological innovations, since with the use of modern instruments come new levels of prestige and authority.[6] It is fearful that in some cases it is the technologies' self-authority that dictates, rather than patients' interest and the physicians' freedom in their choice of therapy. Therefore, doctors should also learn when to use these machines, besides being instructed in handling them. A phenomenon associated with this issue is the industrialization of medicine.[7] Check-ups on a conveyor-belt basis, surgery as outpatient treatment, routine medical intervention; all effectively make both doctors and patients forget that healing is indeed an art, that should be based on a personal and intimate relationship.

Another negative side effect to medical practice is presented by the spreading of a reductionist view. Medicine increasingly tends to deal not with the sick person, or with the complex sickness itself, but with specific parts of the body

that seem to be malfunctioning. The "human machine" viewpoint that is inherent in Western medicine (Descartes, La Mettrie) is further strengthened by all the instruments, machines, and other devices, until humans appear as fine mechanisms awaiting repair, or, in a more modern approach, as complexes of techno-biological information, thus losing all pretense of individuality.[8]

Machines are capable of many things, yet they can never substitute for a physician's personal understanding, support, and encouragement. Medicine that fails to incorporate its technology into the coherent whole of the helping-healing dialogue between doctor and patient loses its human orientation.

Physicians

The use of complex and sophisticated apparatus has changed many aspects of medical practice. In the past, it was the doctors' moral obligation to do everything for their patients that was within their power. Inadequate knowledge and the lack of proper tools, however, severely limited the scope of successful treatment for centuries. Today it is the doctors' moral obligation to decide which path to follow for the benefit of their patients, within the spectrum of scientifically and technically feasible options. How can the risk involved be cut back to a bare minimum? How can a compromise be reached between the interest of the individual and other patients, taking the always-limited funds into consideration? Torn between these moral dilemmas, doctors face decisions that cannot be made without sincere and open communication with the patients. The more questions arise in modern medicine the more important the physician-patient dialogue becomes.[9]

The meaning of the entire medical profession has also changed. Besides medical proficiency, technical know-how has become indispensable. Technical knowledge enables physicians to operate new devices and becomes more highly valued as machines become more complex. This results in an ever-increasing specialization of the fields of medicine. Each physician has a deeper and deeper insight of a more and more minute domain. In the process of becoming specialists, however, doctors lose their perspective of the whole, as in the entire disease and the whole human being.[10] Their specialty and professional competence is not targeted at the treatment of the patient, but rather at the proper handling of technical equipment. This practice may lead to a novel form of autonomy and prestige, but within lurks the danger of doctors losing their status as spiritual helpers, instead becoming biomechanics. They are forced into the roles of highly trained repairmen, who diagnose malfunctioning organisms, and refer them to proper service stations where the broken-down machinery is fixed or replaced.[11] A physician sworn to the aid of patients should never forget that there is a human being hidden somewhere behind all the lab results and x-ray pictures.[12]

In older times, doctors, when setting up their diagnoses, could hardly rely on more than personal observations and conversation with their patients. The patient would explain their problems and relate the story of their illness. These stories contained little exact data, but provided much useful information about the personality of the patient, their background, and so forth. Today, a doctor

could look at the case history and establish a diagnosis without ever having met the patient. Prof. Wolfgang Huhmann complains that his young specialist colleagues know everything there is to be known about technology, but very little about "conversational medicine". In his opinion, the more complicated a procedure that a doctor is planning to carry out, the more he should converse with his patient.[13]

Specialization changes the relationships among physicians as well. General practitioners become increasingly rare, while specialists are more and more numerous. A specialist will only deal with a certain body part or organ—other organs are the competence of other specialists. In modern hospitals a patient will be treated not by individual physicians, but by groups of doctors forming medical teams instead. This raises an abundance of issues. Who does the patient "belong to"? Whose responsibility is it, if a whole team works on the problem? Professionally each doctor is responsible for his or her own field of specialty, but sometimes the real responsibility can get confused among the jumble of tests, instruments, machines, and other paraphernalia.[14] The need for traditional trust among colleagues increases, as physicians have no option but to trust in their colleagues' competency and efficiency and the accuracy of the reported test results.

In general, doctors have neither the time nor the opportunity to exchange information about patients beyond what is absolutely necessary. Thus questions may remain unanswered. Who will explain the aims, advantages, and drawbacks of a procedure? Who will evaluate the results? Who will sit by the patient's bed for a spell to provide verbal support and care, as is a doctor's classic moral duty?

Patients

The effects of modern medicine on patients are ambivalent. On one hand, technological advances mean more precise diagnoses, less danger, less operative stress, and therefore the inspiration of more trust. Foreign studies have shown that most patients in intensive care units found the presence and low noise of the machines comforting.[15] On the other hand, the complicated instruments can incite fear or anxiousness. The patients suddenly find themselves being processed by high-tech devices, without knowing what is being done to them.[16] Anxiety and the feeling of helplessness can be alleviated if the physician and the rest of the medical staff talk to patients, and explain what they are doing and why. Informing the patient becomes especially crucial if the planned procedures are unusually stressful and/or dangerous. It is also important to maintain sincere communication with the patients if the available instruments can only provide a more precise diagnosis without any proper therapy being available.[17]

Specialization in medicine is not without its consequences towards patients either. The good news is that a specialist naturally knows more about the possible dysfunctions of the given organ, and therefore may be able to provide better therapy for that particular part of the body. On the other hand, a specialist is possibly less informed about the disease in its entirety. In the long run, there is a potential danger that patients will not experience sickness as an element of the whole dimension of their lives, but in an "objectified" manner, broken down to the level of body parts. In older days, disease concerned the entire human being,

being the "mode of existence" of the individual.[18] Today, however, the modern medical attitude that views the body as an infinitely fine mechanism affects the patients' point of view. Illness is no longer the alarm bell of the body, but dysfunction of organs—headache, backache, ruined nerves, heart valve needs to be replaced, etc. All in all, patients will pick the easy way out and let the symptoms be treated with no regard to the cause; receive treatments, take their medicine, and so on. It is easier than revaluating one's lifestyle.

In a modern clinical environment, due to the system of professional teams treating patients on a large scale, any single patient is bound to meet several physicians for a relatively short time in each case. There is neither time nor opportunity to establish a classic, trust-based doctor-patient relationship. Instead a series of field- and situation-dependent physician-patient relationships is created. Communication with the patients attains higher value in some fields (e.g., psychiatry, palliative care, hospice), but in most cases conversational medicine is cut back to a bare minimum. Silent medicine or "wordless" medicine, as the German phrase goes, is especially typical in single examinations involving high-tech instruments, such as ultrasound, CT, or PET. The patients find themselves at the mercy of both doctor and machine.

Conclusion

Today modern medicine is unimaginable without technical instruments, tools, and devices. By themselves—just like other achievements of science—these are neither good nor bad. Instead they present possibilities that may be used either well or badly. As long as physicians control and direct these machines towards the restoration and conservation of their patients' health, these possibilities are beneficial. But if technology itself starts to rule medicine, doctor and patient likewise could fall at its mercy.

To counteract this possibility, when more technology is involved, more attention should be paid to patient communication—communication that is based on honesty and mutual trust. If the patients encounter a lack of communication, sooner or later they will turn to alternative forms of medicine. It is no accident that alternative medicine is becoming more and more popular. It provides what patients are seeking: a holistic outlook, consideration of the patient's personality, conversation, natural therapy, and a boosting of the patients' belief in recovery.

The seemingly limitless possibilities provided by novel technology can create the impression, in patients and physicians alike, that medicine is omnipotent. The great expectations and demand make us forget that healing is not only a science of bio-technology, but also an art—the art of handling patients and instruments. The difficulties modern medicine is facing arise from insufficient communication rather than the use of technology. Technology is not inherently alien to us, but we are alienated silent medicine.

Heinrich Schipperges, German physician-historian, said once that we are not only to stop the bleeding, but also to wipe the tears.[19] Pathos is not compatible with techno-medicine, but it would be a shame if such words were to fall on deaf ears. E&M

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HUMAN EMBRYOS, HUMAN INGENUITY, AND GOVERNMENT POLICY

ROGEER HOEDEMAEKERS, PHD

Introduction

New technologies have brought new moral dilemmas, as seen in the developing field of stem cell technology. The use of human embryonic stem cells in particular has become the subject of fierce debate, because deriving them from early embryos in the blastocyst stage (approximately 14 days old) implies that these embryos are destroyed. This has renewed the debate on the moral status of embryos and the respect that ought to be given to them (begging the question, can we respect what we destroy?).[1] In this debate ingenious moral arguments have been put forward to defend a difference in moral status between early embryos and embryos at later stages of development (or fetuses). Surveys of national review bodies are said to 'have consistently refused to find that embryos are themselves persons with intrinsic rights, and they have recommended that research be permitted with spare embryos when necessary for good medical or scientific purposes'.[2] Legislation in various countries tends to be based on such public policy. Implicit here is that respect to embryos is not necessarily shown by banning all research with embryos or aborted fetuses, but by discriminately allowing such research only when good reasons exist for engaging in it.

In The Netherlands a law was passed in Parliament which permits the use of supernumerary embryos for research and—in five years time—the use of embryos especially created for research.[3] A major assumption of the political coalition responsible for creating this law was that the moral respect owed to embryos intended for implantation in the uterus was greater than the respect owed to embryos intended for research. However, this law stipulates that research with embryos especially created for (stem cell) research can only be carried out under very strict conditions, suggesting a higher moral status of embryos created for research than for spare embryos. One would expect these embryos to be treated rather with lower moral status, because they are not even intended for implantation. A similar line of argument is presented, for example, by McGee and Caplan, who propose that the moral status of an embryo depends on the 'institutional context'. Embryos are seen to acquire different meaning when they are found outside their ordinary context (i.e., reproduction).[4]

Political parties who wish to uphold full protection of an embryo from its earliest beginnings face a dilemma, once the instrumental (therapeutic) use of embryos has been made possible by law. They can continue to reissue their arguments for full moral status. This may not be very fruitful in view of the social and political support, as in The Netherlands, for ascribing a lesser moral status to an embryo in the earliest developmental stages. Another possibility is to investigate how a common policy can be developed—together with other coalition partners—which does justice to the principle of full moral respect for embryos.

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The Scientific Institute for Public Policy of the Christian Democratic Party in The Netherlands has chosen the second option in a recent report. It explores the major arguments for embryo research, concludes that these arguments are not sufficiently strong to change the party's position of full moral protection of the embryo, and investigates the possibilities for a common policy of maximal reduction of the number of embryos used for research. This paper presents the report's main arguments for adoption of such a policy.[5]

What Is an Embryo?

On the basis of what is now scientifically known about the beginning of human life it is justified to mark the process of fertilization as the beginning of new human life—a process which takes about 24 hours and begins with the penetration of the ovum by the sperm and ends with the creation of a new genome. Crucial in this process is the moment of recombination (fusion) of the genetic material of both gametes into a new and unique genome which starts a programmed gradual development towards the completion of becoming a new human individual.

An embryo can therefore be defined as a cell or group of cells which is totipotent and which—in its natural environment—has the potential to develop into a human individual. At present a new genome cannot only be created in the womb, but also in petri through various techniques. Creation of new human life through cell nuclear transfer is the most recent technique, where the genetic material in a cell nucleus is transferred to an egg from which the original nucleus has been removed. Through electrofusion a new cell is created which is totipotent and which, in an appropriate environment, has the potential to develop into a human individual. Such a cell falls within the definition given above and deserves the same protection as other embryos.

An important question for human embryonic stem cell research is at what stage of development the growing cluster of cells is not totipotent anymore. A totipotent cell can, in principle, be separated from this cluster and develop into any of the many different types of body cells. Also, when it is brought into the appropriate environment (uterus), it can develop into a new human individual. Totipotent cells can therefore also be regarded as embryos. They must be distinguished from pluripotent cells, however. These cells can still differentiate into many, but not all, types of body cells or tissue, and more importantly, they do not have the potential anymore to develop into a new human being.

In principle, it is possible to transform pluripotent embryonic stem cells into totipotent cells by fusion with a blastocyst. But from this it does not follow that pluripotent cells have the moral status of totipotent stem cells. Pluripotent stem cells can best be compared with gametes. Only after fusion (or fertilization) has taken place can they develop into a new human being. That fusion is the crucial element, not the pluripotent status of a cell, is underscored by the very process of cell nuclear transfer. In principle every body cell can be used to transfer its nucleus to an egg for the creation of an embryo. This does not give these cells a special status, however. As every body cell can develop into a new embryo through this technique, it would be absurd to state that they should therefore possess special moral status.

When a cell is isolated from the developing embryo which is not totipotent anymore, it cannot be regarded as an embryo and can therefore be used for research purposes—if the separation does not lead to the destruction of the source. The present state of the art does not justify a definitive conclusion with regard to the moment the embryonic cells are not totipotent anymore. It is unknown whether an isolated cell from a human embryo at the eight-cell stage will develop into a new human being. It is assumed that in the eight-cell stage five cells are involved in the development of the trophoblast (the layer of cells in the embryo which will establish relation with the uterus) and three cells which will eventually develop into the embryo proper. This would imply that cells at the eight-cell stage are already differentiating and cannot be termed totipotent anymore, but until now there is no certainty about this. This uncertainty should therefore lead to great restraint in using these cells.

Embryos and Moral Ingenuity (1)

Moral ingenuity has assigned to some types of embryos a greater moral status (therefore deserving of more protection) than others. For example, a distinction has been made between 'spare' embryos, which remain 'unused' after fertility treatment, and embryos especially created for research purposes. Proponents of embryonic research point to the many embryos left over from an IVF procedure. They argue that from a moral point of view it is better to use these supernumerary embryos than to create embryos especially for research. At first sight this seems a reasonable approach, but this position can be rejected for a number of reasons.

(a) Improvements in fertility treatments will reduce the number of spare embryos and the number of embryos potentially 'available' for research will therefore become smaller. It is therefore reasonable to assume that use of spare embryos is only the first step, leading inevitably to the creation of embryos for research when the number of spare embryos is insufficient.

(b) It could be tempting to create a few extra embryos in an IVF procedure, which could then be used for research after the procedure is completed.

(c) If the creation of a new genome is taken as the starting point of a programmed development of an embryo into a human being (see above), a distinction in moral status between spare embryos and embryos created for research purposes cannot be defended. From this it follows that, once the use of spare embryos is accepted, it will be difficult to stop the creation of new embryos for research, precisely because there is no difference in moral status between spare embryos and embryos created for research.

(d) More importantly, the expectation is that the use of spare embryos will lead to a more general and societal decrease of respect for embryos. This expectation is felt to be real. In the past, acceptance of more inefficient IVF procedures implied permission to create a greater number of embryos than truly necessary. This led to a request to use the extra embryos for research purposes. Permission would imply further instrumental use of embryos. The next step now is to create embryos especially for research purposes. This process is clearly visible in the new Dutch Embryo Protection Act. It permits use of spare embryos

(when certain conditions have been met), because there seems to be enough public and political support for it. In fact, it even speculates on a further shift in public opinion towards acceptance of the creation of embryos specifically for research within five years. This search for public support is not only found in The Netherlands. Also the NBAC states: 'We do not, at this time, support the federal sponsorship of research involving the creation of embryos solely for research purposes. However, we recognize that in the future, scientific research and public support for this kind of stem cell research may be sufficient in order to proceed'.[6]

(e) Another distinction in moral status is made between human embryos used for reproduction and embryos used for therapeutic reasons. The argument is that—when used for research purposes—these embryos do not have the potential to become human beings because they are not transferred to the uterus. This distinction in moral status can also be rejected. The crucial point is that the moral status of the embryo cannot depend on the intentions of the creators. An embryo created in the dish possesses a new genome and has the potential to become a new human being. It is an act of the human will that it is not placed into the appropriate environment (the uterus) and that this potential will not be fulfilled. Accepting a different moral status for research embryos would imply that the moral status of the embryo is dependent on the arbitrary intentions of the scientist. The implication of this position for spare embryos is that at the very moment an embryo is not selected for implantation its moral status changes. By analogy, can parents who are expecting a baby change the moral status of a developing embryo or fetus simply by wishing for or having an abortion? This position denies the intrinsic worth of all developing forms of human life. In a similar form of reasoning a difference in moral status is grounded on the probability that an embryo will develop into a new human being. This probability is greater if it is implanted in the uterus, and this embryo has therefore a higher moral status than an embryo which is not transferred. Obviously, here, too, the moral status is dependent on the intentions of the 'creator' to transfer the embryo to its natural environment or not.

(f) A distinction in moral status has also been based on different processes of creation. Embryos can be created by traditional fertilization techniques or by cell nuclear transfer. It is argued that embryos created by cell nuclear transfer are not intended to develop into a new human individual.[7] This argument not only disregards the various attempts to clone human beings, but is also based on the assumption that the intentions of the 'creator' are decisive for the moral status of the human embryo. The crucial moral moment is, however, the creation of a new embryo, which in principle can become a new individual. It is man who decides what happens and in which kind of environment an embryo is placed. These arbitrary decisions cannot determine the moral status of the embryo.

(g) The 'appeal to nature' argument, put forth in support of the Embryo Protection Act, can also be rejected. The argument is that many embryos are lost in the uterus also. This apparently also justifies the destruction of embryos for research purposes. This argument is rejected because the oversight is that man is not morally responsible for natural processes in the womb. He is responsible, however, for the creation of embryos in the dish and their subsequent development as well as for their intentional destruction.

For our purposes it is noteworthy that both proponents and opponents do assign moral status to the embryo. 'Many parties to the debate, at least, do agree that the embryo should be treated with respect'.[8] So the difference is not between embryos with no moral status at all and full moral status, but between embryos with full moral status and embryos with a somewhat lesser status—a difference of degree. The implicit assumption underlying the attempts to create differences in moral status is that it is easier to weigh the moral value of embryos against the interests of future patients. But this is an approach which presents considerable difficulties (see below). Another approach is to take seriously the fact that all political parties subscribe to a moral status for embryos. Can this be taken as a starting point for public policy? In The Netherlands this would not be without a precedent.

Respect for Unborn Human Life

In the abortion debate three basic positions can be discerned with regard to the moral status of new unborn human life. The first emphasizes the continuity of the process of development and gives full protection to the developing embryo (fetus) from the moment the new genome has been formed. In this approach abortion is not permitted. The second position emphasizes a discontinuity in development. A distinction is made between human life and personhood, and a fully protected status to unborn human life is given only from the moment it has the status of person. This moment is fiercely debated, however. There is neither agreement about which characteristics are typical of persons, nor is there consensus with regard to the moment personhood begins. The advantage of a distinction in moral status is, however, that it permits abortion up to the moment the fetus is ascribed personhood, because the lesser moral status of the developing human life makes it easier to weigh it against the interests of others (mother or parents). The third position emphasizes a gradual growth of a fertilized ovum into a human person. As the developing human life grows it is given greater moral weight. The early embryo deserves protection, but a fetus of three or four months deserves more protection. In other words, the more the unborn human life develops, the weightier the arguments must be to terminate pregnancy.

The discontinuous and the developmental approach have in common that a lesser moral status is assigned to the embryonic and early fetal stage—but not without considerable difficulties. Both approaches are to a certain extent vague. It is not at all clear what sort of protection an embryo or early fetus ought to be given, and, consequently, which interests are compelling enough to justify termination of pregnancy. In addition, the gradual approach offers no concrete criterion. This partly explains why it is seldom used in legislation, where a very definite stage (or time) in the development of the fetus usually defines the limits of induced abortion.

It is important to note that there is common ground. The first approach (continuity) gives full moral status to unborn life, independent from its stage or form. The discontinuous and developmental approaches assign embryos and early fetuses a lesser moral status. All three positions recognize, however, that early unborn human life does deserve moral respect. In the past this common

basis could form the basis for the introduction of abortion legislation. The Christian Democrats did not give up their position of full moral status for the fetus. Given the fact that abortion legislation was unavoidable in view of the social and political support for it at the time, they aimed at the next best thing—the greatest possible reduction of the number of abortions. Accepting that termination of a pregnancy can sometimes be justified in complex and exceptional cases, even for those who support full protection of the fetus, they limited abortion to only those emergency situations of real physical and/or psychological crisis. The other parties could not but accept their position, because they too recognized that moral respect was due to the fetus.

The question can be raised whether a similar "embryo-saving" policy with regard to embryos is feasible and morally defensible. Before this question is answered a brief exploration of the moral issues created by the instrumental use of embryos for stem cell research is useful.

Embryos and Moral Ingenuity (2)

Research with human embryonic stem cells is undertaken because of their (assumed) 'potential for significant advances in tissue transplantation, pharmaceutical testing and embryology'.[9] Destruction of a human embryo is not justifiable for those who seek full protection for the embryo. But those who accept a lesser moral status face a difficult question: which (therapeutic) interests have more weight than the protection of early forms of human life? Such a weighing of interests is complex.

In much of the present moral debate it is assumed that the interests of (future) patients with degenerative and debilitating diseases outweigh a lesser moral status of embryos. Embryos can therefore be justified for use in medical research or for new therapies. It proves very difficult, however, to determine precisely which therapeutic aims are weighty enough to morally justify instrumental use of embryos for research. Precise and concrete criteria to determine this have not yet been offered and until now the balancing of interests tends to be intuitive, precisely because the specific moral status of embryos has not been defined yet, and, consequently, the degree of moral respect they deserve. It is not clear in advance which forms of research are important enough. Therefore there is a real possibility that, because of lack of criteria, there is a more or less ad hoc solution, subject to scientific, financial, or patient pressure.

The impossibility of defining precise limits may have been one of the reasons that other ingenious arguments have been put forward to defend embryonic stem cell research. Analogies have been sought which could justify instrumental use of embryos, but they are not thoroughly convincing, as the following examples demonstrate.

(a) One justification is based on a comparison made with soldiers who expose themselves to life-threatening situations in war to serve a greater cause.[10] This analogy is weak, because embryos cannot possibly make a conscious choice to sacrifice themselves. Soldiers do have this choice, and if they do not, there is a reasonable chance and in most cases the explicit intention of survival, unlike in the situation of embryo research.

(b) Another analogy is based on the principle of solidarity. Instrumental use of embryos for therapeutic research can be interpreted as sacrificing embryos for a greater and common good.[11] Eventually it will be to the benefit of many who are seriously ill. This argument can also be rejected. The embryo has no choice; others determine whether it should be sacrificed for reasons of solidarity. A possible objection based on the fact that parents decide for their offspring when they cannot decide for themselves can also be rejected, because the implicit assumption of parental decisions is that parents decide in the interest of their child. A parental choice to destroy the embryo can hardly be seen as such.

(c) Embryos have also been compared to innocent citizens who are killed in a war.[12] To achieve greater aims (e.g., the upholding of democracy, the destruction of dictatorship, or the annihilation of terrorism), sometimes (large numbers of) citizens are sacrificed. This is also a curious analogy. Killing citizens can sometimes be unavoidable to achieve the aims named above. But the word unavoidable is crucial. In embryo research such a predicament does not yet exist. It is not unavoidable, especially when alternative forms of medical research (research with adult, fetal, or umbilical cord stem cells) also prove to be promising.[13]

(d) It is inconsistent to accept termination of pregnancy and reject embryo research.[14] This argument is also rather far-fetched. It will certainly not be acceptable for those defending full protection. But it is also not a good argument for those accepting a lesser moral status for embryos than for a fetus (the developmental approach). Induced abortion can only be defended in situations of crisis. Using embryos for therapeutic purposes can not be defined as a crisis situation, neither physically nor psychologically.

(e) The claim of the mother that she can decide over her own body (and therefore about donation of embryos for research) is not a good argument either. The decision is not about the mother's own body but about a potentially new human being. When a mother decides to provide embryos for therapeutic research she decides about their destruction for a purpose not related to either herself or the embryo.

Implications for Public Policy

The difficulties of moral justification of differences in the moral status of embryos as well as the unconvincing moral arguments in support of the instrumental use of embryos have not led to a change in the basic position of the Christian Democrats in The Netherlands. But they now have to accept the fact that legislation with regard to the embryonic research was introduced which they did not, indeed, could not support. They still completely endorse the principle of full protection of unborn human life from its earliest beginning. The political difficulty for them is, however, to find different ways to uphold this principle of full protection of the embryo in a situation where there is no parliamentary majority which agrees on changing the law and where political coalitions are necessary with parties who do not support their viewpoint.

Earlier, in connection with the abortion issue, we noted that in spite of differences in moral status assigned to unborn human life, public policy with

regard to termination of pregnancy could be based on the fact that there was no disagreement among the political parties about the position that all forms of unborn human life deserve moral respect. This led to legislation aiming to reduce the number of abortions as much as possible. If this is taken as an example to determine a common policy of maximal reduction of use of embryos for research, the Christian Democrats have to answer three questions. (1) Is this politically feasible? (2) Is this policy in line with the principle of full moral respect for embryos? (3) How can such a policy be given form?

(1) The feasibility of such a policy is dependent on three conditions. The first is that a central government should not limit itself only to the development of procedures to enable interested parties to weigh and balance their interests. The second is that a central government should recognize that it has a moral responsibility of its own. Especially with regard to the protection of (all forms of) human life a government has a normative task. Although important, it is not enough for a government to base public policy on public opinion and public debate. The moral status of embryos should not depend only on the degree of social support that happens to be present in a specific community. The third condition is that all political parties which do not support a full moral status for embryos, but which subscribe to a 'lesser' moral status for embryos, should take this position *very seriously*. The real implication of this stance should not be that political parties offer possibilities to 'destroy what one respects', but that they see it as their duty to do one's utmost to reduce the total number of embryos destroyed for research purposes. For a coalition government in which political parties ascribe varying degrees of moral status to embryos this can form a basis for common policy. Such a policy is based on the biological fact that the creation of a new genome starts the development towards a new human individual. It is this process of development which deserves maximum protection.

(2) For the Christian Democrats in The Netherlands an 'embryo-saving' policy is defensible for a number of reasons. In the first place they can point to a precedent. With regard to the introduction of abortion legislation the choice was for a policy of maximum reduction of induced abortions and permission only in situations of great emergency when alternatives are absent. True, in practice a wider interpretation is often given to this condition, but this is an important reason for the Christian Democrats to demand a thorough assessment of the present practice. Secondly, the fundamental position with regard to the moral status of unborn human life is not abandoned. It is only given a different form through a shift in emphasis, and in view of the current political context and majorities. Now that the Embryo Protection Act has been passed, the aim can no longer be to forbid the instrumental use of embryos. Instead, the focus becomes to minimize the number of embryos used for research wherever and whenever possible. In accordance with the position on abortion the instrumental use of embryos should be regarded as exceptional and only be considered when there are truly no alternatives. Thirdly, the major purpose of this change in emphasis is first and foremost the prevention of a general moral devaluation of embryos. As illustrated above, this is a real possibility.

One objection to such an embryo-saving policy is that promising therapies for serious and debilitating diseases thus blocked, but the question remains whether this reproach is fully justified. The present state of the art in stem cell

research does not make clear that human embryonic stem cell research is the only alternative left for developing therapies.[15] True, a choice for a specific sort of stem cells (e.g., fetal or adult stem cells) does imply a restriction of research possibilities which can cut off the development of some therapeutic possibilities. But at present there is no certainty about this. Also, it is not yet clear how many of the existing cell lines are needed for fundamental research. This justifies a choice for first prioritizing human embryonic stem cell research, which is more morally controversial. Now the crucial moral question is whether more rapid research results counterbalance a broad societal diminishing respect for human embryos. A morally convincing public policy will be grounded on the presupposition that first the morally most defensible route will be taken before morally controversial routes are pursued.

(3) Such an approach can have important policy consequences for human embryonic stem cell research. These include:

- In fertility treatments every effort should be made to restrict the creation of excess embryos.
- Selection of embryos in petri to avoid multiple births should be reduced.
- 'Extra' embryos should not be created in an IVF procedure.
- No human embryonic stem cell research should be undertaken before it is clear that alternatives do not lead to successful therapies. Preference should be given to research on adult stem cells, not embryonic stem cells. Embryonic stem cell research should only be undertaken when it is clear the alternatives do not lead to real therapeutic options.
- There should be active (financial) stimulation of research with stem cells from other sources (including fetal tissue).
- Import and use of existing cell lines should be accepted, although this should not lead to an increase in the creation of new embryos for research abroad. In this time of globalization and international regulation and legislation one is also morally responsible for what happens abroad.
- Use of totipotent embryonic cells for further research should be forbidden.
- Use of spare embryos is only permitted if the alternative forms of research are not successful.
- The creation of new embryos for research purposes must be forbidden.

If political coalition parties can agree on such a policy, there is a real possibility that a social devaluation of the moral status of embryos can be stopped. E&M

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Is It Right or Is It Useful? Patenting of the Human Gene, Lockean Property Rights, and the Erosion of the *Imago Dei*

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Collection of blood at American Red Cross blood banks. Donation of a kidney to save the life of a beloved brother. Implantation of fetal brain cells into Parkinson's patients. Extraction of stem cells from newly re-defined "pre-embryos." Insertion of human genes into precisely developed strains of laboratory mice. Artificial insemination with the sperm of an anonymous donor. Cutting hair to make wigs for cancer patients. Replacement of a diseased heart with the healthy heart of a recently deceased accident victim.

All these are instances of the use of parts of the human body. Some are heroic. Others are sinister. Each of them touches on the question of what it means to be human. Is a human being more than a body? Do we own our selves? Or, to whom or what does the human body belong?

These legal, ethical, and social issues are inextricably intertwined with the decoding and patenting of the human genome. The international cooperative race to map the human genome and its ahead-of-schedule completion have already set the legal course. Although initially funded largely by the U.S. government, the Human Genome Project attracted investment by other nations, pharmaceutical companies, and biotechnology firms. Millions of research dollars have been spent based on the legal protection afforded by exclusive rights via gene patents. Are these patents ethical? The issue can be examined from a variety of perspectives. This essay will compare the general approaches in Europe and the U.S., with particular attention to arguments for and against patenting the gene.

The American constitutional experience has been shaped in great measure by the philosophy of John Locke. The fruit of this philosophy will be weighed against the biblical doctrine of man[1] as *imago Dei*. It is evident that the more we learn about the *material* of man, the less we understand about the *nature* of man.

The Human Genome Project and Patenting

History of the Human Genome Project

The Human Genome Project (HGP) project was conceived in 1990 as a public initiative coordinated by the U.S. Department of Energy and the National Institutes of Health. Its goals were to identify all the genes in human DNA (approximately 30,000 genes); determine the sequences of the three billion chemical base pairs; store the information in databases; improve tools for data analysis; transfer the technologies to the private sector; and address the ethical, legal, and social issues raised by the project.[2] Commercial interests—biotech

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firms and pharmaceutical companies—jumped on board several years later, eager for the prospect of profits from new drugs and diagnostics.[3]

A working draft of the entire human genome sequence was announced in June 2000, and analyses were published in February 2001, two years ahead of schedule. The final map will not be an exact match for the DNA of any individual. Anonymous individuals donated male sperm and female blood to the library. The DNA of about ten to twenty individuals, male and female, was the primary source, but neither the donors nor the scientists know whose DNA was actually used.[4]

Although millions of dollars are being spent on identifying genes and gene fragments, it is but a fraction of what is required to determine gene function and develop and test drugs and diagnostics. There are enormous costs and risks in the process, costs that cannot be borne by public funding alone. Businesses will not commit capital to research and development if they cannot reap the profits of success. Discoveries and innovations can be protected as trade secrets (until a competitor figures out another or better process) or by patenting. Patenting raises ethical issues, but none as intense or potent as the patenting of a living organism—the building blocks of life.

European and American Ethical Viewpoints

The European and American ethical discussions follow one of two approaches: deontological or consequentialist. The European approach is generally deontological, focusing on the inherent or intrinsic rightness or wrongness of ownership. In contrast, the American public conversation is primarily consequentialist, arguing about the harmful or—most often—beneficial consequences.

The U.S. has relied almost exclusively on the discernment of the U.S. Patent Office and the courts. The predominant legal philosophy finds its roots in John Locke's theory of natural rights and property, stretched to absolutist proportions. Individual autonomy and property rights are enshrined in the U.S. Constitution. Broader moral and social implications are sidelined to the courtyard of the church, separated by a fictitious constitutional wall from public policy.

Europe has taken a more reflective and communitarian approach. Continental European law is characterized by civic duty, rather than individual rights. Citizens, through their government, are responsible for the welfare of the entire community. While property is protected, ownership carries with it duties to the welfare of the larger community. In constitutions and laws, specific language about duties, morals, and values is common. This concern for impact not only on the individual, but on society, marks the European conversation about the propriety of patenting the human genome.

American patent law is more comprehensive and more defined than that of the various European nations. Its forward motion has pulled Europe in its wake. Most of the patents on genetic information are held by U.S. and Japanese companies, whether granted by the U.S. or European nations. How did this significant policy shift crop up?

United States Patent Law and Life Forms

In the U.S., patent protection is specifically protected by the Constitution[5] and by statute. This peculiar property right was deemed necessary to provide the incentive to innovate. Patents are granted for utility, design, or plants. Gene patents fall within the utility category, an innovation designed to serve a specific function. The invention must be novel, useful (have an articulated practical use), and non-obvious (to an ordinarily skilled person in that field).[6] The patent gives the holder a monopoly, with exclusive rights to benefit from his or her invention for twenty years. By court decision, certain things are not patentable: products of nature, physical phenomena, laws of nature, scientific principles, and abstract ideas. Varieties and hybrids of plants are patentable. But, prior to the late 20th century, biologic life forms were not.

Human biological materials have been patented, such as cell lines and hybridomas.[7] These are tissues, not discrete biologic life forms. But, with respect to the human genome, only the information, not the actual sperm or blood, is of interest to the innovator. At the current pace, the entire human genome soon will be patented. Is the patenting of the genetic information—not the individual's tissue sample—ethical? The legal branch has answered that question in the affirmative.

Whether the courts should be the arbiters of what is moral is beyond the scope of this discussion. Suffice it to say that Professor Mary Ann Glendon astutely observes: "Whether meant to be or not, law is now regarded by many Americans as the principal of those few moral understandings that are widely shared by our diverse citizenry."[8] Prior to 1980, few would have believed that a living organism could be patented.

The legal—and moral—landscape shifted that year with the Supreme Court's decision in *Diamond v. Chakrabarty*.[9] The Court ruled by a razor-thin margin that a genetically engineered bacteria capable of dissolving oil spills was patentable. Seven years later, the U.S. Patent and Trademark Office (PTO) issued a policy statement that non-naturally occurring non-human multi-cellular living organisms, including animals, would be considered patentable subject matter.[10] Within one year, a patent was granted for the "Harvard Mouse," a "transgenic non-human mammal," a mouse genetically engineered (with insertion of human genes) to be highly susceptible to cancer. And shortly thereafter, HGP began. Reaction to the suggestion of patenting the human genome came from both sides of the Atlantic.

Europe and the Patenting of the Human Genome

Europe, of course, is not a single nation, as is the U.S. European governments have organized themselves into both the Council of Europe (COE) and the European Union (EU).[11] Common borders symbolize their communitarian approach. The Green parties have influenced European practice, spawning public outcry against genetically modified foods or animals. The European Patent Convention, which applies in most EU countries, permits denial of patents on grounds of public interest, and where issuance would be contrary to *ordre public* or morality.[12] On these grounds, patents are not permitted for the human body or any part of it.

In 1991, shortly after HGP began, the French science minister, Hubert Currien, objected to patenting of the genome: "[S]uch a development would be ethically unacceptable. A patent should not be granted for something that is part of our universal heritage."[13] This sentiment has remained fairly strong, although more recently the biotech industry and the European Commission have attempted to expand patent protection.[14]

The ethical claim that the genome is the common heritage of mankind is shared by many, including The Human Genome Organization (HUGO)[15] and UNESCO.[16] HUGO, an international organization of over 1,000 researchers from over 50 countries involved in HGP, was founded to promote international collaboration on HGP. HUGO's opposition to gene patenting is shared worldwide. For example, former director general of the Indian Council of Agricultural Research M.S. Swaminathan opposes the patenting of human genetic material as "totally unethical," and argues that commercial profits must come from new drugs and vaccines.[17] Luigi Luca Cavalli-Sforza, founder of the Human Genome Diversity Project, concurs, but admits that the potential commercial value of the information unlocked by HGP may make that an impossible stance to maintain.[18]

In 1994, the Danish Council of Ethics concluded that although modified synthetic genes created in the laboratory could be patented, complete human genes could not.[19] The Council did not answer the question of who *does* own naturally occurring genes and information: the individual, the family, or humankind.

After the PTO began granting patents for expressed sequence tags (ESTs) HUGO publicly objected. ESTs are small portions of genes used as research tools that are necessary for all subsequent innovation. Patenting them renders further research untenable. HUGO urged immediate public release of all human genome ESTs "in order to secure an optimal functioning of the international network, as well as to avoid unfair distortions of the system."[20] The PTO continued to grant patents.

In 1997, COE signed the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997)("Convention on Bioethics"). This is the first international treaty in the field of biomedical ethics. It was signed by twenty-one of the 40 member countries of COE, with five countries expected to sign shortly thereafter.

The Convention was intended to establish a framework of the most significant principles, with "additional standards and more detailed questions" to be worked out in additional protocols.[21] The Convention affirms protection from improper use of medicine and biology at three levels. First, it primarily protects the individual, above the interests of science or society. Additionally, there is specific recognition that the individual is part of "a social corpus sharing a number of ethical principles and governed by legal standards."[22] On the third level, the convention addresses the human species, establishing safeguards to protect the identity of the human being. These society-wide and species-wide ethics are absent from American legal standards.

Chapter VII most nearly applies to the issue of patenting genes. Article 21 prohibits financial gain from the human body and its parts "as such." Interestingly, the Explanatory Report echoes the concern with human dignity.[23] The issue of patents is not addressed, due to the complexity of the issue. But the Council's position is clear. "[T]he European Community has issued a proposal for a Directive containing the principle according to which "the human body and its elements in their natural state shall not be considered patentable inventions."[24] All issues are delegated to the public community for medical, social, economic, and legal discussion.

European opposition to patenting could not hold. Shortly after the Convention on Bioethics was signed, the EU issued an ambiguous directive permitting human gene patents.[25] Naturally, France Biotech (similar to BIO, the U.S. based Biotechnology Industry Organization) supported the change. ("Follow the money" often is an apt description of contemporary ethical conclusions.) The French National Assembly vigorously countered the directive. Deputy Jean-Francois Mattei, a pediatric geneticist, stressed: "The human body is not a saleable commodity—nor are its genes."[26]

The EU directive was narrower than U.S. patent policy. It only supported patenting of genes whose function was fully known, but not ESTs or single nucleotide polymorphisms (SNPs, the smallest building blocks of DNA which can serve as markers to locate and identify deleterious gene mutations). In response to the EU directive, HUGO issued another statement forcefully objecting to patenting of any ESTs, SNPs, or genes whose function was unknown.[27]

About the same time, the General Conference of UNESCO unanimously adopted the Universal Declaration on the Human Genome and Human Rights. Although it did not explicitly address the issue of patenting, it reaffirmed that the human genome is part of the heritage of humanity. The document stated that "in its natural state [the human genome] shall not give rise to financial gains."[28] Finally, the Declaration pressed for the "free exchange of scientific knowledge and information."[29]

The concern about hoarding information via patents extended into the pharmaceutical community. In 1999, ten major drug companies and the Wellcome Trust announced a $45 million SNP Consortium to map individual genetic differences (SNPs), publish the information, thereby ensuring "free and equal access to all in the world-wide medical research community."[30] As a means of preventing other entities from attempting to patent the information, the Consortium intends to apply for patents, but will not enforce them.[31]

Patenting of the Human Genome

Several companies raced to patent sequences before releasing them, limiting the data to paying customers.[32] The ensuing contest prompted U.S. President Bill Clinton and U.K. Prime Minister Tony Blair to issue a joint statement in March 2000 endorsing the public release of data. Making this data available as quickly as possible was intended to protect the sequences from patenting, to keep the data available free of charge, and to encourage useful applications.

The PTO continues to grant patents. By the fall of 2000, more than 15,000 patents on human genes were pending. The top ten human gene patent holders have been awarded at least 2,003 patents.[33] Gene patents have been granted to universities, pharmaceuticals, and biotech companies. There are three distinct "layers" of ownership in the human gene, each with its own patent: 1) identification of the actual gene, 2) identification of its function, and 3) diagnostics or treatments for the underlying disease. Most of the patent applications to date are for genes of unknown function. If another developer discovers its function, or develops a treatment, licensing fees or royalties must be paid to the holder of the underlying gene identification patent.

American law, for the present at least, has determined that patenting of the human genome is ethically and legally acceptable. The decisions have been made by a handful of patent officers and lower court judges. Neither the U.S. Supreme Court nor Congress has directly confronted the legal and moral issues. Although highly improbable, the patent of the human genome (at least its identification) could be found to be against public policy or unconstitutional.[34] That should not preclude examination of whether patenting of the human genome *should* be permitted.

To Patent or Not?

Arguments Against Patenting

Arguments against patenting or ownership may be loosely characterized as deontological or consequentialist. The primary arguments about its intrinsic morality center on issues of fairness, justice, and protection of our human heritage.

1. The human genome is the common heritage of all mankind. It is wrong to allot its ownership to particular entities.

2. It is wrong to claim ownership of another human being. The Thirteenth Amendment prohibits slavery or ownership of another human being. Genetic identity is unique to each individual and belongs solely to that person. (Of course, human genome mapping does not rely on a specific individual.)

3. Since it is wrong to sell one's own body parts, it is wrong for another person to claim ownership of any part of the body.

4. Patenting unjustly exploits various population groups—those who are of interest to biomedical research due to their ethnicity, geography, or family identity.

5. Patenting violates principles of distributive justice. It violates the principle that there be an equitable allocation and access to the resources and goods produced by the genetic research.[35]

Additional arguments raise the harmful consequences of patenting or ownership of the genome.

1. Patenting, which requires the disclosure of all information, may violate the privacy, if based on the genetic information from an individual (rather than from a group).

2. Patenting is a commercial activity, which leads to commodification of the human body.

3. Patenting enables holders to gain enormous profits, even from life-saving therapies and techniques.

4. University researchers who gain financially often carry out their work with public funding.

5. Patenting increases the cost of diagnostic tests and drugs for the patient.[36]

6. The human genome is a limited, finite resource, and therefore should not be controlled by a small group of individuals or companies.

7. Patenting of genes of unknown function permits "hoarding," barring others from attempting biomedical research.

8. Current patents on the human genome violate patent law; patents cannot be issued on things that exist in nature.

The ELSI (ethical, legal, and social issues) project of HGP lists several additional concerns. Only one raises the morality of ownership.[37] All others deal with potential harmful consequences.

1. Patent stacking (allowing a single genomic sequence to be patented in several ways such as an EST, a gene, and a SNP) may discourage product development because of high royalty costs owed to all patent owners of that sequence; these are costs that will likely be passed on to the consumer.

2. Because patent applications remain secret until granted, companies may work on developing a product only to find that new patents already have been granted, with unexpected licensing costs and possible infringement penalties.[38]

3. Costs increase, both the direct cost of paying for the patent, and also for determining what patents apply and who has rights to downstream products.

4. Private biotech companies who own certain patents can monopolize certain gene test markets.

5. Patent filings are replacing journal articles as places for public disclosure—reducing the body of knowledge in the literature.[39]

Arguments in Favor of Patenting

There are fewer arguments in support of patenting. The primary deontological argument in favor of patenting asserts fairness to researchers and investors.

1. Patenting is the only fair way to protect investment. The inventor should enjoy a temporary monopoly on the innovation and earn royalties if another entity uses it.

2. The genes would not be identified ("discovered") without particular technology and the skill of the researcher.

3. Patenting of a genome does not dishonor the human body. People can already donate parts of their body (hair, blood, organs, tissue) to enhance or save the life of another or to benefit the advance of science.

Other arguments dwell on the efficient use of resources and on the potential benefits to society.

1. Patenting requires public disclosure; ownership or protection via trade secret law does not. With a patent there is no hoarding of information and other researchers have access. (This claim ignores the reality that thousands of patents have been filed on genes of unknown function.)
2. Government and university funding is insufficient. The possibility of profit encourages the private sector to rapidly innovate and develop technology, particularly in new and high-risk areas.[40]
3. Widespread access to information helps avoid wasteful duplication.
4. Gene patenting is not the same thing as ownership of a human being. No single entity "owns" the entire genome.

The Philosophical Foundation of American Property Rights:

John Locke and the Ownership of Human Life

John Locke's writings laid a significant foundation for constitutional and legal protection for property rights. Locke persuasively expounded the principle of natural rights. We enjoy these rights in our natural state, independent of any positive grant or recognition by a government. These rights are enumerated in the familiar text of the Declaration of Independence—life, liberty, and the pursuit of happiness—and the Constitution (life, liberty, and property). Men enjoy these rights because they are "given by their Creator."

"Life" and "liberty" obviously relate to the integrity of the human body and freedom. However, Locke was "the first philosopher to mention ownership of the human body,"[41] thereby incorporating the concept of a property interest in one's person. In his Second Treatise of Civil Government, Locke wrote:

> Though the earth and all inferior creatures be common to all men, yet *every man has a property in his own person; this nobody has any right to but himself*. The labour of his body and the work of his hands, we may say, are properly his. For this labour being the unquestionable property of the labourer, no man but he can a right to what that is once joined to....[42]

This property or ownership includes both the right to the fruit of his labors, as well as the right not to have his property (both his body and what he produces) infringed upon by others. Locke's assertions have led many Americans to claim ownership of their body and its parts, as well as property rights in frozen embryos.[43] No continental Enlightenment philosopher shared the same expansive view of property.

Locke would have rejected contemporary "propertization" of the body. He believed that life is a gift from God and that God is the source of man's natural liberty. Man does not own himself; God does. Life is "the property of God, because God is the maker of man."[44] He may not commit suicide, or enslave or sell himself to another:

> [A] man not having the power of his own life cannot by compact or his own consent enslave himself to any one, nor put himself under the absolute

> arbitrary power of another to take away his life when he pleases. Nobody can give more power than he has himself; and he that cannot take away his own life cannot give another power over it.[45]

Locke's philosophy underlies the constitutional support for patenting one's inventions, the creative fruit of labor. However, Locke could not have contemplated the possibility of innovation including the exclusive rights to decoded DNA in a blood sample. A proper application of his principle would prohibit the sale of any part of the body that would cost that person's life (since one does not have power over his own life). Nor would the non-fatal sale of a part be permissible. Life may not be sold; it may be given. Cadaveric organ donation is ethically consistent. One is not selling a gift from God, but is giving that gift of life, in essence, to another.

The U.S. Supreme Court has abandoned the Lockean vision of the integrity of the person and life as a gift. The Court interpreted the Fourteenth Amendment's guarantee against undue deprivation of "liberty" to include privacy rights. Shocking at the time, the Court delineated a bloated concept of individual autonomy that extends not only to one's own body but also to the body of another. By granting a woman the constitutional power to choose abortion, it inescapably granted her power over the body and life of her unborn child. How? The Court concluded that the unborn child is not a constitutional "person," and thereby outside the protection of the Fourteenth Amendment. The Court thereby chiseled a gaping fracture in the wholeness of the human being. By separating legal personhood from physical and other attributes, the Court dictated that membership in the human family is not inherited; it must be achieved, first by living long enough to be born. The inevitable consequence is that some human beings are worth less than others. Bioethicists are quite willing to redefine "human being," driving a logical wedge through the fissure the Court opened.

A Christian Perspective on Human Life and the Human Genome

Imago Dei

The public discussion on gene patenting has paid modest attention to its impact on our understanding of what it means to be a "human being." We do so at our peril. The relentless, virtually unstoppable urge to patent all forms of human genetic information poses grave danger for the future of the human family.

The faith community that received the Old Testament is heir to the biblical record account of the creation of man:

> Then God said, "Let Us make man in Our image, according to Our likeness....And God created man in His own image, in the image of God He created him; male and female He created them. (Gen. 1:26-27)

The 'image of God,' or *imago Dei*, is the "key to the Christian understanding of human nature."[46] Humanity—every single human being—bears that image. It is profoundly significant because our image reflects in some way the nature of God. The value of being a human is not because it is our species, but because we are *God's* species. God bestowed this identity on only one species, *Homo sapiens*. All other species, plant and animal alike, are subordinate to man; God instructed

man to rule "over every living thing that moves on the earth" (Gen. 1:29). We, of all creation, are image-bearers. None of us is a perfect reflection. Even so, being created in God's image bestows each of us with infinite dignity and worth.

God did not leave us guessing about the infinite perfection of His nature. First, He breathed His life into our flesh, drawing us up into Himself. Then, He descended unto us, encasing His deity in a body of blood, bones, and beating heart. The incarnation is God's seal of approval on the *imago Dei*. The Father gave us a perfect image of Himself. "And He [Jesus] is the *image* of the invisible God, the first-born of all creation" (Col. 1:15; emphasis supplied). "And He [God's Son] is the radiance of His glory and the *exact representation* of His nature, and upholds all things by the word of His power" (Heb. 1:3; emphasis supplied).

The mystery of the Incarnation and the *imago Dei* is that God made us in His image; then He became one of us so that we could become like Him. In Jesus, we can see just Who it is that we are reflecting. Jesus' incarnation authenticates the ultimate significance of *Homo sapiens*. God's Son was not born as a cat, a carrot, or a chimera. He came as a baby, a child of a human mother. What God dignified with His very being is of infinite dignity indeed. Every human being bears that priceless worth.

The Human Person: Being or Body?

The Sum of Our Parts or Indivisible?

The Incarnation and the reality of the *imago Dei* illuminate the nature of the human being. Is a human *being* distinct from his or her human *body*? When God made man in His image, man was in a body. But, God was not known in corporeal form. Therefore, as image, man must have reflected something other, or in addition to, mere body. Man's essence included spirit and soul. He was not a fractured being, but an integrated, indivisible whole. As Leon Kass says, "The body may be more than stuff, but the man seems to be more than his body."[47]

Kass was concerned about the visible cutting, transplanting, implanting, and reshaping of the body (and I am not here arguing the ethics of that). But this is dwarfed by the unraveling and splicing at the cellular and sub-cellular level. The massive international race to map and sequence the human genome, the insertion of portions of human genes into laboratory animals, the teasing out of stem cell lines from thawed embryos—all these biomedical innovations are dividing man into smaller and smaller parts.

Fracturing the Image

The relentless effort to dissect, distill, recreate, and improve upon "man" has eroded moral, social, and legal acceptance of all human beings. Professor Peter Singer advocates animal liberation, and claims that a preference for humans is "speciesism." Being born to human parents with the genetic identity of *Homo sapiens* is insufficient for a newborn to remain in the human family. Singer argues that the infant must meet certain standards (both physical and mental); if not, her parents have both the right and implicit duty to terminate her life. The inexorable outcome of this ethic is exclusive. Either by definition or categorization, more and more people are pushed to the margins of the human

family; eventually—and at an ever-increasing rate—they fall off.[48] Not surprisingly, the definition of who is "human" ends up remarkably similar to the characteristics of the bioethicist creating the definition. Singer, a clever man, favors advanced intellectual capacities, disdaining genetic identity as morally irrelevant.[49] "Made in the image of God" has been exchanged for "made in my own image."

Patenting unavoidably divides the human being into bodily parts, with potential profit for each gene and fragment. Patent attorney Stephen Sherry points out that patents are "by definition a utilitarian legal construct with an economic purpose."[50] If a thing may be patented, its inevitable consequence is commodification. Once a thing has commercial value, it loses intrinsic value. The human genome is treated as a commodity with vast economic potential. Drugs and diagnostics will be developed to capture an ever-growing market of consumers paying to predict, diagnose, treat, or cure an array of diseases.

The development of these products does not depend exclusively on decoding genes and fragments. Drugs must be tested, preferably in animals that react just as the human body would. Human genes have been inserted into mice, for example, to test cancer treatments. How many mouse genes can be replaced with human genes before the mouse is no longer a mouse? "Transgenic" animals have been legally recognized. What about "transgenic" humans?

The law has no workable definition of "human being." Sherry points out the dangers in this confusion (or deconstruction) of what it means to be human:

> Consistent with the current law, a genetically altered human being would not be considered a human being. The patent law has already recognized that a genetically altered mouse is distinct from a naturally occurring, non-altered mouse. That same distinction may be sufficient for opening the door to the granting of a patent on genetically altered human life.[51]

Sherry may be overstating the case, but he is not alone. Another critic raised the specter of a "near-human" genetically engineered to have no brain, but to be a supply for organs, a subject for testing pharmaceuticals and surgical techniques, and even a surrogate womb.[52] The attempt has already been made. The European patent office admitted it mistakenly granted patent number 695351 to Edinburgh University for a process which could be used to create "transgenics"—genetically altered humans.[53]

Thus, our American legal system has chosen the pragmatic way. We have used a distorted notion of property rights in the human body and ignored our responsibility to the human community. For the sake of an admitted good—improving health and eradicating disease—we are willing to divide the human being into smaller and smaller parts, to be parceled out to those who can afford the fee. For the sake of making some members of the human family more comfortable, we are willing to manipulate and exclude others. God has given us a mirror of what and Whose we are created to be. Instead, we have chosen to see man in a cheap, chipping mirror, fractured into a hundred distortions. The erosion of the *imago Dei* has commercialized man. The gift of unique human life has become a commodity.

Addendum

The issue of gene patenting could be resolved in an ethically acceptable way. The core issue is the ownership of the actual genetic information, the gene itself. If no entity, individual or corporation, is given ownership of genetic information, ethical objections may be met. As outlined below, the common genetic heritage could be held in trust, as a gift to be carefully stewarded.

Following are three possible resolutions.

1. Issue a permanent moratorium on all patenting of DNA. This is presently an aspiration, rather than practical objective, as thousands of sequences have already been patented. It is uncertain how this would affect the legal status of existing patents or pending applications.

2. Petition the International Court of Justice to make a ruling on the ethics and morality of patenting the human gene. Of course, this runs the risk of an adverse ruling.

3. Establish a Human Genome Trust. No individual, university, or company could hold a patent on any gene or gene fragment. The genes would be held in trust and be licensed to university research centers or biogenetics companies.[54] This addresses the ethical concerns of ownership, because there would be no "ownership" per se. A trust establishes the concept that the genes are held on behalf of, and for the benefit of, the entire human community. E&M

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4 "Whose Genome Is Being Sequenced in the Human Genome Project?" (accessed 26 September 2001); available from http://www.wellcome.ac.uk/en/genome/hgpwho.htm; Internet.

5 U.S. Constitution, Article 1, §8.

6 Barbara Looney, "Should Genes Be Patented? The Gene Patenting Controversy: Legal, Ethical, and Policy Foundations of an International Agreement," *Law & Policy in International Business* 26 (1994): 251.

7 The ownership and use of human tissue presents legal and ethical issues. The most important case is Moore v. Regents of the University of California, 793 P.2d 479 (Cal. 1990), cert. denied, 499 U.S. 936 (1991). Mr. Moore sued his physician and others for a share of the rather handsome profits they made from a cell line derived from Mr. Moore's spleen. Moore's charge of conversion (a property claim) was rejected.

8 Mary Ann Glendon, *Rights Talk: The Impoverishment of Political Discourse*, (New York: The Free Press, 1991), 87.

9 447 U.S. 330 (1980).

10 Stephen Sherry, "The Incentive of Patents," in *Genetic Ethics: Do the Ends Justify the Genes?* ed. John F. Kilner, Rebecca D. Pentz, and Frank E. Young (Grand Rapids, MI: William B. Eerdmans Publishing Co., 1997), 116.

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20 "HUGO Statement on Patenting Issues Related to Early Release of Raw Sequence Data" (accessed 25 September 2001); available from http://www.gene.ucl.ac.uk/hugo/ip1997.htm; Internet.

21 Explanatory Report to the Convention for the Protection of the Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Directorate of Legal Affairs (Strasbourg, May 1997) DIR/JUR (97)5, para. 7.

22 *Ibid.*, para. 14.

23 The document states that the prohibition on financial gain does not refer to "such products as hair and nails, which are discarded tissues, and the sale of which is not an affront to human dignity." *Ibid.*, para. 133.

24 *Ibid.* para. 134. Cites omitted, quote marks in original.

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26 "COE parliamentarians want ban on human gene patents," *Ibid.*

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28 *Universal Declaration on the Human Genome and Human Rights*, 1997, Article 4 (accessed 19 September 2001); available at http://www.unesco.org/human_rights/hrbc.htm; Internet.

29 *Ibid.*, Article 19(a)(iii).

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32 "A Genome Available to All" (accessed 26 September 2001); available from http://www.wellcome.ac.uk/en/hgphisava.htm; Internet.

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the patent on the genetic mutation that causes the disease. "Science Policy: On the Patenting of Knowledge," *Science Week* [journal online] (accessed 19 September 2001); available at http://scienceweek.com/2000/sw000915.txt; Internet.

37 "Human being" is not even mentioned. The argument is that "Patent holders are being allowed to patent a part of nature—a basic constituent of life; this allows one organism to own all or part of another organism." "The Human Genome Project: Genetics and Patenting" (accessed 26 September 2001); available from http://www.ornl.gov/hgmis/elsi/patents.html; Internet.

38 This has already happened. In April 2000, the University of Rochester was granted a patent on the Cox-2 gene. It immediately sued G.D. Searle, which markets Celebrex, a highly lucrative ($1.5 billion in sales its first year) pain-killer. The university's patent merely identified the gene and described the general idea of using a drug that blocks Cox-2 to alleviate pain. "Science Policy: On the Patenting of Knowledge," *Science Week* [journal online] (accessed 19 September 2001); available at http://scienceweek.com/2000/sw000915.txt; Internet.

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42 John Locke, *Two Treatises of Government* (New York: Hafner Publishing Co., 1947): §27, 34 (emphasis supplied).

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47 Leon Kass, "Thinking About the Body," *The Hastings Center Report* (February 1985): 21.

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50 Sherry, at 121.

51 Stephen F. Sherry, "The Incentive of Patents," in *Genetic Ethics: Do the Ends Justify the Genes?* ed. John F. Kilner, Rebecca D. Pentz, and Frank E. Young (Grand Rapids, MI: William B. Eerdmans Publishing Co., 1997), 119.

52 *Ibid.*

53 James Meek, "Mix-up Over Human Gene Patent," *The Guardian*, 22 February 2000 [journal online] (accessed 25 September 2001); available from http://www.guardian.co.uk/Print/0,3858,3966252,00.html; Internet.

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Withholding and Withdrawing Neonatal Therapy: An Alternative Glance

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Neonatal care has greatly improved in recent years and it has become possible for very low birth weight or asphyxiated newborns to survive. Until a few years ago, many of these babies inevitably died early. Now we can prolong their life, but with handicaps in many cases. A recent debate centred on whether it is ethical to withhold or withdraw therapy, sometimes in an active way, allowing newborns, presumed unable to lead a normal life, to die. [1,2,3,4,5,6]

Attitudes on this ethical question in neonatal intensive care units of four Western countries,[7] France,[8] The Netherlands,[9] and other states[10] have been published. Guidelines have been proposed for withholding or withdrawing therapy from high-risk newborns,[11] actively hastening death,[12,13] suspending parenteral feeding,[14,15] and seeking parents' advice.[12,10,16] To justify this practice, it has been proposed that newborns need not be regarded as persons[14] and that such intervention is in the interest of the baby, otherwise unable to lead a normal life,[6] or in the interests of parents, unable to accept a handicapped child[7] as broadly defined to consider physical harm as well as social, psychological, and or financial harm to related third parties: *"there are firm ethical norms that should serve as the basis for coherent and consistent perinatal policy. These include 1) a grant of full moral and legal status to the newborn but only partial moral and legal status to the late-term fetus, 2) a general prohibition against feticide unless to save the life of the mother or prevent the birth of a fetus facing certain death or severe pain and suffering and 3) a general endorsement of neonaticide subject to a parent's assessment of the newborn's interest."*[7]

I believe another view that has not received much space in the literature, but which in some countries[17] motivates reluctance to withhold therapy not to dying babies, but also to babies with a high risk of brain damage, can be taken.

Realism: The Problem of Brain Damage

Brain damage, and how severe it is, become clear as time passes.[8] In most cases it is not possible to obtain a certain prognosis at birth. Echographyc periventricular hyperechogenicity with EEG evidence of positive Rolandic spikes (considered a highly sensitive index of cerebral palsy) in a newborn indicates a risk, not a certainty. However, the same criterion is often used to suspend therapy.

A recent study[18] compared the results of two different attitudes: that of "interventist" NICUs where all sick children are actively resuscitated and that of "selective" NICUs where babies to be resuscitated are selected on the basis of risk of brain damage. There was no statistically significant difference in the percentage of healthy and handicapped babies in the two groups. In other words,

Ethics & Medicine, 19:2 (2003):99-102.

selecting who should live reduced the number of both handicapped and healthy survivors. This sacrifice can hardly be justified. Prudence is always advisable: before acting, one should have a clear aim and avoid harming third parties.

Rationality: All Factors Considered

a) It is a widespread principle that parents should always be consulted,[12,14,16,19] but in practice this does not happen.[4,18,19] Consulting parents means giving them an almost unbearable weight which can lead to a personal or family crisis, possibly worse than raising a handicapped child. Not consulting them is paternalism, which is unacceptable in Western society. Although our aim is parents' well-being, proposing their offspring's survival as their own or doctors' choice risks creating the opposite effect, similar to a depressive syndrome.[20,21]

b) Parents' reaction depends on the way the news is disclosed.

In Western society, mishaps are viewed as definitive and unforeseen events are unacceptable: both are associated with the idea of death. Western women *"cannot accept the possibility that their pregnancy may end with the birth of a baby whose condition may make normal motherhood impossible."*[22] When a birth anomaly is announced, their world comes crashing down, as if "drama" and "tragedy" were the same thing. They do not understand that tragedy is a one-way road in darkness, whereas drama is suffering, but not the end of the world. Parents can be helped to see this difference by the manner in which the news is communicated by caregivers, by the way the physician looks at the baby. There are guidelines on how to break the news of birth abnormalities. All insist that the newborn must be present,[23] because parents' acceptance of the baby is shaped by the physician's attitude and how the parents perceive that. *"If the physician is incapable of elaborating positive representations of the baby, the risk is to identify with the parents, to take extreme positions from scientific detachment to acritical empathy, from rejection to over-protectiveness."*[24] Caregivers who fail to highlight the potentialities of the newborn, lose their supportive role,[25] because despite handicaps, the newborn has moods and humour and these must be supported and encouraged from the outset.[26]

How Much Does It Concern the Doctor?

A flaw of modern Western medicine is that it has increasingly become a mere rendering of services. Once medicine could not avoid the idea of solidarity, which sprang from recognition of physicians' and patients' limits. There has been a shift from the ethics of solidarity in facing troubles to an ethic of escape and fear, escape from relationship and fear of losing the mask that everybody creates when faces someone's pain, withholding therapy in a sick baby is an easy shortcut: maybe too easy to be effective. The feeling of anguish experienced by doctors withholding life support (*"Anguish invades us and leaves its mark. We baptise him and then we kill him"; "On days of withholding care I don't feel good: they are heavy, they are not like other days"*[8]) arises from this point. But one cannot always escape from the unknown, i.e., what he cannot manage: *"Modern western medicine is 'scientific', in the sense that it presumes to control and dominate*

things. But death is unavoidable."[27] Thus withholding or withdrawing life supportive care on the basis of fear of a future handicap is also ominous for caregivers. It is a negation of the desire and wonder of existence, however imperfect; it means negation of the wonder and desire of our own existence, however flawed: *"The caregiver's dialectic is identical to the patient's dialectic. To what extent is the caregiver able to accept a person who is suffering, especially where he is suffering?"*[28] The caregiver here falls prey to sentimentalism: *"He who participates in another's pain so deeply as to be crushed by it is capable of com-passion but lacks force. He cannot care for the other, because he cannot give him com-fort. . . . This temptation grows in the field of loneliness."*[29] We cannot forget that eugenic selection is often masked by compassion.

Conclusion

It is well worn practice to withhold or withdraw therapy from seriously ill neonates. I propose another approach that I call the "ethics of wonder": *"We suggest that one source of both moral and intellectual renaissance for the contemporary physician lies in recapturing a sense of wonder for the human body, its place in the natural realm, and its miraculous functioning as the fount, and the medium, of embodied human experience."*[30] Let us not exclude the possibility of diagnostic errors, let us not identify drama with tragedy a priori, let us stop and ask the baby, our patient, "Who are you?": our patient will always be more than the sum of his parts and more than the suffering that oppresses him. E&M

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"Do Everything!"
Encountering "Futility" In Medical Practice

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Case Report

Baby S is a former 23-week 610-gram infant now two weeks old who is currently hospitalized in the Intensive Care Nursery. The infant's course has been tumultuous since his birth and he has experienced several complications. The initial cranial ultrasound revealed bilateral Grade IV periventricular-intraventricular hemorrhages and serial follow-up has suggested early post-hemorrhagic hydrocephalus. Despite exogenous surfactant, corticosteroid therapy, and increasing conventional ventilator support, the infant's respiratory status is worsening, and the initiation of high frequency ventilator support is under consideration. Inotropic blood pressure support continues for hypotension. Necrotizing enterocolitis with bowel perforation was diagnosed on hospital day five and at exploratory laparotomy, a significant amount of small intestine was removed. The anterior portion of the left foot is gangrenous, likely a result of an umbilical arterial catheter-related embolic event; the catheter has been removed, and venous access is tenuous as well. A recent blood culture revealed Candida albicans, and parenteral Amphotericin therapy continues. In view of the myriad complications and likely suffering experienced by the infant, the attending neonatologist approaches the parents to discuss the "futility" of continued aggressive support. The parents, devout Christians, are hoping for miraculous healing and tearfully insist that the medical staff "do everything" to save the infant's life.

Introduction

The goals of medicine have traditionally addressed beneficence and non-maleficence, i.e., to promote the patient's welfare, or at least to cause no harm to the patient. Throughout most of medicine's history, little benefit could be offered to the sick and dying patient. Contemporary medicine, however, is a two-edged sword: its powerful technology can be an agent in great healing or in great harm. The dark side of modern medicine can prolong the dying process, adversely impact one's quality of life and unjustly squander precious resources.

With the recent advent of the legal and ethical primacy of patient autonomy, patients have become emboldened not only to refuse unwanted medical interventions but also to demand potentially useless and harmful therapy. Often, physicians have unilaterally refused to provide such therapy on the basis of "medical futility," the definition of which has proven elusive.

Issues of futility often arise in clinical medicine. Typically, patients or their surrogates request therapies that are viewed by their physicians as non-beneficial. Less often, physicians propose therapies that are viewed by patients or

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families as futile and intrusive. Conflict is inevitable in such circumstances and resolution is often not straightforward. "Futility" touches on values, concepts of benefit, language and communication, surrogacy and family dynamics, conflicts of interest and secondary gain, grief and guilt, trust and religious beliefs.

"Medical futility" is an enormous topic and one which involves a variety of medical, ethical, legal, sociological, cultural, religious, and economic issues: at least one textbook[1] and perhaps several hundred articles[2] have been written to address these aspects of futility. The sheer vastness of the recent body of work regarding this topic precludes recapitulation in this very brief paper. However, in assessing futility from a Christian perspective, it may be worthwhile to examine several salient features. First, the history and current status of the tension between physician paternalism and patient autonomy will be reviewed. Next, the difficulties inherent in attempting to define "futility" will be addressed. The question, "Must we do everything?" will be viewed from a variety of different perspectives. Finally, suggestions for a practical clinical approach to the problem of futility will be offered.

Physician Paternalism Versus Patient Autonomy

As suggested above, the "futility" controversy highlights the tension between physician paternalism and patient autonomy. Pellegrino, in his excellent essay, "The Metamorphosis of Medical Ethics: a 30-year Retrospective,"[3] masterfully summarizes the evolution from physician primacy in medical decision-making to that of patients, who are empowered by autonomy, American individualism and the concept of informed consent. The ensuing power struggle has fomented a backlash by the American medical establishment, the so-called "Futility Movement."

The Hippocratic tradition of medicine, which stood in the West for 2500 years, was fundamentally paternalistic.[4] The physician held exclusive authority for decisions regarding patients' health care. The mid to late twentieth century witnessed the Nuremberg War Crimes Tribunal and the Tuskegee syphilis study (both raising the issue of medical experimentation without consent), the ascendancy of individual rights (including women's rights and minority rights), the mistrust of authority (Vietnam, Watergate), the rise and bureauracratization of third parties in medical care, and court decisions supporting the rights of patients to decline burdensome medical therapies (e.g., *Cruzan v. Director*, 1990). As patient rights to autonomous self-determination became preeminent, the authority to make medical decisions shifted from physicians to patients or their surrogates. Of late, patients have been emboldened to demand therapy that, at least in the view of their physicians, affords little benefit. By labeling such therapy "futile," physician authority regains ground lost to patient autonomy, because "moral reasoning in ancient and modern medical ethics...public policy...and case law"[5] justifies the concept that physicians are under no obligation to discuss, much less provide futile therapies. Additionally, in recalling Ramsey (*The Patient as Person*, New York: Yale University Press, 1970),[6] Guroian suggests that discerning the irreversibility of the dying process and whether or not medical treatment is futile lies in the purview of traditional medicine. Guroian notes, "God entrusts determinations of whether we are biologically

dying to our physicians, whether they themselves trust in Him or not."[7] Likewise, interpretations of Jewish law suggest that the judgment of the physician, guided by the best knowledge available, determines when life-sustaining treatment should be used.[8]

Thus, given these influential attitudes, determination by the physician that a requested therapy is "futile" can be used as a trump, irrespective of the physician's true motives, to override the patient's autonomy and refuse to provide it. There is significant danger here, because physicians can experience substantial conflicts of interest in determining the inevitability of death and the "futility" of continued support. The physician's emotional pain in response to the patient's condition might be assuaged by the patient's death. In a capitated reimbursement system, the physician or the hospital might suffer financially if care is not limited for a chronically ill patient who is maintained long term by costly intensive care. Similarly, chronically ill patients occupy bed space and divert available resources (equipment, medication, time, and effort of the medical and ancillary staff) from other needy patients. Contrariwise, physician ego ("Nobody dies on my shift"), scientific curiosity, or concerns about the adverse impact the death of a patient might have on research data or individual physician or institutional medical or surgical statistics may unduly cloud judgment and subject patients to inappropriate therapy that prolongs dying.

However, like physicians, surrogates and families are not immune from conflicts of interest. The intense emotional suffering of families as they witness their loved one struggle with illness, or their fear of severe burdens (family or marital stresses) in the event the patient survives, may also be eased by the patient's demise. Once third party payments are exhausted, family savings might begin to disappear, creating the possibility of additional burdens as well. Alternatively, there may be opportunities for secondary gain for the family if the patient's dying is prolonged: perhaps Social Security payments will continue, or tenuous personal relationships will be sustained.

It is of note that recent judicial rulings have generally supported family decision-making and have not looked kindly on unilateral decisions by physicians. Court decisions such as Baby K[9] and Wanglie[10] have supported families who request therapies labeled as "futile" by physicians. In fact, in only one case (Gilgunn v. Mass Gen Hosp) has a judicial proceeding (a jury in this instance) found in favor of physician efforts to terminate therapy against the wishes of the family.[11]

As these issues suggest, the tensions created by authority disputes, "futility" judgments, and conflicts of interest between physician and patient or family are multifaceted and add even more complexity to the already difficult challenge of caring for dying patients.

Futility: A Useful Term?

Futility connotes the idea that the proposed therapy is wasteful, pointless, and ineffective. Furthermore, futile therapy is unlikely to achieve the intended goal or to be of benefit. However, "wasteful," "pointless," "ineffective," "intended goal," and "benefit" are subjective and relative terms that are context-dependent and

value-laden. As a result, there has been a concerted effort by many ethicists to create a clinically useful taxonomy of futility. Schneiderman and colleagues[12] address the notion of futility at its "quantitative and qualitative roots." "Quantitative futility" suggests that futility, representing the unlikely chance a benefit will be realized, can be defined at a certain statistical threshold. In Schneiderman's view, a medical therapy is futile if it was unsuccessful in the last one hundred cases. "Qualitative futility," Schneiderman asserts, is identified when the quality of outcome for the proposed therapy is poor.

However, both definitions raise considerable difficulties. The quantitative approach appears to ignore the inherent uncertainty in medicine's ability to prognosticate disease course and outcome. These predictions are grounded in studies of diseased populations; although such predictions may have some measure of empiric validity in similar populations (allowing for a statistical margin of error), they are notoriously inaccurate when they are applied to the individual patient, who may respond to the proposed therapy in a manner contrary to the population mean. Furthermore, Norman Fost[13] suggests that any statistical threshold is too arbitrary to be meaningful, since thresholds not only fail to account for cost-benefit of the proposed therapy (which is variable and dependent on disease process and prevalence in the community) but also neglect the observation that simply because the therapy was ineffective in the last one hundred patients does not necessarily imply that similar therapy will be ineffective in the next one hundred,[14] particularly as experience broadens and more representative cases are included in the sample.

"Qualitative futility" also fails at the definitional level in that it does not escape the subjectivity or relative valuation characteristic of the broader term "futility." Although a physician may regard a therapy that prolongs life in extreme debilitation for hours or a few days "qualitatively futile," the patient, who may be awaiting the arrival of long-estranged relatives from afar, may find such intervention of immeasurable benefit.

Others[15] have attempted to define a continuum of futility: candidate treatments to be considered futile are those that (1) have no physiologic rationale (e.g., cardiopulmonary resuscitation in a decapitated patient), (2) offer an extremely unlikely chance at benefit, (3) offer benefits but are very costly, (4) offer only questionable or controversial benefits. These authors contend that only (1) represents true futility and that the remainder of the continuum represents "inappropriate, hence inadvisable" therapies. However, this approach proves to be of little help clinically, since "inappropriate" and "inadvisable" may be in the eye of the beholder.

In addition to Schneiderman's quantitative approach, other empirical means have been utilized to assess futility.[16] Severity of illness scoring systems that predict mortalities as a function of physiologic measurements (e.g., APACHE) reflect the populations on which they are based. As with Schneiderman's statistical threshold, critics charge that any scoring system developed from a particular population "can provide relevant, but not necessarily determinative, information for decision-making"[17] in the case of the individual patient. Additionally, attempts to identify thresholds of futility by surveying physicians' predictions of survival in a variety of conditions have been frustrated by a wide

range of responses and lack of consensus.

Fost, recalling Kass, suggests that "technology cannot do moral work,"[18] i.e., the applications we ascribe to technology cannot define our duty to treat. Fost likens the futility debate to a former one, that of the now rejected 16th century Roman Catholic doctrine of "extraordinary" and "ordinary" therapy. According to this doctrine, a physician had no duty to use a therapy that met the definition of "extraordinary." However, these terms are as value-laden, context-dependent, historically intertwined, and as ephemeral as futility, and their use accomplishes nothing beyond obscuring the real issues at hand.

The foregoing appears to recognize a truism: real instances of futility are rare, and like pornography, although difficult to define, "we certainly know it when we see it."[19] A broader concept of futility promotes injustice, devalues physician-patient communication, diminishes opportunities for conversation, degrades patient autonomy, and can be used as a proxy for issues of "cost, convenience, or distribution of medical resources"[20] (a particularly dangerous attribute in capitated managed care). Therefore, we must reject and abandon "futility" (as used in common parlance) as a clinically useful term.

However, a nominalist rejection of terminology does not negate the fact that one party may regard medical treatment valued by another as valueless. The American Medical Association's Education for Physicians in End-of-Life Care (the EPEC Project)[21] has done a great service for clinical medicine by framing "futility" in a new way. "Futility" might be useful after all, since its unilateral utterance by physicians or patients and families might be seen as a red flag, indicating the need to address and resolve underlying conflict. The EPEC Project identifies several areas of psychosocial concern. Commonly, conflict arises because the patient or family misunderstands the diagnosis or prognosis. Often the physician is surprised to learn that the patient and family have never been truly informed or have been given conflicting information. Perhaps a well-meaning physician provided false hope in the past. Denial may play a significant role in the family's refusal to hear bad news. In attempting to communicate information to a patient or family, effectiveness is compromised by the hearers' inadequate cognitive ability or inability to understand, either because medical jargon has obscured the message or because English is not the primary language and the services of a professional medical translator have not been employed. Conflict may also arise because the physician does not recognize the family's emotional distress (including anticipatory grief and guilt) or sleep deprivation brought on by long distance travel prior to arrival at the patient's bedside. Additionally, the family may mistrust the physician, perhaps as the result of conflict with previous providers. Apparently conflicted surrogate decision-makers may have hidden agendas: as noted above, they may stand to gain depending on the patient's course. Finally, the physician and family members may have bona fide value conflicts involving goals or perceived benefits of therapy. These values may be deeply held on a cultural or religious basis and, given the heterogeneity of society, may be completely opaque to the physician. Thus, the EPEC Project suggests that unilateral "futility talk" should signify the potential existence of conflict and the need for continued explanation, conversation, negotiation, and compromise.

Must We "Do Everything"?

The Hippocratic Perspective

Nigel Cameron in his book *The New Medicine*[22] reviews the moral commitments of the Hippocratic physician. Cameron notes that the Hippocratic Oath emphasizes healing with the dual obligations of philanthropy and respect for the sanctity of life. However, despite this emphasis on healing and the sacredness of life, nowhere in the Hippocratic corpus is the physician required to prolong the dying process by employing fruitless medical intervention.[23] Moreover, it is improper for the Hippocratic physician to pursue therapy where there is no hope or when burdens of therapies exceed benefits.[24] The obligation of the Hippocratic physician to any patient is to heal if possible, or if healing is not possible, at least to do no harm. When faced with a dying patient in the grasp of an irreversible, terminal illness, the physician may neither hasten death nor may he apply therapy that not only would fail to heal the patient but also would pose excessive burdens. A maxim to preserve life at all costs despite burdens imposed ultimately interferes with the covenantal relationship between the Hippocratic physician and his patient.

Jewish Perspectives

Dorff has reviewed the traditional Jewish views of death and dying.[25] Because God has the right to destroy his own property, Judaism permits one to pray to God to allow death to come. According to Dorff, all Jewish scholars agree that nature can be allowed to take its course once the patient becomes moribund (goses). Precisely when this state occurs is subject to controversy. A rabbinic ruling approved by the Conservative Movement's Committee on Jewish Law and Standards describes goses as "a person who is 'like a flickering candle' so that he or she may not be moved for fear of inducing death," i.e., when death is hours away. Others believe goses applies to persons up to a year or more prior to death. However, terefah, Dorff asserts, is the appropriate Jewish legal term for those with terminal, incurable disease; the option to forego life-sustaining treatment is reasonable once this diagnosis has been made.

Christian Perspectives

Physical pain and death were absent from God's original creation (which was "very good," Genesis 1:31) but arose as a result of man's free will choice of disobedience to and separation from God (Genesis 2:17; Romans 5:12). Thus, death is a manifestation of man's corruption and an unnatural evil that creates dread, divides communities, and evokes grieving. Even Jesus wept at the death of his friend, Lazarus (John 11:35). It is an error to welcome death as an end to suffering, because suffering can continue beyond physical death (Luke 16:19–31); furthermore, some suffering may be used by God for redemptive purposes in this life (Romans 8:28, 35–39; James 1:2–3, 5:10–11). However, Christians need not fear death as personal annihilation. Christians recognize man's finitude and the mortal nature of his falleness; i.e., death comes to all and is thus ultimately irresistible. Christ has defeated death and has removed its sting (1 Corinthians 15:54–55) by promising life to all who believe in him (John 11:25–26; 1 Corinthians 15:20–23). Therefore, there is no Christian obligation to

recklessly combat death by enduring non-beneficial and harmful therapy, since the battle has already been won. Because the timing of our deaths belongs to God, we must be able to accept death without ever intending it when we could live otherwise.

Since miracles are amply demonstrated in the Bible and are reported throughout history, some Christians may hope for miraculous healing. However, miracles are a matter of divine prerogative and by their very nature occur rarely and unpredictably. Thus, Christians may hope for the best but, in the event miraculous healing does not occur, must prepare for the worst.[26]

Modern medicine has a Janus-like quality: its power contributes either to healing or to harm. Grounded in the sanctity of life specified by the imago Dei and guided by love of other, Christians must resist the use of medicine to abusively prolong the dying process. A vitalism insisting that every human life must be saved no matter what the cost risks this abuse. Guroian[27] observes that both secular and religious vitalists insist on aggressive medical support in the face of impending death: the former demands therapy on the basis of an existential imperative and the latter on the basis of the "sanctity of life." However, Guroian believes religious vitalists fail to make a key distinction between euthanasia and "letting die."[28] Like secular vitalists, religious vitalists devalue the material world because they believe God is absent from it. This way of thinking verges on Manicheism and finds the demonic in sickness and death. By locating true meaning only in the spiritual world, the "there and then," these vitalists fail to recognize God's will for the dying and his illumination of human reasoning in the "here and now" determinations of when the process of dying has become irreversible. Guroian cites Romans 8:38–39 in support of the idea that God does not abandon us in death. Furthermore, he asserts that biblical theism supports the role of human judgment in assessing whether or not death is imminent and whether or not our moral obligation to the patient should become "care" rather than "cure."

The Christian Medical and Dental Associations' Ethics Commission[29] echoes these sentiments. Love, care, and compassion should characterize Christian physicians in all circumstances. God is the source of healing and occasionally uses physicians to promote cure. However, cure is not always possible: we are called to recognize these situations and, in partnership with the patient and family, transition from an emphasis on "cure" to one of "care."

Likewise, Hauerwas finds the potential for vitalism in modern medicine's ethic of curing, not caring. In contrast to Guroian, however, Hauerwas believes the fundamental problem is a lack of shared narrative:

> "Aggressive medicine in the face of terminal illness can be the result of pressure exerted by the patient's family, but it can also be the result our society's inability to place death in a morally intelligible narrative...our lives are fundamentally constituted by chronicity rather than narrative." [30]

The development of narrative depends, Hauerwas asserts, on our ability to assign meaning to our suffering and death. If we believe ourselves to be the children of a gracious God, we are given a shared narrative framework that makes sense of our lives and allows our communities to bear the brunt of our

sufferings. Otherwise, we must create the narrative ourselves. Particularly in the case of children who have not yet had time to "acquire a narrative,"[31] medicine's technological imperative can be applied ruthlessly to forestall the inevitable, thus "buying time" to create a narrative for them.

Some might argue that patients should be given free reign to choose or reject any therapy, based on the principle of autonomy. However, sick people are not autonomous; by definition, their lives and choices are limited by their disease processes. Even in health, a Christian must recall that his body is not his own.[32] Furthermore, Christians are part of the body of Christ (1 Corinthians 12:12–31) in which individual autonomy is subservient to the community and to God. Individual decisions for care must be made in recognition of these realities.

Christian physicians are stewards of health care knowledge and resources.[33] It is an abrogation of the physician's stewardship of resources and duty to patients if physicians stand idly by as their patients unilaterally choose unwisely. On the other hand, decisions regarding resource allocation should not be made by physicians at the bedside of an individual patient under the guise of "futility," but are more properly the domain of public policy.[34]

Stewart *et al*[35] address the difficulty inherent in defining appropriate care for the debilitated by proposing a sliding scale representing the "care-cure" continuum appropriate to the patient's clinical condition and to the demands of Christian morality. The permanently unconscious, imminently dying patient should receive "respect care" (e.g., keeping the body clean and the mouth moist). The permanently unconscious patient who is not imminently dying should receive at least respect care; "symptom care" of related medical problems can be offered at the request of the patient's surrogate or in response to the patient's advance directives. Conscious patients with irreversible conditions who are imminently dying require both respect care and "comfort care"; higher levels of care may be excessively burdensome. Those conscious patients with irreversible conditions who are not imminently dying should receive symptom care in addition to respect and comfort care. Finally, reversible conditions require "curative care" (in addition to respect, comfort, and symptom cares) which seeks to restore health. In cases of uncertainty regarding the irreversibility of the condition or the imminence of death, Stewart *et al* believe that the wishes of the patient or surrogate should be respected, or if those wishes are unknown, that caretakers should error on the side of providing the higher level of care. "Intentional fatal withholding of care," i.e., allowing an avoidable death to occur, is euthanasia and is prohibited.[36]

Conflict Resolution

As Howard Brody notes, "Futility judgments should start rather than stop conversations among physicians, patients and families."[37] The mere unilateral use of the term, rather than trumping the desires of others, should serve as an indication of the need for continued conversation and possible conflict resolution. Several community- and organization-based approaches[38,39] and approaches devised by professional organizations[40,41] have been reported in the literature. Rather than attempting to define "futility," the most promising of these takes a "Fair Process" approach[42] to conflict resolution in individual cases. This

methodological tool allows flexibility in addressing the subjective and value-laden aspects of these deliberations and seeks to avoid judicial recourse. "Fair Process" involves a step-by-step algorithm and attempts to resolve impasses at every step. The goal of this process-based approach is *not* to empower any party to hold absolute sway, but rather to promote active conversation among physicians, patients, and families, so that all might become educated, informed and active participants in *joint* decision-making. Such a process promotes justice, balances physician professional integrity and patient autonomy, respects the physician-patient covenant, and reflects the love and respect due all human creatures.

The "Fair Process" approach as described by the Council of Ethical and Judicial Affairs of the American Medical Association may be briefly summarized as follows:

(1) The initial step (the "preventative ethics" discussion[43]) seeks to identify and acknowledge differences (if any) of the values and therapeutic goals of the physician, patient, and family, as well as the realistic benefits and limitations of the proposed therapy, well in advance of actual conflict. The objective of this conversation if to thoroughly educate and inform all partners in an attempt to preempt subsequent disagreements. Joint decision-making requires rigorous informed consent.

(2) If conflict occurs and is not amenable to resolution after extended conversation and assessment of the complicating psychosocial factors outlined above, a consultant should be invited to render a second opinion. Securing the services of a patient advocate (patient representative, chaplain, social worker) may be appropriate at this time.

(3) If disagreement persists, case review by the institutional ethics committee is warranted. This committee does not adjudicate but rather seeks to provide thoughtful reflection on the issues involved.

(4) If the committee supports the patient's request but compromise cannot be achieved, transfer of care to a willing physician in the hospital is appropriate. If the committee supports the physician but impasse persists, transfer to a willing institution is permissible.

(5) If, however, after a diligent search, no willing institution can be found, and if the request of the patient or family would seriously jeopardize the professional integrity of the physician or the institution (e.g., the proposed therapy has no physiologic rationale, therapy would violate standards of practice, or treatment is morally wrong), the requested care need not be provided.[44,45] In these circumstances, however, the patient is not abandoned but continues to receive all other interventions appropriate to his clinical status as outline above.

Conclusion

"Medical futility" stands in the gap between physician paternalism and patient autonomy. True cases of futility are rare and clearly identifiable; otherwise, "futility" is subjective, value-laden, context-dependent, and historically rooted, thereby rendering its precise definition difficult if not impossible. "Futility" often serves as a proxy for hidden agendas; its use frustrates the physician-patient covenant and cries out for a fairness that is grounded in more conversation, education, negotiation, and compromise. Physicians, patients, and families must realistically examine their conflicts of interest and confront their fears: there is no requirement that dying must be prolonged. Quite the contrary: medical abuse of patients in the name of science or love, grief or guilt is an indefensible use of patients as means to others' ends.

The "Fair Process" model of the American Medical Association seeks to meet the unique needs of individual cases without attempting to define the indefinable. With its use, the ideals of Christian care giving can be upheld as confrontation is transformed into communion.

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28 The Byzantine Orthodox Christian tradition views "letting die" not only permissible but also often desirable (ibid., p. 76).

29 CMDA Ethics statements. Medical futility.

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31 Ibid., p. 126.

32 "Do you not know that your body is a temple of the Holy Spirit, who is in you, whom you have received from God? You are not your own; you were bought at a price" (1 Corinthians 6:19–20).

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45 As noted above, since such decisions may be subject to judicial review that in the past has not favored unilateral physician decision-making, decisions to reject therapeutic requests must be thoughtfully rendered and thoroughly defensible

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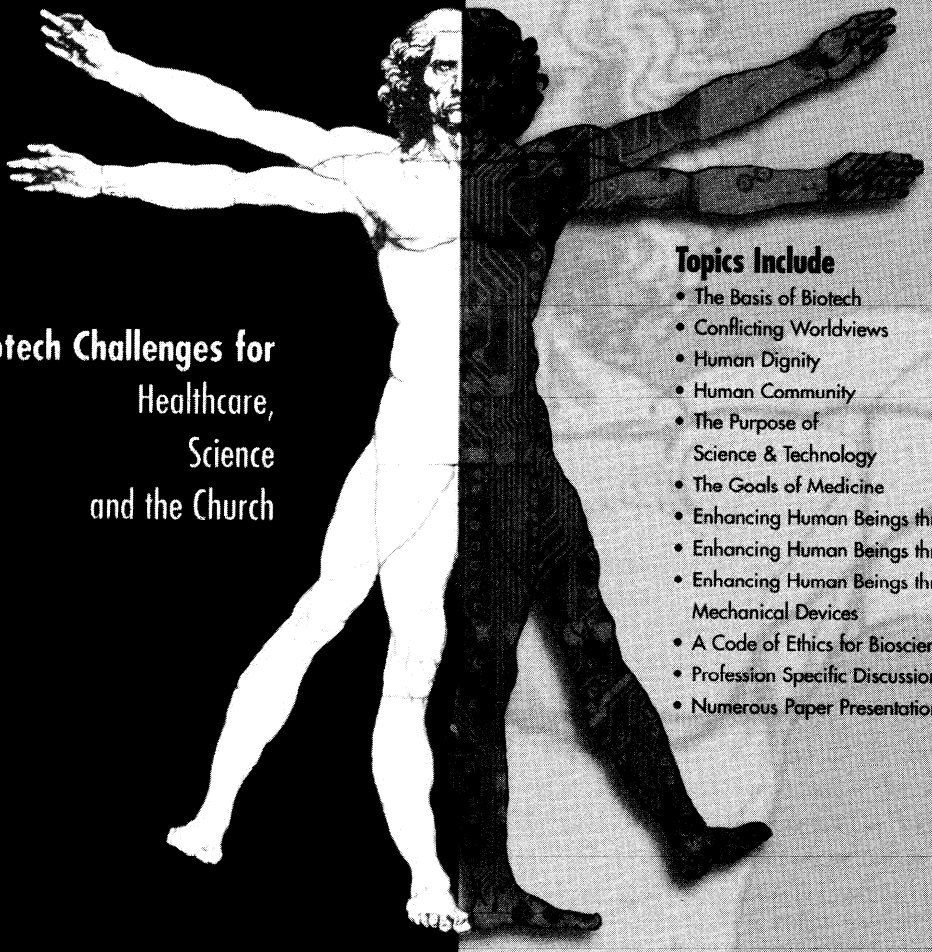

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Vol 19:2, Summer 2003

BOOK REVIEWS

Escape Routes: For People Who Feel Trapped in Life's Hells

Johann Christoph Arnold

Farmington PA: The Plough Publishing House of the Bruderhof Foundation, August 2001

ISBN 0-87486-919-6, 197 pp., paperback, $10.00

This book, the tenth by this author, deals with a wide range of real-life situations and how difficult or dire circumstances turned out positively. Using many specific accounts, often quoting the person involved, the author sets the situations in the context of different problem areas, such as loneliness, despair, alienation, frustration, suffering, sex, and materialism. He then describes how the situation was transformed, an escape route found, in a way that he clearly shows a wider application for those who read the book. Indeed, the various situations described will certainly ring true for many readers and those who, as counsellors, physicians, or other caring professionals, meet with and listen to people facing similar circumstances.

Much of the terminology that Arnold uses is drawn from Biblical (and other religious) backgrounds. Thus he writes of heaven and hell and the need for rebirth in our lives. But it is at this point that caution is needed, for the way he uses these words does not accord with much of their use in Scripture. For him, the primary focus for "heaven" and "hell" is the good and bad aspects in our lives, and "rebirth" means taking steps toward or making a decision to do something to reduce the "hell" and increase the "heaven." He states: "We must change, or die. That is not only a biological fact, but a truth that holds the key to solving the great riddle of heaven and hell in our personal lives" (page 101). He takes pains to tell us that his perspective on this is not the same as that which some others hold. He makes specific disclaimers as to his position—"I cannot embrace a faith whose sole focus in the world to come....Nor do I believe that fretting about the future is likely to improve a person's chance of salvation. On the contrary, the New Testament makes it plain that our first and only task on earth is to love God and our neighbours as ourselves" (Preface, page xiv). Likewise he is critical of some aspects of faith which others may hold dear—"...the popular sort of rebirth offered by the two biggest industries of our day—the New Age movement and 'born again' Christianity...often deliver less than they promise" (page 119). "This is why I am so certain that true rebirth has nothing to do with 'eternal life insurance'" (page 117). "Knowingly or not, pastors or priests whose motto is 'once saved always saved' are perpetrating fraud" (page 89).

The book's frequent references to God and Jesus Christ are limited to the need to espouse love and humility in our present lives, and to change one's self-centred existence for one of selfless commitment to others. With none of this can one take issue, and the real life situations he uses make the point very well. The dramatic change and benefits that accrue are well set out and might be called "success" stories (though presumably that is why he has selected them for the book, but can we be as confident as the author seems to be that these "solutions" will be available, or be appropriate, for everybody?). There is clear emphasis that these transformations can all be achieved primarily through our own effort and decisions (perhaps involving help from a professional or of a close friend). The author makes reference in some of the accounts to the faith of the individual, with specific reference to God and prayer, but does not give any further insight beyond that. Indeed he leaves the issue in the air when he writes, without further clarification—"...thus our transformation depends not only on us, but on another power, and our willingness to submit to it, just as the patient submits to the surgeon's knife" (page 103). Certainly any mention of needing specifically God's power, or the Holy Spirit, to achieve this in us is absent.

But if one accepts that the author has chosen not to detail what might be the specific "agent" or motivating force that helped those he cites (or is already available in others who might wish to heed his encouragement to change) then it is fine to take the book at face value.

There is much wisdom, common sense, and challenge to our own complacency, fatalism, and disregard to fairness and justice for all, that is worthy of adoption in all our lives. Each person reading this book is likely to find at least one chapter of particular personal relevance even if they would choose a different "escape route" to those propounded by the author.

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Making Babies: Is There a Right to Have Children?

Mary Warnock

Oxford: Oxford University Press, November 2002

ISBN 0-19-280334-4, 120 pp., paperback, $13.95

Baroness Mary Warnock's message is that which the Baroness herself contributed as the Chairman of the Warnock Report, which served as a basis for the UK's Human Fertilisation and Embryology Act 1990. Thus Baroness Warnock subscribes to the principle 'that the infertile who want to conceive are entitled to expect that they will be given the medical assistance they need, even if they have to pay for it'. This includes homosexuals. She says: 'Society would be wrong, in my view, if it criminalized consultants of clinics that provided assisted conception to homosexuals'. Yet the book brings two surprises: first, Baroness Warnock has changed her views on the anonymity of sperm donors. Second, she now has doubts about sperm donation as such, though she does not condemn it in the same strong terms as she rejects the idea of anonymity.

Expressing her misgivings about artificial insemination by donor, she writes: 'One cannot wholly disregard the genes of a child, though doubtless too much can be made of genetic inheritance'. She also says that 'there is no doubt about the effect on the family of having a third party involved in the conception of a child, the donor perhaps remaining a shadowy figure in the background of the family'. True enough as regards the third party involvement! The donor cannot but drive a kind of wedge between the spouses and create an imbalanced relationship with the child who from a genetic perspective is related only to its mother. And for these reasons gametal donation involves an injustice to the child and, indeed, the couple do an injustice to themselves too.

As for the issue of anonymity, at present, under the HFE Act 1990, children born by sperm donation in the UK are not allowed to know the identity of their genetic father. Baroness Warnock says: 'At the time of the report of the [Warnock] Committee of Inquiry I was persuaded by the argument that the supply of donors would dry up if anonymity were not preserved, I now think differently. I am convinced that the law should be changed so that children born with the help of donors would be able to have identifying information about the donor'. Why has she changed her mind? She points to the experience of countries such as Sweden where donor anonymity is no longer preserved. While initially the number of donors dropped when the protection of anonymity was lifted, as time passed the numbers stabilised.

She also points to the evil of deception. Thus she notes that children are 'extremely quick to pick up signs that there is some mystery about their birth' and that they may feel 'diminished' and think that they have been 'used by their parents to conceal their infertility', if they accidentally discover the truth. Baroness Warnock's change of heart in regard to the anonymity of sperm donors is to be welcomed. Most of us like to know where we come from. We get a sense of identity from what we know about our genetic origins.

To turn to the controversial issue of cloning, as to be expected, Baroness Warnock is in favour of so-called therapeutic cloning involving the creation and destruction of human embryos in order to cannibalise their stem cells. Indeed, in her view, reproductive cloning too might be justified in certain circumstances. That is, she says that 'perhaps in cases of complete male infertility, when all other remedies have failed, human cloning could be justified. And so she regrets the fact that the UK has joined the rest of Europe in a total ban on reproductive cloning.

Agneta Sutton, Head of Research, Centre for Bioethics and Public Policy, London, ENGLAND.

From Chance to Choice: Genetics and Justice

Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler

New York, NY, and Cambridge U.K.: Cambridge University Press, 2000

ISBN 0-521-66001-7, 398 pp., hardback, $23.00

This book is an indispensable tool for any person concerned about public policy and genetic interventions. Written by four notable political philosophers, this book offers arguments and insights that bring the debate over human genetic intervention into sharp focus.

The central question throughout the book is 'What are the most basic moral principles that would guide public policy and individual choice concerning the use of genetic interventions in a just and humane society in which the powers of genetic intervention are much more developed than they are today?' (p. 4-5). The authors write with the assumption that developments in genetics may be more modest than scientists claim, but the question is unavoidable: What would happen if we gained a complete understanding of the human genome, and we had the power to alter human genes? How would such knowledge and power change our view of human nature? What part of our current moral framework could survive such a radical revision of human understanding and be viable in a society where genetic intervention was practised on a large-scale?

The authors' exploration of these questions is both erudite and comprehensive, ranging from an historical investigation of the evils of the early eugenics movement to the methodologies and policies already existent in the current genetics era to speculations about the future potential of emerging genetic technology. Throughout the analysis the authors conclude that justice is the most viable moral principle in both furthering and hedging our use of genetic interventions.

Justice serves as the key principle not because it is the only moral principle that can survive the new genetics, but because it represents a point of convergence for disparate moral viewpoints. Justice can be widely affirmed, and therefore is a logical moral principle in a liberal democracy for application to emerging technologies. As these genetic technologies develop, society will be faced with three troubling questions that justice can answer, and provide a moral guidepost in new and novel ethical territory. The three ethical problems that will arise as new genetic technologies arise are:

- How to avoid the past evils of the eugenics movement
- How to ensure equal access to life-saving genetic treatments
- How to prevent the use of genetic enhancements to widen the achievement gap between the wealthy and the poor.

These are not the only issues of concern with emerging genetic technology. Several questions surrounding the efficacy, safety, and methodology of genetic treatments need to be addressed, but the authors are here concerned primarily with the political and societal ramifications of genetic technology. Many other books examine the former issues, delving into the minutiae of developing this emerging technology ethically, i.e., without destroying human embryos. What makes this book unique is that it addresses the questions that will undoubtedly follow if genetic therapy becomes as efficacious as many researchers now purport. The value of this book is that it looks beyond the present dilemmas, and provides a framework for evaluating the use of these technologies if and when they become available.

One of the most important features of this book is the lengthy discussion of the enhancement/therapy distinction so widely employed by ethicists working in this issue. The authors critiques and evaluations have philosophical rigor that is invaluable in the ethical explorations of this emerging technology, and give a secure philosophical foundation rooted in justice for the use of this distinction.

This book is a compelling evaluation of the ethical framework that will be necessary to adequately deal with the power and possibilities that will arise as a result of emerging genetic

technology. Though not everyone will agree with the positions taken and arguments offered in this book, every professor and student in bioethics should read it. To fail to do so would be to miss an opportunity to sharpen our arguments and clarify our ethical thinking about a technology that has the potential to radically reshape what it means to be human. Now is the time to critically evaluate genetic technology and construct the proper ethical framework for its use—before genetic technologies reach their full potential. This book provides many resources necessary for such an evaluation and ethical construction.

Leland Saunders, B.S., National Center for Ethics, Washington, DC, USA.

R.U.R. (Rossum's Universal Robots)

Karel Capek (translated by Paul Selver and Nigel Playfair)

Mineola, NY: Dover, 2001

Translation originally published by Doubleday, Paige and Company, Garden City, NY, 1923

ISBN 0486419266, 64 pp., $1.50

In a day where an autonomous robot visits a conference, registers, and goes to give an address to conference participants, the world envisioned by Karel Capek back in 1920 seems increasingly within our reach. It is quite suitable that this important play be reprinted now.

Capek (1890-1938) was a journalist, novelist, and playwright from Czechoslovakia during the period between World Wars I and II. He was a well-known writer from that period who, it's said, would have won the Nobel Prize for literature had the Nobel committee not been apprehensive about offending Hitler. Capek wrote on issues of morality and human values in his works of fiction usually placing the issues within a 'form of science fiction romance.' *R.U.R.* is no different.

R.U.R. is a three-act play which takes place entirely upon the island where Rossum's Universal Robots are built. Rossum was an old man who discovered a chemical substance that behaved just like living matter. Rossum wanted to figure out how to create people to prove that 'God was no longer necessary.' After creating a being that died after three days, his son takes the recipe to create a work force of robots to serve mankind.

Act I begins with the visit of Miss Helena Glory, daughter of the President Glory (evidently the president of the nation whose territory includes this island), to the office of Harry Domin, general manager of Rossum's Universal Robots. She arrives unannounced wishing to tour the facility. However, she has really come on behalf of Humanity League to convince the robots that they should seek liberation.

The robots created by Domin and company are created for work. They are so efficient at the jobs set before them that the prices of goods have plummeted and the world has been plunged into mass unemployment. This is all part of the world Harry Domin envisions. He hopes that one day no one will have to work. Food, clothing, and all necessities will be available for free, with humankind spending its days perfecting itself—a type of utopian technosocialism.

Harry and Helena discuss at length the moral status of robots. Over the years robots have become more intelligent and look very human, causing many people to argue that robots should have rights like human beings. Ultimately the debate circles around whether or not robots have a soul—the factor that determines their worth. Harry is convinced the robots do not have souls, and thus, have no moral worth. Helena thinks that robots could be created to have souls which would grant them the moral worth she believes is due to them.

Act II opens ten years later on the anniversary of Harry and Helena's first meeting. They have married and live together at the island factory. Soon after waking, Helena discovers a recent newspaper that informs us that during the past decade, governments began using robots in warfare. One story tells of 700,000 civilians assassinated by robots in the Balkans. In another story robots have formed an alliance to unite robots in opposition to human control. Another

headline indicates that the world's birth-rate has fallen to zero. Helena asks Harry and the other heads of R.U.R. why they have continued to make robots when they knew such thing were occurring. They offer the free market response—our shareholders demand a profit and our customers demand a product. In other words, it isn't our responsibility.

Ultimately, the situation gets worse as robots gain the ability to hate humans and the desire to be masters rather than slaves. Humanity is annihilated.

It seems that the tendency to avoid seeing the potential downfalls of such technological 'hubris' was not lost on some in the early 20th century. The disappointing fact is that not very many people today seem to realize the pitfalls of technologies on the horizon even though we now have decades of history to examine. As George Bernard Shaw once said, 'If history repeats itself, and the unexpected always happens, how incapable must man be of learning from experience?'

Capek's vision brings many interesting questions. How will we respond to machines that can think like ourselves? Will we relentlessly pursue profits despite the human cost? Will we ever overcome the pride that leads us to make choices that increase the chances of our self-destruction? As the editor of this journal recently wrote, 'the unexamined technology is not worth developing.' As movies such as *The Matrix* and *Gattaca* recently demonstrated, drama is one of the best tools in educating people about technological hubris. For those interested in using a drama as such a tool, this play provides a wonderful opportunity to seriously raise some questions that most people usually yawn at. And at only $1.50 a copy, it's a bargain.

Daniel McConchie, M.A., Director of Media and Policy Relations, The Center for Bioethics and Human Dignity, Bannockburn, Illinois, USA

Two Views of Virtue: Absolute Relativism and Relative Absolutism

F. F. Centore

Westport, CT: Greenwood Press, 2000

ISBN 0-313-31412-8, 195 pp., hardback, $65.00

F. F. Centore's erudite critique of moral models exposes the moral morass of absolute relativism (first three chapters), and develops his own model that he calls relative absolutism (chapter four). He argues for a moral model that avoids the ditch of extremes—moral relativism and moral absolutism. Centore offers evidence to demonstrate that absolute relativism is both philosophically bankrupt and culturally suicidal and hints that moral absolutism is non-compassionate and inflexible.

The three varieties of absolute relativism (individual-centred, group-centred, and goal-centred, designated as One, Two, and Three respectively) are weighed in the moral balances and found wanting. Then, invoking Thomistic natural law tradition (as opposed to Grotius), Centore presents relative absolutism as the 'middle ground between theocracy and man-centered state dictatorship' (p. 134). Undergirding his relative absolutism is the idea of natural law—that 'which derives from a particular kind of nature (essence)' (p. 127), which is human nature or humanness (this is what Francis Schaefer referred to as man's manishness). His point is that 'wherever there is a nature (essence) there is a law. Every nature is fixed on its proper end, which is the good of that kind of thing' (p. 127). Furthermore, for Centore, this natural law is 'found highlighted in the Ten Commandments' (p. 127). Absolute relativism sees man's temporal happiness as the end that confuses is and ought, while relative absolutism understands man's eternal happiness as the end. Happiness/pleasure (the good of the thing) is important, but it must always be 'ordered to man's final end' which is not 'earthly pleasure (sexual, artistic, mechanical, etc.), but eternal happiness' (p. 106).

His argument against all three types of absolute relativism concludes that when carried to a logical conclusion the true nature of man is destroyed. Absolute relativism One exalts personal freedom predicated upon the autonomous will of man, leaving each one free to do his own thing,

which dead ends into nihilism. Kant, Emerson, Whitman, Nietzsche, Camus, and Sartre are associated with absolute relativism one. Absolute relativism Two, built on the notion that the group is the measure of what is right, is identified with such thinkers as Hobbes, Rousseau, John Stuart Mill, Karl Popper, Richard Rorty, and Jan Narveson. Furthermore, it will eventually gravitate towards some form of tyranny and intolerance of any form of dissent from the individual. This view, according to Centore, attempts to have ethics within a materialistic world view, while trying to avoid the inevitable end of nihilism associated with number One. The third type of absolute relativism, Three, Centore identifies as situation ethics or proportionalism. Here the good goal is the guiding moral principle. Centore admits that this approach attempts to be more compassionate and optimistic than One and Two but that it ultimately fails, for in the end, morally 'everything is permissible' and 'good and evil is nothing more than a matter of individual opinion' (p. 103).

As an antidote to pure relativism, Centore offers his relative absolutism (God-centred) moral model. Unfortunately, in spite of his commendable attempt to develop a moral model sufficiently strong to support the truly good society, one may be a little disappointed by this chapter. It seems to promise more than it delivers. He rightly claims that each person is special, regardless of his station in life, because he is 'created to be by God' (p. 141). The concern, however, develops when he defines personhood by man's 'intellect and will' (p. 118) which appear to be purely functionalistic parameters.

Furthermore, in his attempt to make his moral model flexible, he maintains that 'knowing the purpose of the law allows the intelligent person with the power of free choice to apply his or her knowledge to many situations' (p. 107). If one knows the purpose of the law, and under certain conditions the purpose of the law could be fulfilled by not obeying the law, then the intelligent person could act contrary to the law (pp. 107-109). He fleshes this out by saying, 'Lying is always immoral. This is an absolute rule with no exceptions' (p. 111), yet in the very next sentence he introduces exceptions with 'nevertheless, there may be occasions . . .' (p. 111). The third sentence negates the first two sentences and seems to bring the final choice back to the individual—the very position he is trying to avoid. Both issues spell trouble for ethics and bioethics in particular.

It is acknowledged that Centore explains that he is only trying to give a general moral model and that others can discuss how it deals with particulars, but when he tries to discuss the particulars, even for purely illustrative purposes, he unnecessarily introduces seeds of destruction to his own model. Nonetheless, this book commends itself to all who sense a growing urgency to provide a moral paradigm to guide humanity through the expanding moral questions of our day. As an additional benefit, the book has an impressive bibliography and judicious documentation.

Bruce A. Little, D.Min., Ph.D., Associate Professor of Philosophy of Religion, Southeastern Baptist Theological Seminary, Wake Forest, North Carolina, USA.

The Christian Woman's Guide to Personal Health Care

Debra Evans

Wheaton, Illinois: Crossway Books, 1998

ISBN 1-58134-020-6, 400 pp., paperback, $15.99

Evans first wrote this guide in 1991, and republished the 1998 version as a revised and updated edition. She presents her book as 'an informative resource guide,' and as a significant contribution to literature in that no other existing health care guide covers the same material; a statement that is entirely indisputable.

From the onset, the author adopts a heavily gynaecological slant to women's health, devoting three of the four sections of the book to female anatomy and physiology, the menstrual cycle, family planning, assisted reproduction and sexually transmitted diseases. The remaining section addresses doctor-patient communication. Areas such as menopause, health care

maintenance, preventive medicine, and even obstetrics receive surprisingly little, if any, attention.

Evans speaks to the reader in various voices, a salient feature of her prose. At first she sounds dry and factual, like a medical text, diagramming pelvic anatomy and the menstrual cycle. Later chapters resemble self-help books, including quizzes and menstrual diaries to heighten self-awareness. In sharp contrast are paragraphs that read as a tabloid newspaper might, with sensational news exposing physicians as perpetrators of harm. Portions are very much a mother's personal advice, at one point dedicating her thoughts to her daughters. Interspersed are lists of herbs, recipes for tonics, and alternatives to conventional medical therapies.

Christian beliefs are woven into the text primarily in her discussion of birth control. This section is devoted almost exclusively to the rhythm method, complete with drawings of cervical mucus and basal body temperature charts. She strongly advocates the method, and presents a beautiful, though theologically one-sided, discussion of the biblical basis for the three 'acceptable' forms of birth control: abstinence, condoms and the rhythm method.

According to Evans, all forms of birth control (i.e. the Pill, Depo-Provera, Norplant, IUD) are categorised with RU-486 as clearly abortifacient, and for this reason she neglects discussing them objectively. She suggests that couples who are not engaging in the rhythm method are vulnerable to communication breakdown and divorce (p. 119). On the same page, she likens advocating the Pill to advocating abortion and divorce. Finally the author goes as far as challenging the reader to not accept care from a physician who prescribes birth control pills, implying that physicians only do so for reasons of personal profit or negligence.

Perhaps the only cohesive theme of the book is her repetitive warnings against physician incompetence or outright malevolence. She frequently calls into question physicians' training, expertise, motives and repeatedly denigrates the profession. Her discussion of surgical informed consent warns women against C-sections and hysterectomies, claiming most are done for ulterior motives and personal gain. Instead of offering practical tips for getting the most out of talks with doctors, her chapter on patient-doctor communication dramatically depicts the worst scenarios imaginable, portraying physicians as deliberately belittling their patients and taking advantage of them. Throughout the book, Evans cites countless cases of gross physician negligence, malpractice, and malicious medical experimentation. More horrifying yet, she presents these stories as an accurate reflection of the common experience of women in the US.

Because of this approach, and despite its claim, this book is certainly not a suitable health care guide for mainstream Christians, particularly ones naïve to gynaecological care. Instead, it may inflict unnecessary anxiety and negativity. Nevertheless, I maintain, the author's claim holds true. Her writing may smack of bitterness, blatant anti-physician sentiment, and a specific theological perspective, but it undeniably makes a contribution to medical literature. The book may be a comfort to readers who can sadly resonate with the author's experiences. Likewise it would be appropriate for those who agree with Evans' particular Christian outlook. And on a personal note, this book represents the story of one woman. It is a poignant glimpse into the mind of the author, complete with her memories, diagnoses, fears, remedies, wisdom, beliefs, and cynicism. Its literary value is perhaps in the story itself.

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Becoming Good: Building Moral Character

David W. Gill

Downers Grove, IL: InterVarsity Press, 2000

ISBN 0-8308-2272-0, 237 pp., paperback, $13.00

During a period of heightened interest in books written about virtue and moral character, David Gill positions his contribution specifically 'outside the scholarly guild' and primarily to the

'thoughtful Christians' (p. 3). He is also successful in writing a book of interest to the more scholarly and philosophically minded. Through in-depth footnotes, endnotes, and side bar highlights, the more serious reader has resources that allow a deeper dig into Greek philosophies, ethical theories and theological doctrines.

For example, Gill's chapter on 'The Goodness of God' does justice to different philosophical positions on the nature of the good and how we know good. He takes the reader through Plato, Aristotle, Kant, Barth, Bonhoeffer, Ellul and others but lands with goodness coming from God and our ability to be good and know good as we grow in our knowledge of God and His character. The general content of the book achieves his goal of writing a study on virtue and character ethics from a Christian perspective. Over and over we are reminded that our character is not on or off, that we are not to be in character or out of character, but that our character is the ongoing, daily 'inclination of our hearts and minds' (p. 144).

This book is divided into three parts. Part one, called 'Prepare', describes the tools and skills needed to lay a moral foundation upon which our moral character can be built. Gill rightly reminds us that we live in a moral wilderness, born without a morally developed character, and that the life-long process of character formation requires our active attention. The communities we live in, both secular and sacred, help prepare us to become good as we develop skills to live in relationships with one another, through thick and thin. The chapter entitled, 'Ethics Isn't Pretty' challenges Christians to actively engage in the messy business of ethics. Gill states that 'it is a matter of obedience and fidelity to Jesus Christ that demands our interest in recovering a robust, vital, insightful Christian ethic' (p. 23).

Part two, called 'Build', incorporates Jesus' Beatitudes and the Pauline virtues of faith, hope and love into the foundation of our moral character. Gill looks at five roles Christians live out. Through our role as a disciple of Christ, we must become faithful, holy and wise. Our faithfulness must become habitual and foundational so that we can be wise and holy. As servants, we are to be meek, mournful and poor in spirit, willing to assume a servant's position. To be Christian leaders we need to hunger for righteousness and be lovers of mercy, and not get caught in the radical autonomy and personal rights language of our day. If we are to become peacemakers, we need to sacrificially love one another and have purity of heart, promoting reconciliation and the ability for people to flourish. Finally, as ambassadors for Christ we are to be hopeful, joyful and courageous, boldly sharing the Good News. As we build these virtues into our character we become like Christ; we become good.

In the third part, called 'Test', Gill points out what might happen to us if we do not choose to actively involve ourselves in a character-building program. If we do not become faithful, holy and wise we will become conformed to the world and accommodated to our culture. Unless we develop a servant's heart, we run the risk of becoming arrogant know-it-alls. Apathy to our communities and uninvolvement with our world comes at the risk of not being righteous, just and merciful leaders We become divisive and antagonistic if we are not committed to being peacemakers. Lastly, if we deny the hope we have in Christ and abandon our call to serve as ambassadors for Him, Gill accuses us of being selfish escapists.

Becoming Good is not a self-help book on how to live a problem-free life. It is not a book of promises: if you do this then this will happen. It is a call back to the goodness of God, to know God through scripture, and to be committed to the daily effort of following Christ's example of how to live in, but not of, the world. One of the greatest strengths of this book is the set of reflection questions at the end of each chapter. These questions will serve the reader well and also provide a great study guide for small groups looking to learn more about ethics from a Christian perspective.

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A Small, Good Thing: Stories of Children with HIV and Those Who Care for Them

Anne Hunsaker Hawkins

New York, NY: W. W. Norton & Company, Inc., 2000

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A handwritten message is found on the opening page of this book. Amidst ink blots and scratch marks, a twelve year-old boy with HIV shares words of hope and encouragement. He illustrates his thoughts with a drawing of a little heart with arms, legs and a smiling face. In a scrawled line coming from the heart's lips, he writes, 'hold on to your heart'; a pithy preamble to the pages that follow.

The author presents six stories of children with HIV. Formally trained in literature, Hawkins took a sabbatical leave from her academic post at a medical college to shadow a paediatric HIV specialist at a Midwestern US tertiary care centre. Her stated intent was to write a book about the children she came in contact with. She recorded her observations, interviewed families in their homes, and at times taped their conversations. Her close eye for detail, and vivid descriptions bring each child to life. While the book is addressed to the general audience, she dedicates it simply and yet poignantly to the children.

As each child is introduced, Hawkins presents a clinical vignette, detailing medical information, prognoses, and medications. Almost seamlessly, she then journeys beyond the medical office, and entirely beyond the disease itself. The author describes the homes the children live in, their back yards, their religious, financial, and social worlds. She encompasses the lives of the caregivers, parents, foster parents, physicians, nurses, social workers, siblings, etc. She writes of families fraught with abuse, crime, imprisonment, prostitution, drug addiction, poverty, promiscuity, and psychiatric illness. The author's unique approach yields insight into each child's life, well beyond the complexity of their disease. Hawkins combines the medical and human factors of the children's lives, an invaluable contribution to current literature on this topic.

Beyond the completeness of the stories, the author's approach is refreshing and novel. She draws from a wealth of literary work, beginning each section with a relevant quote. Her literary background becomes a 'lens' through which she perceives and interprets her observations. During her sabbatical leave, she deliberately read books that seemed appropriate to the real life stories she was recording. She found that books such as Fyodor Dostoyevsky's *The Brothers Karamazov* and Albert Camus' *The Plague* helped her to articulate her understanding and the view of the suffering she witnessed.

Philip Hallie is quoted at the start of the book: 'In the eye of the hurricane the sky is blue and birds can fly there without suffering harm'. Throughout the tumultuous complexity and tragedy of each story, Hawkins' unwavering focus on the children provides a theme of innocence, peace, and even clarity. This book is not only a powerful tribute to the children and those who care for them, but also a tribute to Hawkins herself, for her courage to stand with them in the swirling eye of the storm, faithfully recounting their stories, and fearlessly taking hold of her heart.

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The Reproduction Revolution: A Christian Appraisal of Sexuality, Reproductive Technologies, and the Family

John F. Kilner, Paige C. Cunningham, and W. David Hager, editors

Grand Rapids: Eerdmans Publishing Company, 2000

ISBN 0-8028-4715-3, xvi + 290 pp., paperback, $20.00

In popular discourse, the issues of artificial reproductive technology, human cloning, and human sexuality are often compartmentalized and people attempt to deal with each of these issues in isolation. The Reproductive Revolution is a credible attempt to demonstrate that these issues really are all part of a seamless garment and must be addressed as such. The work is a compilation of twenty-six different contributions from ethicists, medical professionals, theologians, and lawyers. The book is divided into an introduction and five major sections. The introduction gives different perspectives on reproductive difficulties. Section One addresses foundational issues concerning meta-questions related to the ethics of the new reproductive technologies. Section Two examines specific technologies. Section Three addresses two difficult cases: Surrogacy and the morality of oral contraceptives. Section Four is a response to the sexual revolution while section five is more oriented towards public policy issues.

The best articles in The Reproductive Revolution include the contributions of Nigel Cameron and Gilbert Meilaender, the articles related to the oral contraceptive debate, and section four on the sexual revolution. Cameron's article is entitled 'Separating Sex and Reproduction.' He returns to a theme that he has emphasized in other venues and points out that the cursory debate that occurred twenty years ago among evangelicals about in vitro fertilization has led to a situation in which 'Christians have failed to engage in a theological critique of contemporary challenges to the notion of human value and the significance of technology' (p. 32).

The articles related to the morality of the oral contraceptive pill (OCP) are especially helpful. Randy Alcorn and Walter Larimore assert that the OCP is morally unacceptable because it functions as an abortifacient. In contrast Crockett, DeCook, Harrison, and Hersh argue that the use of the OCP is morally acceptable because 'the abortifacient theory is not a fact' (p. 193). Both articles are respectful of differing opinions and are a good starting point for discussion. Meilaender's article addresses some of the question-begging that occurs in popular debate about reproductive technology. In short, he stresses that there is an intimate connection between the act of sexual intercourse and a proper view of children. He says, 'Many of the new reproductive technologies will involve the use of third parties. In so doing they break the connection between love-giving and life-giving in marriage' (p. 44). The section on the sexual revolution is helpful because the authors do a commendable job of connecting sexual chaos and the corresponding societal problems.

These strengths noted, *The Reproduction Revolution* could have been stronger at a few points. Gracie Hsu Yu's article 'Making Laws and Changing Hearts' is very irenic. However, Yu may give too much credit to the compassionate motives of pro-choice advocates. She does not address the radical notion of autonomy that drives much of pro-choice thinking (a connection alluded to in Kilner's article on pages 132-136). Joe McIlhaney's article, 'Sex in America,' has many fine points, but I feel he blurs some important worldview distinctions between Buddhism and Christianity when he says, without qualification, 'Buddhism has five major precepts, one of which is sexual purity. The Dalai Lama . . . writes very clearly of marriage being the place for sex' (p. 219). It should be made clear that Buddhism's approach towards sex is closely related with the desire to break free from the cycle of reincarnation. He also indicates that Darwin was influenced by Malthus in 1864 (p. 220). In reality, Malthus's influence on Darwin goes back much earlier. As a final thought for possible improvement, it would have been helpful if one article brought the many themes of the book together in a conclusion.

The Reproductive Revolution is a needed contribution to current debate among Christians about the morality of different technologies. As Cameron notes, in vitro fertilization does not occur in a moral vacuum. There are many assumptions about the new technologies that

Christians have not examined with critical minds. This work brings together various issues into one forum and for that it should be commended.

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Respecting Patient Autonomy

Benjamin H. Levi

Urbana: University of Illinois Press, 1999

ISBN 0-252-06749-5, 222 pp., paperback, $19.95

Though autonomy has become the central theme in modern bioethics, the debate over what it means to 'respect a patient's autonomy' continues unabated. Benjamin H. Levi, who holds both an M.D. and Ph.D. from the University of Illinois, offers his contribution to this debate in *Respecting Patient Autonomy*.

Levi's main argument is that a health care provider (HCP) should respect the autonomous decision of a patient even when the patient makes a choice the HCP disagrees with. Levi states his thesis as follows: 'I will argue that if we are to treat [patients] as moral equals, whose ideas and values and aspirations we must take seriously, autonomous beings must be allowed to make their own decisions—even when they make decisions we consider bad or imprudent' (p. 10). Furthermore, Levi sees autonomy as central to his view of what it means to be human: 'My views are grounded in the ontological belief that the moral equality of adult human beings rests on the presumption that adults are autonomous beings' (p. 17). He goes on to assert that three characteristics are necessary for a person to be considered autonomous: continuity of the self, an intersubjectively accepted set of values, and rationality (p. 37).

In order to insure that a patient's true desires have been understood, Levi encourages HCP's to engage in extensive dialogue with patients and he offers several examples of how such dialogue might proceed. This is important because a 'statement's face value may not effectively communicate the intended or underlying meaning, if only because the HCP misunderstands it' (p. 131). Mirroring the individual verses community debate common in current literature, Levi contrasts his approach with relational arguments. He argues that his approach actually affirms the dignity of the individual while the 'relational' approach ultimately leads to coercion. Specifically, he argues that primarily self-regarding decisions should be safeguarded because paternalistic approaches give undue power to override a patient's decisions (p. 123). In short, Levi argues that since autonomy is central to what it means to be human, HCPs should honour autonomous requests. To do otherwise is coercive.

Levi has provided a well-written presentation of a more expansive view of autonomy. He acknowledges positions which contradict his own and he attempts to respond to them. His critique of other positions is generally irenic, though firm. At times, he acknowledges that the position he is arguing for is neither easy to implement nor comfortable. In some situations, it is true that HCPs do not spend enough time listening to their patients in order to determine a course of treatment that honours the patient's wishes as much as possible. Levi's suggestion for more dialogue is a healthy one.

One weakness of the work is that Levi does not devote significant attention to the concept of moral absolutes consistent with the Christian-Hippocratic tradition of medical ethics. His approach would be more well-rounded if he acknowledged the human propensity towards sin and that this propensity is not uniquely related to paternalistic models. While he noted that 'relational' models promote coercion, he failed to note that models based on radical notions of autonomy can result in a form of coercion in their own right. For example, if in the name of autonomy a patient is granted the right to physician-assisted suicide, an attitude may develop which encourages other patients to choose physician- assisted suicide when faced with certain diseases. This would be a form of coercion.

I take issue with Levi on two other specific points: First, he cited John Stuart Mill in support of his version of autonomy (p. 117) while neglecting to point out that Mill himself argued that 'barbarians' could be governed harshly provided that the goal was the improvement of less advanced societies. Also, Levi states that 'no reasonable individual believes that a five year old or someone with Down's syndrome is any less a "person" for lacking their autonomy' (p. 115). However, he seems to overlook the work of people such as Peter Singer who hold to something very similar to this.

In short, Levi's work is an attempt to state an autonomy-based health care ethic with little reference to other moral absolutes. The work is commendable in his emphasis on the need for physicians to interact with patients. However, the lack of reference to transcendent moral accountability beyond the autonomy of individual humans is a significant weakness.

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Children, Families, and Health Care Decision-Making

Lainie Friedman Ross

Oxford, UK: Oxford University Press, 2002

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This is not a "Me, too!" book. A number of books have been written on medical ethics decision-making in the context of society, at a policy level, and in regard to particular clinical decisions. The majority of these focus on broad societal issues, including biotechnology and reproductive concerns. Case study books most frequently deal with reproduction, abortion, or adult medical case scenarios. Lainie Friedman Ross provides us with the first major book-length discussion of decision making with children and their families. She does an admirable job of covering this important topic in an original, engaging manner.

Much of this work resulted from Ross's doctoral thesis, which she produced after completion of her medical degree and paediatric residency. She brings to it the skills of both an astute philosopher and a compassionate paediatrician. Growing up in and continuing to espouse a relatively secular, Jewish mindset, she nonetheless identifies Paul Ramsey and a 'Christian Ethics' course at Princeton as important in her original interest in medical ethics. While this work is not Christian in orientation, many of her principles are compatible with a Christian worldview and frequently at odds with an established liberal, primarily child-focused approach to paediatric decision making.

Ross argues that a child empowerment model, such as that espoused by then First Lady Hillary Clinton and others, fails on three counts. First, it fails to recognise the child's need to obtain necessary skills and virtues. Second, it fails to recognise the parents' role in helping to define the child's well being and conception of the good. Third, it fails to respect the parent's interest in child rearing. In its place she offers a model of 'constrained parental autonomy.'

To frame her thesis, she incorporates four necessary assumptions in her argument. First, she 'assumes that children are members of intimate families.' She elaborates only briefly on this complex assumption, but her model clearly includes the heterosexual, two-spouse model as legitimate and statistically the most usual. Second, she assumes 'that the child's biological parents have and should have primary child-rearing responsibility.' Third, she assumes that 'the family is an important institution in the lives of most people...' Finally, she assumes that in general 'all children are incompetent to make health care decisions and that they should not have presumptive decision-making autonomy.'

In discussing constrained parental autonomy she posits that decisions are to be made primarily by the parents as 'constrained by a modified principle of respect for persons.' She fleshes this out in regard to the child's growing competency by espousing 'an increasing moral obligation to consider the expressed beliefs and wishes of their child as the child matures.' Ross

specifically addresses the roles of child assent and dissent in this process.

In the first half of her book she states her amplified primary positions, and in Part II she considers decision-making in the four settings of research, organ donation, personal health care, and sexual activity. Her discussion of research ethics provides inside details of the Ramsey-McCormick debates in regard to children as research subjects. She reviews their positions and then offers her own model, addressing the categories of a) children unable to give assent, b) children able to give assent, and c) children capable of giving consent. She uses case studies to review the ins and outs of paediatric organ donation and the role that children and families play together in making various complex decisions regarding donation. In the arena of personal child health care she addresses unreasonable parental demands, unreasonable parental refusals, and the growing importance of child consent and assent as the child matures. Lastly, though clearly proceeding from a pro-choice abortion stance, she offers spirited critique of current social and educational contraception and abortion policies that exclude parents from participating in life-changing decisions with their children.

Neither the Roman Catholic Church nor most evangelical churches will be promoting *Children, Families and Health Care Decision-Making* for general parishioner use. Nevertheless, Ross offers an important overview of current thought in regard to decision-making in children's health care. I was gratified with her semi-communitarian view of the importance of parents and consideration of the needs of the entire family in tough medical ethical dilemmas. Ross provides a thoughtful response to the child empowerment movement, and affirms a mutually inter-dependent model of families and health care decision-making. With only 175 pages of text, this is a relatively quick, enlightening, ultimately satisfying read.

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