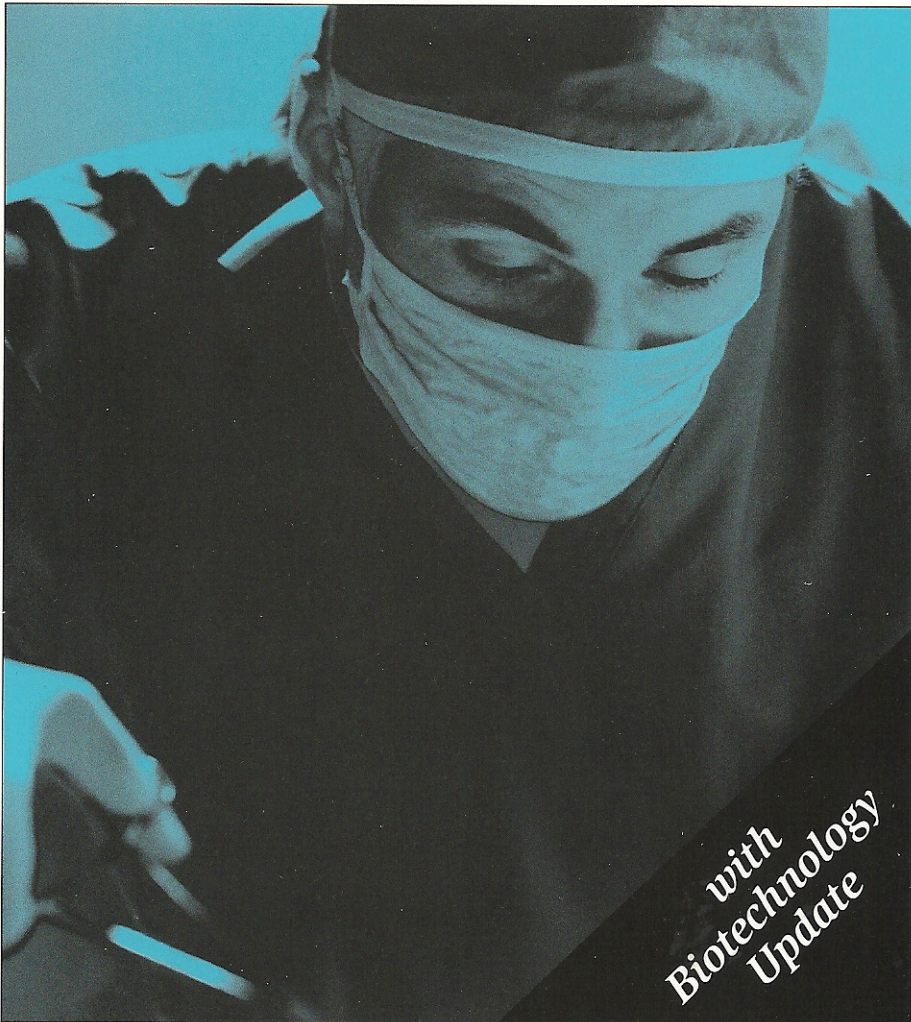


# Ethics & Medicine

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EDITORIAL

## THE RETURN OF EUGENICS

C. BEN MITCHELL

Author of the Father Brown mysteries and political essayist G. K. Chesterton perceptively said, 'We can be almost certain of being wrong about the future, if we are wrong about the past'. The American eugenics movement is one of those historical epochs which we can ill afford to repeat. Yet we are inching increasingly close to doing so.

With the power of contemporary genetic technology a new eugenic enthusiasm has emerged. Our culture's emphasis on the genetically 'fit' and our difficulty embracing those who are 'less fit' fuels this enthusiasm.

The quest for genetic enhancement of our offspring is the most virulent form of the new eugenics. James Hughes, one of the architects of so-called transhumanism, has argued: 'The right to a custom made child is merely the natural extension of our current discourse of reproductive rights. I see no virtue in the role of chance in conception, and great virtue in expanding choice. If women are to be allowed the "reproductive right" or "choice" to choose the father of their child, with his attendant characteristics, then they should be allowed the right to choose the characteristics from a catalog. It will be considered obsessive and dumb to give your kids only parental genes.'

Similarly, James Watson, who with Francis Crick discovered the double-helical nature of the DNA molecule, told *The Guardian* in 2003, 'If you really are stupid, I would call that a disease . . . So I'd like to get rid of that . . . It seems unfair that some people don't get the same opportunity. Once you have a way in which you can improve our children, no one can stop it. It would be stupid not to use it because someone else will. Those parents who enhance their children, then their children are going to be the ones who dominate the world'.

It may be unlikely in our age of reproductive freedom that the new eugenics will be enforced through mandatory sterilization—as in the past. There are, however, other, more subtle forms of coercion. Personal choice and consumerism are much more likely to fuel eugenics today. One day, when genetic tests are more widely available, it might even become illegal to bring a child into the world with a genetic disability.

Discrimination against persons because of their race, gender, or disabilities is an ugly reality. Discrimination based on genetic identity is even uglier. If we would preserve a truly human future for ourselves and for our children we must value individuals for who they are, not for what they can do. The laudable goal of treating human disease and relieving human suffering must not be allowed to become a tool for exercising 'quality control' over our offspring. To do so would be to use the good gift of genetic knowledge for evil ends. Only vigilance on the part of all of us can prevent a bleak genetic future. **E&M**

*Ethics & Medicine*

COMMENTARY

## WHEN DOES HUMAN LIFE BEGIN?

PATRICK YEUNG, JR., M.D.

Many arguments put forward for when human life begins. To simplify the debate, some claim human life begins at fertilization, while others say that human life begins at implantation. While both events are significant in the early development of human life, neither offers a *complete* answer to the question of the beginning of human life.

I will argue for a definition of the beginning of human life that uses concepts taken from systems biology, and will apply this definition to the current debate on somatic cell nuclear transfer and embryonic stem cell research.

Systems biology, an emerging field of research that seeks to understand the fundamental principles of living systems, has sought to distinguish an organism from a cell. In so doing, it offers us two important insights that are particularly helpful in determining when human life begins. First, systems biology recognizes that an organism is an independent, embodied process; that is, a single unified whole that manifests itself in various ways over time. Second, systems biology holds that an organism is a determined system that actively follows a particular trajectory. It is not passive, and does not require outside intervention to develop. Together, these two insights help differentiate static cells from dynamic organisms. An organism, then, can be defined as a *distinct embodied process that actively follows a particular trajectory*. If that trajectory is ever manifest in ways considered human, then the organism *from the beginning* is human.

When, then, does human life begin?

Human life begins when it *first appears* as a determined embodied process. This embodied process, from the outset, has an active capacity to be manifest in human ways. Thus, we speak not of a potential human, but of a human with potential.

Fertilization is the usual event that gives rise to a human organism in nature. It is a moment when a distinct embodied process appears that has the active capacity to develop along a human trajectory. Not all fertilized ova, however, have such a capacity. Hydatidiform moles are a case in point. They have a genome made up of human material and a trajectory that is distinct from its parents. But moles have a genetic make-up that is so different from a diploid zygote that they do not, and will not ever, have the capacity to be manifest in human ways.

Further, fertilization is not the *only* event that produces a human organism. Twinning, for example, is a natural event where an early embryo divides into two separate organisms. A new independent embodied process appears, which can develop along on its own distinct path. Twinning, an event like fertilization,

defines the beginning of a new human life. Fertilization, then, is neither necessary nor sufficient to define the beginning of *all* human life.

Implantation marks a significant point in the development of an embryo, since it demonstrates a particular stability of development. It is a clinical marker for the development of the primitive streak. This is significant because it is the point after which twinning does not occur. Implantation, then, is *a* defining moment of a human since it marks developmental individuality. But, it is not *the* moment when the embodied process first appears. The same process, which was initiated at some earlier time, only continues its development along a determined path. The embryo is, in essence, no different before or after the appearance of the primitive streak. Nothing is added, and nothing is taken away. The appearance of the primitive streak, or its clinical marker implantation, is not the beginning of human life. At best, it gives confirmation that an embodied process is developing along a human trajectory.

To summarize, then, fertilization is the moment when most human life begins, but not all. Implantation cannot be the moment that human life begins. Systems biology, instead, provides a definition for the beginning of human life that is complete and applicable to natural or artificial processes. It also shows the continuity of an organism in early development with a mature organism. Human life begins at the moment when it first appears a distinct embodied process.

This definition for the beginning of human life is relevant to the current debate on therapeutic cloning for embryonic stem cell research. Some claim that the product of somatic cell nuclear transfer (SCNT), formed by the implantation of the nucleus of a somatic cell into an enucleated ovum, can be treated differently from a zygote, formed by the fusion of sperm and egg. The argument is made that the product of SCNT, called a "clonote," is different from a zygote because they are created differently and because they are intended for different purposes. Systems biology denies, however, that one can know what something is if one knows only where it comes from. It is also inaccurate to define something based upon its intended use. Scientifically, the key to knowing what something *is*, is to know what determined trajectory that something will actively follow. A zygote is clearly a determined embodied process with a human trajectory as known by the way it is manifest.

What is a "clonote," then?

A clonote is also clearly an organism, since it is a distinct embodied process that actively follows a particular trajectory. However, we honestly do not know if a clonote is human, since we do not know what that trajectory is and the ways in which it will be manifest. While no clonote has ever matured to become an adult human, the recommendation that a clonote not be allowed to exist beyond 14 days indicates that it could. Of course, if it ever developed a primitive streak, or implanted in a uterus, it would be highly suggestive that it has a human trajectory.

In the face of this lack of full knowledge, the only prudent course of action is to treat the clonote *as if it were* human. In fact, it is *precisely* because the clonote seems to have a human trajectory that its stem cells are thought to be useful for therapy. It should therefore be given the respect deserving of human



life, and not destroyed for the sake of another human life.

Few would dispute the idea that respect for human dignity imposes certain moral directives on scientific research and medical care. However, it does not follow that respecting human life, from its very beginning, will deny patients needed care or restrict scientific progress. In fact, it is the *only way* to ensure its success. Adult stem cell research, so far, is the only area of stem cell research that has produced concrete results. Perhaps mother nature is telling us something. Surely, one should ask, if a clonote were not human, how effective will it be for therapy?  $\epsilon \& \mu$

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# CAN ARTIFICIAL TECHNIQUES SUPPLY MORALLY NEUTRAL HUMAN EMBRYOS FOR RESEARCH?

WILLIAM P. CHESHIRE, JR., M.D., NANCY L. JONES, PH.D.

## Part II. The Meaning of Artificial Life

*(Part I. "Creating Novel Categories of Human Embryos," was published in the previous issue of Ethics & Medicine [21:1].)*

### Abstract

Amidst controversy surrounding research on human embryos, biotechnology has conceived a substitute in the artificial human embryo. We examine the claim that novel embryos constructed artificially should be exempt from ethical restraints appropriate for research on embryos that come into being through natural processes. Morally relevant differences in intrinsic value depend on the sense in which the entity may be artificial, whether in regard to constituent matter, genetic or cellular form, generative means, or intended purpose. Considering each of these Aristotelian categories from a physicalist viewpoint, technology can achieve only limited degrees of artificiality because redesigned embryos still retain most of their natural features and relationships. From an essentialist viewpoint, the very limits of technology preclude the capability of manipulating the fundamental nature or essence of the individual who, even at the embryonic stage of life, cannot be made to be artificial through and through. A human may possess artificially contributed attributes but cannot be an artificial being. Classification of novel human organisms as artificial, therefore, is insufficient grounds by which to relinquish the principle that human moral status should be recognized for all living beings of human origin. In uncertain cases, at least the possibility of special human moral status should be considered present in organisms that are derived asexually, are developmentally defective, or are otherwise technologically altered.

### Introduction

When striving to resolve a conundrum, oftentimes clarity may be found by tracing an intricate problem back to its origin. The physicist seeks to understand initial conditions. The geneticist searches for the gene encoding phenotype. The philosopher asks fundamental questions. The student of human nature examines, among other things, the human embryo.

Having now crafted embryos artificially, modern biotechnology invites us to ponder a perplexing ethical conundrum. Should novel forms of human embryos, such as uniparental, multiparental, hybrid-parental, and xenohybrid-parental embryos, as well as embryos designed as flawed, be considered members of the human species?<sup>1</sup> These entities were previously unknown to nature. Their origins are artificial. What of their natures?

The return to origins finds, in this case, not relief in simplicity but bewilderment in complexity as biotechnology proceeds to invent more curious variations of nascent human life than even Aldous Huxley had bravely imagined possible. This is because the human embryo does not reduce to abstract minimalism on the scale of life in the way that a line collapses to a point. Nor is that of which embryonic stem cell research takes hold sheer nothingness.

The genuinely human impulse to inquire into origins, if pursued in earnest, encounters the transcendent and questions of faith which guide the heart. Much of bioethics distills down to the question asked of Jesus in Luke 10:29, "And who is my neighbor?" The distinction of who is and who is not one of us may be drawn inclusively or exclusively, charitably or insensitively. This paper will explore how technological manipulations of the molecular composition of human embryos influence their moral evaluation. That is, how artificial interventions affect judgments about their human dignity.

## **Embryos Made to Order**

Speculations regarding human cloning and embryonic stem cell research have heightened public awareness of questions of human dignity at the beginning of life. At the same time experiments in custom embryogenesis have further enlarged the boundaries of moral uncertainty, placing on science and society an ever more formidable responsibility to draw ethically valid distinctions to guide this field of research into the new millennium.

Some investigators have suggested that human embryos created through technologically novel means, such as asexual combination of gametes, cloning, or parthenogenesis, lack the moral value of embryos created through fertilization, in which genetic material from one egg and one sperm unite.<sup>2,3</sup> Jeffrey Drazen, for example, in referring to human embryos derived from novel forms of biomedical technology, substitutes the term "genetically compatible biomaterials."<sup>4</sup> Similarly, George Daley writes of the "reconstructed embryo" that nuclear transfer technology only "tricks . . . into reactivating embryonic genes" in the service of the scientist's "right to create customized human embryonic stem cells."<sup>5</sup> Additionally, Ron Green has offered criteria to classify embryos created via parthenogenesis and somatic cell nuclear transfer (SCNT) as something other than human embryos, arguing that they are asexually and artificially created without a history of natural fertilization, intrinsically developmentally incompetent, and laboratory contrived or invented biologic entities never before seen in nature.<sup>6</sup>

Sociologist Werner Rammert writes, "the difference between organic life and mechanical technology is diminishing. In biotechnology, organic life is now fabricated... and can be patented."<sup>7</sup> Does the application of technology to alter the genetic composition of the human embryo result in artificial forms

of life that may be categorized as morally inert and subject to ownership? Such attempts to designate as artificial those human embryos created through technology seem to draw from multiple levels of meaning of the English word *artificial*, which finds its origin in the Latin word *artificium* denoting not only “art or craft,” but also “cunning.”

The proposed criteria of asexuality, defectiveness, and artificiality will be addressed in turn. If these criteria are valid for barring such entities from inclusion in the human species, then arguments that appeal to respect for intrinsic human dignity at all stages of life become irrelevant to their evaluation. It will be argued, however, that because these criteria fail careful ethical scrutiny, such novel embryos should not be hastily categorized as nonhuman.

### **The Meaning of Asexual Origin**

Considered first is the question whether the *asexual* embryo is human. Nature frequently provides examples of genetically identical humans arising through an asexual process. In the case of identical twins and multimeres, a single recombination and fertilization process occurs. Identical twinning transpires though a nonfertilization or asexual process by later separation of the blastomeres.

Embryologists have mimicked this process *in vitro* by mechanically splitting embryos in the Petri dish to generate genetic clones following a single fertilization process. “Tetra,” a rhesus monkey and only one of four separated blastomeres to result in a live birth, was created by such a manipulation.<sup>8,9</sup> The SCNT technique of creating a genetic replica is novel, because the clone (cloning to gestation currently being only hypothetically possible in humans) would be of an adult, rather than of an embryonic sibling.

There are, therefore, examples of natural and artificial processes of asexual reproduction in the human species capable of giving rise to humans who, apart from genetic correspondence to their twins, are indistinguishable from humans conceived sexually. The criterion of exact genetic replication or asexual means of procreation is insufficient to designate an embryo as nonhuman.

### **The Meaning of Defectiveness**

#### *Perfect and Defective Life*

Whether defective embryos could be human has also been debated. For novel entities created in the laboratory, the first questions arise from within the field of biotechnology and concern the practical matters of whether defective embryos can be useful for research to elucidate normal embryology or safe if their cellular material were developed into therapeutic products. Biotechnology thus lays the groundwork for an essential question of philosophical anthropology, namely, whether embryos incapable of survival to term qualify as human organisms or human beings.

Must an embryo achieve a minimum number of cell divisions, or implant in a womb, or actualize certain potential anatomical or functional features such as a primitive streak or a circulatory system, or survive birth, or cry, or begin

to reason and attain self-awareness, or master spoken or written language, or receive a university degree, or perform some other function before qualifying as a human being? Contemporary views on when human life begins vary considerably and are informed by diverse personal, religious, and political perspectives, comprehensive analysis of which is beyond the scope of this text. The question, nonetheless, prompts another question, which is whether a non-arbitrary demarcation can be drawn along a continuum of development.

This discussion will limit its analysis to a comparison among embryos. It will focus on the specific question of whether the defective human embryo differs in moral status from the normal human embryo, noting that many thoughtful people are willing to attribute special status to this earliest stage of biologic human life. The question is also relevant to scientists and policymakers who do not believe that normal embryos have moral standing, for the prudential reason that research programs which avoid entanglement in public controversy can be more easily sustained and receive universal acceptance.

The capacity for continued life may be divided into the stages of viability and gestational competence. Often quoted is that up to 60% of embryos fertilized naturally in a woman do not implant.<sup>10-12</sup> John M. Opitz, in a presentation to the President's Commission on Bioethics, summarized that chromosomal abnormalities and imbalances, such as trisomies, monosomies or monosomy X, are the commonest defects of human development.

"It is estimated by multiple sources and authors and has been for decades that at the very beginning of life, of human development, of conception, about 50 percent of all potential human beings have a chromosome abnormality, mostly a lethal chromosome abnormality. Chromosome abnormalities are the commonest cause of death in humans. They kill at the very minimum two-thirds of potential humans, more likely 80 to 90 percent, and they mostly do so through these lethal aneuploidies."<sup>13</sup>

Much of the high mortality rate for human embryos in nature is due to lethal aneuploidies reflecting infidelity of genetic inheritance, particularly from faulty oocyte maturation. For this reason viability improves significantly when in vitro fertilization (IVF) procedures select euploid and reject aneuploid embryos for implantation.<sup>14</sup> The fleeting life span of the severely aneuploid embryo offers a narrow time window in which to detect physical signs of interest to the assessment of moral status. It may be concluded either that the failure to survive is itself a moral criterion, or else the true moral status in such cases is extremely uncertain, if not unmeasurable. Early embryonic death due to severe genetic defects has often been interpreted as "nature's spell checker."<sup>15</sup>

Of embryos viable into the fetal stage, the next survival threshold is gestational competence. Arguments for classification of embryos created via SCNT and parthenogenesis as nonhuman have emphasized their inherent gestational incompetence. Despite SCNT having produced a number of cloned mammals, as of the date of this writing no human clone has been reported to complete gestation. Although it has been possible to clone human embryos having a diploid human genome, complete gestation has been impossible due at least to the absence of correct genomic imprinting of developmentally critical genes. In

the case of parthenotes, gestational failure results from deficient imprinting as well as exposure of naked genetic load.<sup>16</sup> For these reasons successful human procreation requires genetic contributions from both genders.

Of the host of genetic and cellular variables that contribute to the viability and gestational competency of the embryo, it would be convenient to identify a single biologic factor that stands out as an unambiguous determinative criterion on which to base human moral status. The clearest biologic landmark, based on current science, would seem to be the structural and informational discontinuity of syngamy. Syngamy, defined as the fusion of gametes to form a new and distinct genome, represents the sharpest genetic singularity in the emergence of new life. The study of parthenotes and of other living products of biotechnology now blurs what previously had seemed at syngamy to be a sharp defining moment. An increasing number of novel examples of futile syngamy have been studied or designed in which embryos with new, distinct human genomes are fundamentally incapable of further development.

Remarkable advances in the ability to manipulate embryos have thus generated an ethical dilemma. Despite astonishing advances in knowledge about embryogenesis, in creating genetically flawed embryos for nonprocreative purposes, biology has nonetheless failed to discover the answer to the question of whether such entities should or should not be counted as brief human lives. To the methodology of empirical investigation this may be an intractable question.

The phenomena leading up to or distinguishing early life may also be viewed collectively. The threshold for moral worth could depend on the ability of the embryo to achieve the status of a unified, self-integrating organism possessing a human diploid genetic constitution. In addition to a distinct and complete genome, a minimal definition of a living embryo might require the possession of a functioning metabolic system and an active process of genetically directed cellular development.<sup>17</sup> The emphasis here would be less on genetic information content and more on unified, self-integrated, viable function. Yet there exist at every stage of growth intermediate examples of defective metabolism and developmental arrest leading to intrinsically truncated lifespans. These examples challenge intuitive judgments about what stage of development or maturation must be reached before a collection of cellular material has become a human organism and, indeed, whether that can even be detected or known in all cases.

The evidence from science suggests more and more that locating the boundary of humanity at the distinction between perfect and defective embryos is a false dichotomy. Normal human life, it turns out, usually begins and remains somewhere in the expansive middle ground of partial defectiveness. Defectiveness would appear to be a ubiquitous if not defining attribute of human life. If human life matters, then society's attitude toward defective human life, whether at the stage of elderly adult, newborn infant, pre-born child, or embryo, matters profoundly.

## **Perfect and Defective Philosophy**

Evaluation of the defective embryo should avoid defective reasoning. Also to be avoided is the fallacy of believing perfect truth to be discoverable through reason alone. The history of philosophy is replete with discourse on the question of what distinguishes human nature from the rest of nature. Philosophy's historical timeline has followed turns and twists that resemble more a convoluted—and in places blood-stained—roadmap than an incremental, progressive realization of uninterrupted moral progress. "History," said Thucydides, "is philosophy teaching by examples."<sup>18</sup> Correspondingly, history has provided examples both benevolent and disturbing of how the privileged have treated their defective neighbors.

In our time both the triumphs and blunders of thinking about nascent human life can be instructive. Contemporary philosophical trends have by and large withdrawn from the idea of an intrinsic basis of value present throughout human life.<sup>19</sup> Human dignity will not be put completely to rest, however, because human nature cannot help but provide, through biotechnology and its applications to culture, fresh indications that human dignity is alive and well no matter how skeptical some observers may prefer to be. The question of artificial embryonic life has revived the opportunity to reflect once more on the meaning of human dignity. For novel human life forms have moved into the embryonic neighborhood and are beckoning us to answer whether they are our neighbors.

There are at least two competing philosophical perspectives on the ontology of human life. While more sophisticated descriptions are possible, and although there are risks of misinterpretation and oversimplification whichever typology is chosen, nevertheless, for the purpose of this discussion on artificiality the following general framework seems helpful.

One view, which we will call the *physicalist* view, defines human life as contingent on the presence of a particular set of physical attributes. These are recognized by specific anatomical structures such as a human genome, a human face, fingers, or cerebrum, or by their functional qualities which may include respiration, perception of pain, self-awareness, or reasoning. By the physicalist view, function precedes dignity such that the moral status of humanity is to be found beyond a certain threshold of empirically measurable structure and behavior of the organism. Within this view living organisms which lack a critical defining function may not attain, or once acquired may lose, the moral status of human personhood. Physicalist views thus accommodate notions of gradual hominization as well as varying degrees of humanness or subhumanness. The physicalist perspective on life, in general, is compatible with a materialist worldview. Although ontologically reductive, as will be considered later, it need not be causally reductive.

The second view, which we will call the *essentialist* view, defines human life as a substance. The substance of human life, by its nature, has the potential, unless prevented, to develop structural arrangements and physiologic functions recognizable as human, yet ontologically precedes them and cannot be reduced to any one physical quality. By this view function is contingent on being, and the beginning of human life is intimately simultaneous with the onset of biologic



life. The embryo, by this view, is not understood to be a potential human life, but rather an actual human life directing her own development and in possession of the potential to actualize the structures and functions consistent with her special human nature. The human being then continues to exist as an individual person, throughout life retaining integrity of substance despite bodily change. The essentialist view accommodates the notion that humans are more than just physical arrangements of molecules, and also more than emergent higher functions, but without dismissing the body as unimportant. Under the essentialist umbrella, dualist interpretations recognize an immaterial level of reality joined to the physical, whereas holistic interpretations recognize transcendent value in life composed of a mysterious unity of the material and immaterial. The essentialist view also acknowledges the belief that all humans, qua humans, have equal rights which in the United States are protected Constitutionally.<sup>20</sup> The essentialist perspective, moreover, is compatible with worldviews that recognize a spiritual dimension to human life.

It is important to note that neither the physicalist nor the essentialist view is empirically verifiable. It can no more be proved through scientific investigation that human beings have purpose or immaterial souls than that human beings are matter in motion and nothing more. As the embryo develops into a fetus and child, the emergence of recognizable human features and functions will appear to the physicalist as evidence that human life now exists, and to the essentialist as evidence that already existing human life is now detectable. One's appraisal of human embryos both normal and defective depends, therefore, not only on scientific data but also one's underlying philosophical presuppositions and worldview.

What it means to be a defective human embryo depends on whether the embryo already is, or has not yet become, a human being. By physicalist criteria the nonviable or gestationally incompetent human embryo that possesses a distinct genome and behaves at first as would a normal embryo might not be fully human. Whether that defective embryo is a human being by the essentialist view is less certain. The physicalist may claim that the severely defective embryo never satisfied criteria for inclusion within humanity. The essentialist may concede that the minimal biologic substrate for human life was never there, or in other cases may appreciate the possibility that such an embryo is an immature human being who bears the burden of a genetic disease and is in need of repair. The criterion of defectiveness for one cancels the assignment of life, while for the other it may be interpreted as a degree of imperfect health.

Defectiveness need not be a matter of incompleteness. Impaired survivability can result from something lacking, or from something added. Inheritance of an extra chromosome, for instance, is responsible for trisomy 21 or Down syndrome. Overexpression, not absence, of certain genes such as p27Kip1 results in apoptosis or programmed cell death.<sup>21,22</sup>

Caution is needed when drawing from survivability data conclusions about moral value. Noting the statistically high rate of loss of preimplantation embryos in nature, it is sometimes argued that moral significance should not be placed on an entity with which nature seems so wasteful.<sup>15</sup> By that argument researchers should not be held to a level of accountability higher than nature.

To justify destructive research on the grounds that the cumulative outcome of embryo death seems no greater than the expected incidence of embryo mortality by natural causes, however, ignores the fact that the researcher knowingly has become the causative agent. Although "The sword devours one as well as another" (2 Samuel 11:25), intent matters.

Nature once appeared similarly wasteful in infant mortality. Modern—one might even say artificial—improvements in prenatal and obstetrical care have, over the last five decades, brought the infant mortality rate down from 29 to 7 per 1000 live births,<sup>23</sup> presumably without bringing about any change in the moral status of infants. Moreover, differing rates of infant mortality, when grouped by ethnicity (e.g. 5.8 for White, 14.1 for African-American, and 2.9 for Chinese-American infant deaths per 1000 live births in 1999), or by sex (e.g. 7.7 for male and 6.3 for female per 1000 live births of all races in 1999),<sup>24</sup> certainly do not reflect differences in moral status. We prefer to interpret these data to indicate that all human life is fragile. Although that fragility may differ according to genetic, social, medical, environmental, and other factors, fragility itself does not diminish the value of the individual human life. There are, in fact, numerous examples where children are born against significant odds due to inheritance of genes that often result in a high risk of mortality during gestation.

The philosophical beliefs that influence society's judgment concerning the moral status of embryos will likewise influence judgments concerning those at the margins of human life at other stages of development. It should be emphasized that current bioethical debate has questioned not only the moral status of human embryos, but by parallel reasoning also that of human infants, with particular attention to those who are defective. Professor John Harris, who is a member of the Ethics Committee of the British Medical Association, asserts for example, "I don't think infanticide is always unjustifiable."<sup>25</sup> To this Professor Peter Singer of Princeton University adds that, "...to end the lives of people against their will, is different from ending the lives of beings who are not people."<sup>26</sup> Singer clarifies that, in his estimation, such eligible nonpersons can include "newborn infants and some intellectually disabled humans."<sup>27</sup>

Science has become to bioethics a double-edged sword. While one edge of research explores the possibility of designing human embryos that some might judge to be morally neutral on the basis of developmental defects, the other edge discovers ways in which those defects might be repaired. Defects that potentially are correctable, on honest reflection, may entail a higher level of obligation, especially if their correctability were to promote a shift toward thinking of defective embryos as impaired humans.

Although reproductive embryologists currently lack the ability to correct inherent deficiencies in embryogenesis from uniparental or unisex sources, strides are being made to surmount these barriers in animal models. Considering that SCNT has now been achieved in nonhuman animals, and that parthenogenesis can be naturally procreative in some lower nonhuman animals, in principle it may be possible to learn to overcome the genetic obstacles to these alternative modes of procreation in humans.<sup>28</sup> Natural barriers once believed to be insurmountable and thus convenient biological landmarks for defining

the boundaries of human life might, in principle, be broken down by scientific advances just ahead. One prominent advance was the recent live birth of parthenogenetic mice, the first such birth in a mammal.<sup>29</sup>

We are not arguing for the protection and attempt to bring to term of severely aneuploid embryos that last only a few cell divisions or are intrinsically incapable of completing gestation. It is one thing to accept what happens in nature, especially when corrective resources are unavailable. It is quite another actively to proliferate nature's mistakes. We seriously question, therefore, whether science should set as its aim the creation of defective human life, even brief life, intending that life for destruction.

Those who hold to a physicalist view of humanity might not object to the loss of defective embryonic life, regardless of the cause, on the grounds that such embryos never had the potential to become persons and hence never possessed human moral status. In response, we maintain that it matters whether we allow ourselves to become the kind of people who consent to the destruction of life that, at least symbolically, is related to the human family. It matters also how society views defective members of our kind, for similar logic has been used to deny the potential worth of certain classes of impaired, defenseless children and adults.

We value highly the methods and contributions of the sciences. We also recognize that material criteria provide only a partial glimpse of the meaning of human dignity. There is more to truth than empirical investigation can apprehend and more to human nature than forceps can grasp or pipettes plunder. The view from the commanding heights of science, while accurate, yet is incomplete. This is why the exact sciences have never been the exclusive disciplines in our universities. Contributions from the arts, from reflection on the truth written on our hearts, and from the faith traditions greatly enrich our understanding of the value of human life.

The inadequacy of unaided naturalistic methods to provide a comprehensive, coherent account of the origin, meaning, and purpose of human life exposes the enduring incompleteness of the physicalist view of humanity based on materialistic presuppositions. Recurrent, gnawing reminders that life is more than matter should be reason enough to pause and contemplate at least the possibility of the essentialist view.

For those who hold to an essentialist view of humanity, very brief embryonic lives are, nonetheless, in some sense human lives. If the essentialist view is valid, then engineering for nonprocreative purposes human embryos that die prior to displaying unambiguous evidence of their humanity cannot be the same as engineering cells that never enter into human moral existence.

## The Meaning of Artificiality

### *By Means*

Three categories of artificiality may be distinguished. First, something can be artificial by *means*. A natural substance can be restructured by the intervention of nonnatural processes. For instance, by combining in the laboratory gaseous

oxygen with two parts hydrogen, it would be possible to construct water molecules by an artificial method that differs from the usual process whereby water is generated in nature. The resulting water molecules, once assembled, would be indistinguishable from ones occurring naturally. Natural and artificially generated water, in the language of Aristotle, would be identical in matter and form, but they would differ in efficient cause, that is, in the agent or power which brought about their molecular arrangement.

Through artificial means the 16<sup>th</sup> century alchemist Paracelsus purportedly fabricated the legendary homunculus. Paracelsus imagined that he saw in the stirring of incubated human sperm the quickening of a tiny, artificial, human being.<sup>30</sup> Contemporaneous speculation that such homunculi would eventually turn on their creators suggests a timeless intuition that artificial means of creation is insufficient grounds for ownership of one life by another.

The human being created through IVF also comes into existence through a contribution from artificial means, because technology is utilized to overcome natural barriers to procreation. The resulting human is artificial in that sense only. To illustrate this point, if the police office were to receive a call complaining that a next door neighbor conceived through IVF was a synthetic human, it would be the caller and not the neighbor who would likely be taken in for psychiatric evaluation.

### *By Information*

Secondly, something can be artificial by *information* content. An example would be an ice sculpture, in which matter is rearranged to give new form to something (water in its solid state) that already exists. Altering an embryo's genetic composition or selecting one from a group of embryos in order to ensure the survival of a desired genetic trait are examples of artificial interventions that impose information or order — Aristotelian formal cause — on something that in other respects remains a natural entity. These other respects include the considerable amount of structural information the entity retains in its natural form, for artificial modifications consistent with life would alter only a fraction of its constitution. Even if an entire functioning genome could be engineered without using existing cells, such an organism, though supposedly artificial, would necessarily utilize the same genetic code and generate the same types of macromolecules common to all organisms in order to partake of the nutrients nature provides. Rearranging embryos' structure does not extricate them from nature, and so it cannot render them totally artificial. Artificiality of living form, therefore, can be at most a partial artificiality.

Because informational content does not exhaustively explain the human person, someone who undergoes reconstructive surgery on part of the body or, hypothetically, receives gene therapy to correct a genetic defect receives an artificial structural alteration, yet that person remains what all would acknowledge to be a natural human being.

The larger view shows that life does not exist alone. Biological organisms participate in ecosystems in which they have purpose in relation to others. Enmeshed in the given reality of the natural order, living beings have natural ends. Aristotle called this final cause. Now that science has come to understand a

great deal about ecosystems, the question arises whether science should attempt to design alternative ecosystems, including alternative types of organisms, perhaps even altered human organisms that would find new roles within those systems or within research economies. Even aside from the disturbing hubris of such a proposition, there remains the precautionary concern that such designs could clash with and disrupt the delicate balance of nature as we know it.

The engineering of novel types of human embryos for the purpose of scientific applications is an attempt to harmonize the design of the embryonic entity to the investigator's research program, imposing upon the embryo a reconstructed nature or artificial final cause. Such embryos would exist for science and belong to science alone. If that premise were accepted, then there would seem to be no logical reason to restrict the generation of as many artificial embryos as researchers might desire. There would be no compelling reason to oppose projects that would cultivate to the fetal stage, to gestation, and perhaps to maturity, these beings whose sole purpose for existence was to be slaves to the scientific laboratory. After all, would they not be artificial? Yet surely they would not be artificial through and through. There is still more to consider in regard to the artificial and the natural.

The reach of artificiality to the composition and form of human life has further limits. Manipulating the informational content of biological structure yields artificiality of physical form. But there are many aspects to human nature that seem irreducible to explanation by exclusively physical terms. A complete account of all we know to be true of human beings must consider such phenomena as consciousness, free agency, the sense of unity of personal identity through bodily change, morality, and the capacity for awe. Mere possession of informational content, moreover, inadequately explains intentionality, the ability to enter into personal relationships, sacrificial love, insistence on justice, the search for meaning and purpose, even the desire to pursue scientific knowledge.

These higher human capacities are one of the most wondrous of mysteries. Where one looks for explanation depends on what one regards as fundamental to human nature. One model of human anthropology that, for the moment, enjoys widespread acceptance within scientific circles is reductive materialism. To the reductive materialist, who trusts only in matter and holds that the behavior of the parts fully determines the behavior of the whole, such capacities will seem illusory and subject to logical elimination. Occasionally nonmaterialist explanations are opposed with a vigor that exceeds what materialism should be able to supply. Ironically, artificiality to the reductive materialist can be no more than an illusion because human art and creativity themselves ultimately reduce to the blind causal chain of what are believed to be deterministic natural forces.

There is also the anthropology of nonreductive physicalism, which regards the human being to be a purely physical organism, while accounting for higher capacities as emergent properties arising from highly complex neural systems.<sup>31,32</sup> Within this framework, artificial rearrangements of an organism's molecular and cellular parts would not invariably render their higher capacities artificially determined. Nonreductive physicalism's appeal to a top-down

direction of causation, in which higher capacities influence lower level systems, locates human agency and intentionality within the complex feedback loops of neurological interaction and permits an understanding of self-determinism that might be viewed as auto-artificiality. But for the embryo, which has not yet actualized the potential for developing higher neurocognitive capacities, it may be that any and all characteristics are subject to external artificial alteration.

Nonreductive physicalism has little to say about the value of the little human organism which, although immature, yet has positively begun the trajectory toward developing the highly complex structures from which higher capacities will emerge. What is often overlooked is the marvelous unfolding of the human nervous system, with its ten billion integrated neurons and a hundred trillion interconnections, all from a set of molecular genetic instructions. This nontrivial process, many orders of magnitude more complex than any artificial product of technology, is actively set into motion during embryogenesis. Perhaps this human capacity, too, is morally significant, operating at an advanced level of function despite being microscopic in size, arising from as yet unexplored microlevels of complexity that nonreductive physicalism ought to take into account.

Nonreductive physicalism finds dignity also in interpersonal relationships. In those relationships, emphasis is not on the right of the individual embryo but rather on the moral obligations those with fully developed human capacities have to the vulnerable, the defective, and the underdeveloped of our kind. A robust community-based understanding of human dignity would therefore not necessarily require that all members included within the community have yet developed the higher neurocognitive capacities intrinsic to their nature. The community, as the agent responsible for the application of technology, may in fact have a greater obligation to those members whom it has artificially modified.

There is also the anthropology of substance dualism, which grounds personal identity in an immaterial soul that is intimately connected to the physical body during life and separates at the moment of death.<sup>33</sup> Whereas physicalist anthropologies hold that an organism's parts metaphysically precede the whole, substance dualism understands the person's internal essence to be from conception a unified whole that metaphysically precedes its parts. A person's unity to the physicalist is composed of parts, some of which may be artificially crafted, but to the dualist personal unity derives from a complex natural essence deeper than artificial interventions can penetrate. The irreducibility of the essence of the immaterial soul, and hence its independence from physical conditions at the beginning of life, implies an immunity from artificial impositions. This point leads to the third sense of artificiality.

### *In Being*

Thirdly, something might be artificial in *being*. In this case an intervention would not simply reshape matter. Rather it would completely cause the reality of the thing that is. Consideration of the category of being necessarily looks beneath and beyond the physical realm, and hence outside the methodological limits of science, to the metaphysical and to what some will regard as speculative and others will regard as scripturally revealed knowledge that begins to complete

the portrait of reality that science despite its splendor only roughly outlines.

For the essence of something to be artificial, it would not suffice to reshape existing matter. Rather it would have to be humanly created out of nothing, artificially begotten as well as made. The natural process of human procreation regularly achieves what technology alone cannot duplicate. Technology simply lacks the competence to create being. Its contribution is limited to manipulating what already exists. Likewise science, which measures the quantifiable, i.e. matter, energy and their information content, cannot offer a complete explanation of human life that accords with life experience and that can satisfy our deepest questions.

The prime example of creation of being is found in the theistic understanding that the universe and the creatures that inhabit it came into being *ex nihilo*—out of nothing—through the transcendent act of a divine creative intelligence. All that is natural is the product of divine creation, whereas human creativity, defined as artificial, imitates the divine.

Every human life is something that never before existed in nature. The physicalist view identifies that uniqueness in the means of origin and in the physical (molecular, genetic, cellular, and organic) constitution shaped at syngamy and subsequently reshaped and developed by the process of living and interacting with the environment. Nonnatural or human interventions at personal and cultural levels result in artificial impressions on human life.

The essentialist view recognizes, in addition to these, a radical form of uniqueness at the level of being. To the essentialist, no human can be an artificial being because the root of being is beyond the grasp of technology. Whereas the physicalist view acknowledges the first two categories of artificiality, only the essentialist view recognizes the third and most profound. Human life to the essentialist is not simply matter rearranged. It is also a mystery.

The sense of mystery is deepened by a philosophical problem inherent in all nonreductive human anthropologies. The problem is how mind shapes matter, and in particular how agency creates handiwork. The dualist is challenged to explain how immaterial substance can exert causative influence on material substance. The physicalist is challenged to reconcile higher level nondeterminism with lower level determinism, and to explain how higher level emergent properties can exert causative influence on lower level systems from which they arise. Causality somehow must bridge a categorical gap. And since the flow of causality is the medium through which artificiality is imposed, the nature of artificiality eludes full description.

## Conclusion

To answer the question whether artificial human embryos are our neighbors, physicalist and essentialist perspectives of human life provide helpful insights into the meaning of artificiality. These models approach the puzzle of artificial life quite differently. Whereas at the hand of technology the physicalist finds the possibility of artificial life, the essentialist finds only natural life with what may be an artificial contribution to its genetic constitution. When faced with novel human embryos assembled through technological interventions, the physicalist

view accommodates the claim that such embryos lack moral worth deserving of the respect that might be afforded to natural embryos. The essentialist view, in contrast, maintains that there is no such thing as an artificial human being. If artificial human embryos were truly possible, then so also might be artificial human beings at later stages of maturation, even child and adult automatons presumably lacking moral worth. From the perspective of the essentialist, the physicalist has mistaken origin by artificial means or artificial arrangement with artificiality of being. The idea of artificial human beings turns out to be itself artificial.

And yet the exploration of physicalist and essentialist views leaves much about human nature, including embryonic human nature, unexplained. This is reason enough to respond with great caution to the prospect of manufacturing artificial human embryos for research and to question whether subsequently destroying them would be good for humanity.

The answer to confrontations of biotechnology and ethical quandaries should not be to chart a science freed from ethical constraints. That would be an artificial hope. The work of science should always be directed toward the good of humanity, even of those too young, too small or underdeveloped, too unlikeable, or considered too defective to receive universal sympathy. While the moral status of human embryos has recently been disputed, it should be remembered that research done on the most vulnerable of human beings, particularly those unable to speak on behalf of their own interests, has traditionally been held to a higher ethical standard of ensuring the protection of its subjects.

The threshold of moral certainty in classifying novel versions of nascent life to be human or nonhuman should be held to a high precautionary standard. Although unequivocal evidence of protectable moral status may not be measurable or unambiguously verifiable in all cases, yet where reasonable uncertainty exists, the burden of proof should fall to those who propose to sacrifice uncertain human life. In regard to proposals that would design and sacrifice human embryos thought to represent artificial lives, the better part of wisdom is restraint.

To classify novel versions of nascent human life as nonhuman would have far-reaching consequences for how society will come to view vulnerable human beings at other stages of life who might not meet a given standard of perfection. The universal application of a logic that dismissed one category of human life could similarly be applied to bar from inclusion in the human family other examples of vulnerable lives which society ought to regard as being fully human despite their frailties and deficiencies. Indeed, to be human is also to be in some way defective.

A science perceived to be free from ethics would not lead to a free society, but to one with increasing divisions of who belongs to the human community and who may not. Even the embryonic steps of such a direction should be decisively avoided. **E&M**



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## ETHICS & MEDICINE

### CLINICAL ETHICS DILEMMAS

COLUMN EDITOR, ROBERT ORR, M.D., C.M., WITH ROBERT CRANSTON, M.D., M.A., F.A.A.N.; DANIEL BEALS, M.D., F.A.C.S., F.A.A.P.

*Editor's note: With this case discussion, we begin a new feature for Ethics & Medicine. Each column will present a case that poses an ethical dilemma for patients, families and healthcare professionals. The scenario will be based on a real case, though some facts may be changed to preserve confidentiality. The same information given the reader will be given to one or more Fellows in Clinical Ethics at the Center for Bioethics and Human Dignity who will write commentaries in the format of a clinical ethics consultation. Our goal is to offer careful ethical analyses and recommendations that are consistent with biblical standards. As will be seen in this first column, the consultants may not agree in their conclusions. Readers are encouraged to comment on our commentaries. Column editor: Robert D. Orr, M.D., C.M., Director of Clinical Ethics, CBHD.*

**A pediatrics resident called the clinical ethics consultant with the following question: May we accept this adolescent Jehovah's Witness' refusal of blood transfusion?**

Jennie is a 13½ year old girl who was well until two weeks ago when she developed knee pain. She subsequently ran a fever and was admitted to Community Hospital with a septic knee from a *Staphylococcal* infection. She was transferred to the Medical Center Pediatric ICU eight days ago with toxic shock and was subsequently found to have *Staph* sepsis (bloodstream infection), osteomyelitis (bone infection) of the femur and bilateral staph pneumonia with large pleural effusions (collections of fluid around her lungs). Her osteomyelitis has been drained and she was transferred to the Pediatrics ward three days ago. It has not been possible to relieve the effusions using standard drainage procedures or placement of CT-directed chest tubes, and surgical removal of the infected material (decortication) has been proposed for today. Her hemoglobin and hematocrit have dropped from 11.5grams/34.9% to 6.1/17.9. She was begun on erythropoietin several days ago in an effort to stimulate her bone marrow to make more blood cells. She is currently being treated with two antibiotics and is on supplemental oxygen and total intravenous nutrition.

Jennie is the oldest of five children in an intact family that has a long and strong Jehovah's Witness tradition. Her parents were both baptized as adolescents twenty years ago and regularly attend Kingdom Hall, raising their children in the faith. A grandfather and two uncles are Jehovah's Witness pastors. The patient is an excellent student in the 8th grade, and her teacher has told the pediatrics team that she is very mature for her age. She was baptized into the church five months ago after examination by the elders of the local congregation found her to have sufficient understanding.

The ethics consultant spoke with the patient (parents, one uncle and grandfather present) and she clearly articulated the Jehovah's Witness position on receiving blood or blood products. She quoted scripture and explained her understanding of Jehovah's prohibition and did not "want it on [her] conscience" to accept blood. She asked that blood not be used, "if possible." When questioned on this last point, she clearly stated that she did not want blood even if it meant that she might die as a result. She repeated this sentiment on re-discussion without her family present and after being told that the ethics consultant would accept her statement as her true desire rather than assume she wanted the doctors to over-ride her refusal.

Her physicians believe they must proceed with more aggressive intervention because of the lack of response of her pulmonary condition. The pediatric surgeon reports that decortication is likely to involve significant blood loss, and he believes it would be too risky to attempt this surgery without first giving her transfusions.

## **Commentary #1**

### *Assessment*

This mature adolescent agrees with her parents and church to refuse blood products. The surgeon believes surgery is too risky without a transfusion.

### *Discussion*

Blood transfusions for Jehovah's Witnesses continue to cause disagreement among patients and medical professionals. Many hospitals have transfusion policies and most physicians are willing to accept adults declining transfusions for themselves. It is more difficult, however, to allow parents to make such decisions for their children.

There is a growing consensus among pediatricians<sup>1</sup> and ethicists<sup>2</sup> that decisional capacity is not an all-or-none phenomenon conferred on children at the legal age of majority, eighteen in most jurisdictions. Most experts believe it appropriate to consider an adolescent's level of maturity and respect his or her input in making important treatment decisions.

In this case, the patient (a) is considered mature by her teachers and physicians, (b) has thoughtfully accepted the Jehovah's Witness faith before this event, (c) can articulate the consequences of her decision, and (d) continues to adhere to Jehovah's Witness standards in and out of her family's presence.

Honoring her refusal would be more troublesome if (1) she were younger, (2) she disagreed with her parents, (3) there was dissension in the family or fellowship, or (4) she was teetering more emergently on the brink of death.

We may attempt to dissuade her from this decision, but we cannot coerce her.

### *Recommendations*

- 1) Clarify what procedures are acceptable to this patient. Some individuals or fellowships will accept alternative measures (e.g., hemodilution techniques). Meet with the patient, family and local spiritual leaders to establish parameters.
- 2) Postpone surgery, if possible, long enough for erythropoietin to improve the anemia.
- 3) Obtain a second opinion if, after parameters are known, the surgeon refuses to perform the operation. The local Jehovah's Witness leaders may know surgeons who would be willing to honor their convictions.
- 4) Consider transfer outside the system if no local surgeon is agreeable. 100,000 surgeons in 150 countries—many in the US—are strongly committed to low blood loss surgery for their Jehovah's Witness patients.

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### **Commentary #2**

#### *Assessment*

A fully conscious thirteen-year-old adolescent and her parents are refusing a potentially life saving blood transfusion. The ethical dilemma centers around whether this refusal should be considered valid and what course of action should be taken.

#### *Discussion*

Misconceptions abound about both adolescent consent and blood transfusions for pediatric Jehovah's Witness patients. Adolescents have a limited amount of autonomy predicated on their advancing age and behavior. Except in limited situations, primarily concerning reproduction and birth control, adolescents are not considered legally competent to make independent medical decisions in most jurisdictions.<sup>1,2</sup> This is especially true in emergent situations when there is not sufficient time for the child to understand and digest all of the various ramifications of consent or refusal. In most instances, the parents then would have the authority to give consent. In situations like this, legal opinion is quite clear. Although the adolescent child can accurately articulate the Jehovah's Witness belief on blood transfusion, she should not be considered competent to make this decision in an independent manner. The parents who are free to decide for themselves about a blood transfusion therapy do not necessarily hold that authority for minor children. As one court declared "while parents may feel free to become martyrs themselves, they are not free to make martyrs of their children".<sup>3</sup>

Although this legal reduction is quite clear, medical care is not so. Healthcare workers should acquiesce to parents' and children's wishes as

much as possible if such treatment is compatible with standard care.<sup>1, 4</sup> In this case, the decortication surgery could probably be delayed for a few days. It is possible that pre-operative preparation and judicious surgery could accomplish everyone's goals without the necessity of blood transfusion. If surgery is undertaken, the surgeon would have to be prepared to provide immediate life saving transfusion if such became necessary during the course of the surgery or afterwards by obtaining a court order for this therapy.

Expecting consent from either the adolescent or the parent for blood transfusion in this case is problematic. Jehovah's Witnesses believe that blood transfusion is sinful and can cause eternal separation from Jehovah. To ask consent for a blood transfusion is tantamount to asking the family to recant their faith.<sup>5</sup> This would be especially troublesome if the adolescent was pressured to accept blood transfusion. The patient and family beliefs about blood transfusion should be properly assessed by the healthcare team, however once established, the decision to perform blood transfusion should become a matter of court decision and the family should be so informed.

### *Recommendations*

In light of the patient's age and uncertainty as to whether blood transfusion is truly necessary at this time, the following treatment options would be ethically permissible.

- 1) After confirming the family's preference about blood transfusion, a court order should be obtained for such a transfusion, but blood products should be given only in the case of true emergency. In this way, the family's preferences are respected up to the point where the healthcare team can truly say transfusion was only given to save the child's life. Conversely, since the family did not consent to blood transfusion, they have not recanted their faith and they may not consider the forced infusion of blood products as a damnable offense, but more akin to battery.
  
- 2) Although the case is presented as a single decision for more aggressive therapy, there may be other options such as minimally invasive surgery or the use of fibrinolytic agents. Although these may be less effective and have the potential for complication, they should be considered if the end result would be compatible with standard care.

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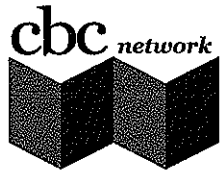
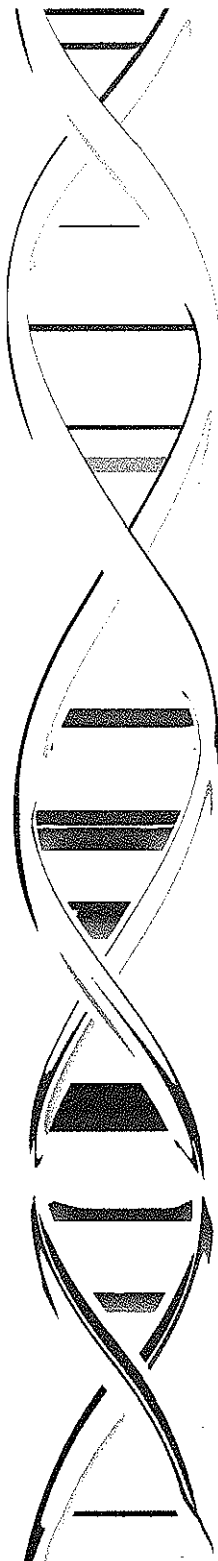
### Case Follow-Up

The child was transferred to another hospital with a “bloodless surgery” unit. The needed surgery was performed a few days later without transfusion of blood products. The patient survived. **E&M**

- 1 Committee on Bioethics, American Academy of Pediatrics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995;95(2):314-7
- 2 Jonsen, Siegler, Winslade. *Clinical Ethics*, 5th ed. McGraw-Hill: New York; 2002:50

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# APPLYING THEOLOGICAL DEVELOPMENTS TO BIOETHICAL ISSUES SUCH AS GENETIC SCREENING

PIERRE MALLIA AND HENK TEN HAVE

## Abstract

Catholic movements within the centre of Roman Catholic doctrine recently have discussed Trinitarian theology as applied to sciences, arts, economics, health and other social areas. We explore the possibilities Trinitarian theology offers to bioethical debate, concentrating particularly on genetic screening and testing. It is important therefore to analyse the philosophical implications of this approach onto the bioethical world, where much disagreement occurs on fundamental issues. It is Catholic basic teaching to recognize and see God's hand in plurality, not merely as a cliché and then doing what we feel is right, but to recognize how to live in a pluralistic world. We recognize, in agreement with these theologians, that in order for a Trinitarian mode of understanding to be used by those doing bioethical debate, there is a need to depart from fundamentalism.

## Introduction

New developments in the understanding of Trinitarian theology by Catholic movements<sup>1</sup> in the heart of the Roman Catholic Church is exploring the impact of this new mode of living in areas ranging from economics to health care. This paper explores the possibilities offered to bioethical debate, with special attention given to genetic screening and testing, by such developments with a particular hope of an abandonment of fundamentalism and an embracement of pluralism, which, most theologians agree, should form the attitude of Christians in the third millennium. The basic issues that lie at the heart of genetic screening and testing are fundamental issues of bioethics, which have been debated since the birth of the subject. These can be summarized as the status of the embryo, discrimination against the disabled, and questions of justice towards those who would have genetic tests. The first two come down to selective discarding of fertilized ova to be used for implantation and selective abortion of embryos found to have unwanted genes, either for the purposes of eliminating particular disorders such as congenital malformations or genetic diseases as is Down's syndrome, or, to aim at having the "perfect baby" (term taken from McGee) by selecting genes (McGee, 1997; Gosden, 1999). At the base is the question of the status of the embryo. Although some advocates for the disabled have indeed expressed themselves as pro-choice the issue here is not the status of the embryo but discrimination, it has in fact been argued (Parens

& Asch, 1999, p. 2) that such an argument has little logical validity. Be that as it may, whilst no one has expressly denied the rights of the disabled, the fact that people may chose to kill an embryo to eliminate a genetic disorder (but not a *newborn* with the same disorder), shows that the argument is not on infanticide but about the status of the embryo.

Indeed market forces form a sort of symbiotic relationship with medicine; the one provides the service, the other the drug. There is a mutual need to achieve both ends. But whilst one end teleologically is that of providing care and cure, the other end, which inevitably is to be respected, is concerned with financial outcome. It is in this scenario that genetic tests are marketed. A Trinitarian approach as applied to these test is discussed.

### **A Trinitarian Approach to Dilemmas**

Catholic bioethics, or Catholics doing bioethics are faced with these dilemmas on one side and counter philosophical forces on the other. Whilst the worst opposition is a liberal force of relativism, that which takes heavy precedence in western thought today is a more pragmatic analysis, which although confessing not to be relativist (Rorty, 1988, p. 160), is indeed a call to put aside some values when debating issues of biological significance (McGee, 1997, p. 170). Faced with these stances, the Catholic has two roads of action. The first is a direct resolve to work against such forces; a 'crusade', for example, to safeguard life. A second approach being proposed (Gambon, 1999; Coda, 1987, 1998, 2000; and others) is the contemporary rediscovering of a trinitarian approach which in understanding the 'other', empties oneself from preformed prejudices and aims to 'be one', in unity, with the other, thus proposing a new 'ethics' of behaviour. Paradoxically, this 'emptying oneself' resounds of a pragmatic approach. But emptying oneself does not mean accepting what one perceives as wrong. Rather it is a more non-judgemental approach where both sides are open to change. Although such an approach relies also on spiritual faith, rather than merely the rational, the method merits philosophical discussion if we are to understand whether it has a sound working basis.

It is not the first time that the Catholic church has changed stance on controversial issues. Maybe the most important issue tackled the past century was that when the mother was sacrificed to save her baby. Such a situation was reversed in 1985 by the Belgian Episcopal Conference, which used the principle of double effect to effectively reverse the situation and allow the sacrificing of a life, which is unintentional, in order to save another life. That the opposite effect can be brought about also rationally, and with the same force and faith as pretext, is indeed an act not only of courage but of emptying oneself from preconceived ideas to become one with society to understand its problems. Such are the pretexts of *kenosis* and *perichoresis*, the trinitarian corner stones of dialogue.

*Perichoresis* (Gr. *Perichoresis*, "penetration"; Lat. *Circumincessio*, "incoherence") indicates the intimate union, mutual indwelling, or mutual interpenetration of the three members of the Trinity, the Father, the Son and the Holy Spirit, with each other (McKim, 1996, p. 206). *Kenosis* (Gr. *Kenosis*, "emptying"; Lat. *Exinanito*), on the other hand is the theological term for

the 'self-emptying' of Jesus Christ, through which he relinquished heavenly authority to accomplish the work of salvation by his death and resurrection, emphasizing strongly the humanity of Christ (Ibid., p. 153).

The first part of this article looks at the history of Trinitarianism in the philosophy of Hegel, who was the first to introduce new concepts. This is followed by a look at how and where this new philosophy is being conceived; finally the third part asks what are the prerequisites for such a model to work in the field of bioethics focussing specifically on genetics. Whilst it is understood that a Catholic may use trinitarian concepts of emptying and being-one with the patient, it is less conceivable how one can understand resolution of dilemmas using this approach. Naturally this implies a different approach than has been achieved so far with each side trying to find philosophical argument to justify its position. It involves a change in the 'lifeworld', so much argued for by Habermas (1984).

### Hegel's "Congenial Intuition, but Fatal Betrayal"

Hegel's philosophical influence on contemporary theology is undoubted and if we are to understand the logistics of how contemporary Trinitarian theology is to be lived-in-the-world, we must first appreciate these foundations. He was the first to centralize the concept of the 'negative' and the ontological and existential significance of 'non-being' in Trinitarian theology (Coda, 1987, p. 396). The International Theological Commission (1980) recognized that Hegel was the first to underline the importance that an understanding of God must include the concept of the abandonment on the cross. It clearly stated however, in its brief examination of Hegelian philosophy, that Hegel's concepts of God's negativity do not conform to the Catholic conception of God. The commission did not give any reason for this, leaving open the possibility for theologians to make further in-depth studies of Hegel's philosophy when contrasted with Christian faith (Coda, 1987, p. 22). On the other hand, as noted by Lafont, who has been described as a keen and equilibrated theologian (Ibid.), it is the duty of theology today to work for a reconciliation between classic and modern theology, which presents itself under the negativity of Christ on the cross (Lafont, 1979). It is for this reason that Kasper (1982) has noted that Hegel and German ideology have an urgent need to be elaborated upon by modern theology. Modern theological views on Trinitarian historiography thus depart from Hegel.

Coda (1987), Catholic theologian at the Roman Catholic 'Pontificia Università Lateranense' in Rome, has made a clear attempt to reconcile Hegelian philosophy of the negative with Trinitarian theology. Hegel was the first philosopher to centralize the concept of the negative and the ontological and existential significance of the 'non-being', as playing a central role in Christianity. It is clear therefore that even for his concept of 'negativity', he made a "congenial intuition" but a "fatal betrayal" (Ibid., 396) because he failed in centralizing the concept of the person, which was the reason for the Commission's conclusion. Hegel however did centralize with precision where one should approach the mystery of the non-being as disclosed to us by the *kenosis* and the death of the Word, that is, the mystery of the Cross. In reality, if Christ on the cross reveals the mystery of the trinity, it is because he reveals,

in that abyss of *emptiness*, represented by His death on the cross, the profound mystery of being-a-person of divine Beings. This signifies that the mystery of Divine Beings lies in their paradoxical *non being* in a state of love (Ibid., 397).

The moment of Christ's abandonment on the cross, when He calls out asks why He has been forsaken by the Father, is a crucial moment which can only take place in this state of non-being: the emptiness described as 'kenosis', or the kenotic experience in which He empties himself of Divinity to take on all sin – the greatest possible suffering for a Divine Being. It is in this moment (not recognised by Hegel) however that He is united with the Father (perichoresis). For Christians to love the cross is not merely a manifestation of love towards this divine being who took onto Himself our sins for our salvation, but also to love suffering and live like him. Not because our suffering unites us to him in paying for the sins of the world – he surely does not need us mortals – but because in all the suffering we see around us we can recognise Him (Ibid., 399). Was it not He who told the faithful that they will find him in the poor, in the undressed, in the prisoner... Therefore, abortion, euthanasia, prostitution, are construed as negative and thus as manifestations of His suffering. Hegel is deemed wrong is in defining this non-being of Christ as an alienation from God (Ibid., p. 399). In fact it is not, because paradoxically it is in this non-being that, albeit remaining three divine Beings, They become one. This is what the Greek 'fathers' called perichoresis, which Hegel, with his reasoning could not conceive. Lacking an exact hermeneutic of the trinity, Hegel could not comprehend the authentic significance of nothingness.

### **The Significance of *Kenosis* and *Perichoresis* and in Ethics**

What significance does all this have for bioethics? For Christians the Trinitarian life can be expressed in many situations. In marriage two people can become 'one body', yet remaining physically different. If a couple mutually lose themselves in each other for love they act perichoretically (Gambon, 1999, p. 33). For this to happen, each must empty oneself of his or her being in order to enter the other. This allows the possibility of truly comprehending the world of the other. When this attitude is mutually reciprocated, then one can be said to have a perichoretic experience. Gambon lists how this perichoretic rapport has been explored in other settings.<sup>2</sup>

However, whilst it is easier to conceive of how Catholics can live their lives in society, it is less easy to see how fruitful such 'principles' of kenosis and perichoresis can help in an area where people of different religious denominations or secular groups come together to discuss issues on which there is such profound difference. Issues of rights to assisted suicide, to cloning, to abortion, to selective non-treatment of malformed newborns etc., cannot be resolved however, as has been in matter of fact, by mere argument. Even the Catholic world has tackled bioethical issues in a less Trinitarian fashion albeit with reverence to fundamental beliefs. But it is undisputed that the present day crusades of the Catholic laity and media has concentrated more on hosting wars against abortion, say, and lobbying for legislation which does not favour these immoral standards. There are no studies to show how many pro-choicers, say, have been converted by mere rational argumentation. It is often the case

in fact that one argument leads to a counter argument which in turns leads to another, making the field of philosophical debate a quagmire of contrasting rationalities.

Rational arguments seem more intent on convincing legislators than on converting the ideas of people. The Society for the Protection of Unborn Children (SPUC) recently launched a High Court bid in London (Feb. 12, 2002) to halt over-the-counter sales of 'emergency contraception', on grounds that the pills cause early abortions. The intent is to place a question mark on the legality of this kind of contraception as they go against the 1861 Offences Against the Person Act.

It would be appropriate, after almost four decades of bioethics debate, to ask the 'quo vadis' question. If bioethics has been merely an area of debate and has not been instrumental in also *changing* hearts of people by rational argumentation, then we can clearly say that something more than rational argument is needed to convince the other. There must be a 'code of conduct' to guide people doing bioethics from whichever secular or religious denomination they come from.

## Relation Between Trinitarian Theology and Ethics

### 1. Social Attitudes for a Kenotic/Perichoretic Foundation

At this stage we propose to describe some characteristics and attitudes which characterise this ethic. Cambon (1999) has described a number of social attitudes that characterize foundations of kenotic/perichoretic principles. The first is Solidarity (Ibid., p. 75-78). Today's globalisation is undeniable. Teilhard de Chardin had written that the time of nations has passed and we need to construct the earth (o.c., p76). Gambon recalls President Kennedy's famous remarks on independence – that we should declare an *interdependence* among peoples reflected also in the encyclical *Sollicitudo rei socialis* where Pope John Paul II declares interdependence, not only between people but also between nations, as a necessary social and *ethical* norm for solidarity (o.c., 76).

A second attitude is Liberty (o.c., p. 78-80). Historically those who dominate and win over others have been considered truly free. In slave societies, only lords and the rich were free; slaves, women and children were not. The free man's liberty meant oppression for others, his power meant submission, his riches, poverty. Today we understand that every individual can be a barrier to another's freedom. Every individual is free in his or her own sense, but may remain inconsiderate towards the freedom of others. Such may be the industrial concerns to promote a test, compromising the freedom of others not to have that test done, when social pressure considers it a must. An AIDS test today, if refused, even by people who are not high risk individuals will compromise insurance cover. True liberty is that liberty which is communal; that which is charitable. I am free not only when I feel free and when I open my heart towards others, but when those others respect and allow my freedom of being and open in turn *their* lives towards me and share it with me. Liberty as dominion, in all its forms, destroys communion; liberty as communion, by contrast, destroys power and hatred between social classes.

Yet a third attitude is Participation (o.c. p. 81). There can be no true liberty and solidarity, and hence no true Trinitarian life, without the opportunity for all to participate. Without attention to those without a voice and to the side-cast of society, these members cannot participate in the community. In this regard Habermas' communicative ethics plays an important role in setting the scene for members of the community to participate in dialogue. 'Reaching understanding is the inherent telos of human speech' (Habermas 1984, p. 287). Communicative action, or 'action oriented to understanding', is contrasted with strategic action, in Habermas' work, or 'action oriented to success' (Scambler 1998, p. 47). Habermas contends that modern societies have witnessed a fundamental 'uncoupling' between the economy and state on the one hand and the private and public spheres in the 'lifeworld' on the other. These four domains are interdependent and each relies on what the other has. The economy produces 'money', the state 'power', the public sphere 'influence' and the private sphere 'commitment' (o.c., p. 48). For Habermas, the principle of universalisation has to do with moral questions of 'justice' and 'solidarity'; the principle of discourse ethics conversely has to do with ethical questions of the 'good life' (Habermas 1990, p. 66). Discourse ethics promotes priority to moral questions of justice and solidarity as a deontological theory (Scambler 1998, p. 51). Discourse ethics does not purport to resolve substantive ethical issues, but resolves to bring together those involved who must then find out the answers in a procedure of decision-making (Habermas 1990, p. 211). What is required in this regard, according to Scambler is an extension of substantive democracy, which alone affords genuine participation of citizens in processes of will-formation (o.c., p. 52).

On the other hand Scambler, referring to Habermas' work, contends that a critical society is committed to removal of deliberative inequalities of power, communication and politics (o.c., p. 63). Yet a Trinitarian society, by default, *recognizes* inequalities and asymmetries in society. This recognition is a fourth condition or attitude to Trinitarian principles (Cambon, 1999, p. 86). As Adorno would describe love as the capacity to find similarities in what is different and Hegel that there is no love without differences, disparity is an invitation to seek mediation. *Only by valuing what is different* can we have an effective interdependence (Tommasi, 1996, p. 44). Habermas can be said to have worked the framework for dialogue but stopped short of a method. However we can see the beginnings of a link between trinitarian theology and ethical argument.

Another attitude is Plurality. Unity-Plurality, is another way of describing what is Trinitarian by definition. This is perhaps the most important attitude to bioethics. Again Gambon describes well what pluralism means to the Catholic. Certainly a unity which is expressed in plurality is not simply accepted because there is no alternative, but which would readily be avoided. Neither is it a demagogic concession to appear modern and open, or some strategy that then in reality seeks the prevailing of one's own convictions. It is conversely a necessity, "if one is to support God's plan on earth" (o.c., p. 91). It constitutes an attitude that all people are called to live. Now it is clear that a pluralistic society, even though more human, needs a greater maturity, because it becomes more complex and requires more responsibility. But the Christian, who knows the value of suffering and has at heart the unity of humanity, has to feel the need to absorb even these tensions that pluralism brings about. A Trinitarian pluralism

besides being able to interpret the more difficult social situations and conflicts requires 'historic patience' and an utopian/creative capacity, (Bastianel, 1990: 230). These indeed are deep rooted words which may even be misunderstood by Christians not well versed in Trinitarian Theology. Yet they open the road to a value-pluralism, where fundamentalism would be difficult.

The final two attitudes presented here are 'Openness to Others' and 'Alterity'. The first seems obvious as openness is synonymous with kenosis in many senses. Now Cambon notes that Merleau-Ponty has criticized Christians as being poor revolutionists and bad conservationists (o.c., p. 97), and it would seem just to weigh such criticism. In fact the Christian is called to revolutionize his world, because God's plans are always much greater than one can ever comprehend. The Benedictine theologian G. Lafont (1994) has noted that if the ways Christians uphold monotheism is Trinitarian, it will open new ways and values, which are more communal, and pronounce more attention to just causes and to the novelties of every generation and epoch. He contrasts this to merely upholding an image of one-God, itself of value, but which also upholds an immutable stability (o.c., p. 97).

Alterity (in Italian *alterita'* = *il porsi come l'altro*; hence 'being' or 'living' the other, which in effect is close to empathy) is a typical Trinitarian aspect which has evolved from western contemporary thought. It is found very originally in Levinas' work on the 'face of the other'. Levinas (1984), identifies the ethical attitude as the capacity of the 'I' to give space to the 'other'. When the human being acts in this way, he resembles God, who empties oneself and makes space for the 'other' – that who is different. 'Creation' signifies an 'infinity' that assimilates into oneself a being 'outside oneself' (Levinas, English trans., 1969, p. 293). This is exactly the primordial aspect of kenosis (Gambon, 1998, p. 87). Levinas identifies this capacity of recognizing and being recognized with 'the face' (Levinas, o.c., p. 198-199).

The face is equivalent to the person. 'To give face', 'to look into ones face (or eye)', 'to save face', are all expressions with profound meaning. To be able to look directly into the face of someone means being able to treat that person with respect and fairly. For the bureaucrat it means giving his services, for the governor, the doctor, the businessman, as not considering persons as being mere numbers (Gambon, o.c., p. 88). Therefore whilst in the classic ages, especially Greek, the vogue word was 'being'; in modernity it was the 'I'; in the third millennium it should be the (Mancini, 1989, p. 68-69).

We can continue to debate and to counter argument each other on journals or otherwise without ever making a true effort to 'be with' and comprehend the other. This requires making space for the other, making an emptiness, whilst at the same time maintaining identity (perichoretic) and not annihilating one's values. This is where pragmatism differs from Trinitarianism. By simply negating the arguments of the 'other', even if for noble and fundamental reason of faith, we are effectually 'killing' the other; we cease to look him in the face as a person expressing his liberty and communication and solidarity; a person which longs to be heard.

## *2. Can One Use These Concepts Outside a Trinitarian Spirit*

Prima facie one may say that these principles may be applied to bioethics without invoking Trinitarian Theology. One must therefore secure the relation between this theology and ethics. In fact it is this which gives Trinitarianism its strength. One can envisage that Trinitarianism as a lived experience comprises all these mid-level principles; yet one can envisage also presenting them as a coherent group of prescriptions for dialogue in bioethics without invoking a religious title. It would be impossible to see people of other denominations, or non-believers, to be persuaded to use "Trinitarian" principles as their mode of dialogue. But when presented neutrally, without the theological label, they are easily adapted. The lived experience is not in acknowledging the one is using a theological prescription but in the inherent use of these mid-level principles. The ethic is in the appropriate dialogue rather than in the spirituality behind it. As an analogy, most religions advocate love towards others as a way of living. But someone who loves others need not acknowledge or indeed know he is living a particular spirituality, which, at the end of the day he is.

However it is important to emphasize that one is not prescribing a core of mid-level principles but a paradigm of a *lived* experience of kenosis and perichoresis. It does engage however a discernment which requires a continuous 'dying' to one's own 'absolute' positions; being ready to lose that which is not from God and which seeks unity rather than uniformity and conformity. It is therefore an ethics of *lived experience* — a phenomenological experience.

There is a danger of course of identifying any of the conditions, teasing them out, and saying that one can perfectly live in perichoresis and kenosis, which omitting this particular principle. One can say that Trinitarianism is perfectly possible without value-pluralism. But celebrating value-pluralism is not a form of relativism. It is rather an exercise of all sides 'dying' (kenosis) to their own fundamentalisms. We usually want 'the other' to lose his fundamental beliefs; but that does not apply to us. But since all sides are participating in this equation, then we remain where we are. Gambon (o.c., p. 93) considers three current versions of Christian groups: the *traditional*, the *progressive*, and the *social change*. The first is a paternal position which is faithful to tradition and authoritarian memories. The second is more humanistic which recognises the legitimate autonomy of the various earthly realities. It evokes the filial attitude who 'became one of us'. The third emphasis a praxis and a social involvement reminiscent of the spirit of love. Yet each of these three attitudes requires the other unless they fall into their respective faults - the paternal risks of becoming too rigid, sterile; it does not listen to what the other has to say, becoming individualist and intimidating in the process. The second, open to its legitimate attitudes risks atheism - not listening to the traditional paternal dimension of the Church. The third, even worse, risks using social involvement without the discernment which comes from doctrinal reflection. It ends up in a form of anarchy. One needs the other just as the three members of the Trinity require each other.

## *3. Approaching Genetic Screening and Testing with Trinitarian Principles*

Certainly, making an ethical argument which is sufficiently clear and strong



without creating an effect of a juxtaposition rather than an integrated argument is not easy when trying to convert theological reflections into bioethics. We have discussed the necessity of working and integrating pluralism and moving away from fundamentalism as suggested by Lafont. The interdependence of societies and culture, respecting true liberty, participation and communicative action all need a recognition of *inequalities* and *differences of opinion*. Pluralism is not a mere cliché. It requires openness and alterity — which gives space to ‘the other’; the other who disagrees with my view on abortion, euthanasia, genetic testing, etc.

Cambon reflects upon this as a ‘new logic’ (o.c., 195). He affirms the only sense in which a Trinitarian spirit of dialogue is possible is through an abandonment of fundamentalism as it cannot insert itself in social life without a sense of mediation. “The Trinitarian paradigm does not offer us technical ‘recipes’, but a style of life...at the same time, in order to put into practice such criteria an objective analysis of reality, formulating concrete projects and social, political and economic necessities (o.c. 196). He also affirms that one cannot have an ‘ideological instrumentalization’, that is use Trinitarian theology simple to affirms one’s convictions.

Translating this into the Bioethical reality may need more thorough analysis as many of the issues boil down to fundamental beliefs. It may be used to prevent consumerist abuse of genetic tests. One can envisage the use of genetic technology once a couple has opted for IVF because of infertility and who know they carry a genetic disorder such as Huntington’s, to avoid implantation of fetuses carrying defective genes (without of course having otherwise fertile couples using IVF solely for this purpose). Reaching a consensus on polar body biopsy would allow the moral appropriate path to use genetic selection before an embryo DNA is formed. Naturally each of these suggestions would need scholarly argumentation beyond the scope of this article. However Bioethics may pose deeper problems in departing from fundamentalism than are political, social and economic norms.

Genetic testing poses its problems of treating the person as a means to generating revenue from genetic tests (Chandros Hull and Prasad, 2001). Genetic tests are marketed in a way which bypasses the health care professions, and even proper counselling. Clearly any counselling done by a representative of the company promoting the tests would tend to be directional. A dialogue is necessary between the marketing world and the medical world, which exist in symbiotic relationship. An attitude of primordial kenosis and perichoresis can be encouraged and engendered in most parties and the industry brought to understand that notwithstanding its teleology of profitability and marketing, the person must remain at the centre of debate, not instrumentally but ideologically. Instead of seeing the marketing potential we the person-centered reality.

The World Health Organization (1983) may think twice before issuing statements as the one issued for Cyprus as a clear example of how one can eliminate genetic disorders. Clearly the person is not central to such statements and the focus is on economic trends and eliminating burdensome costs to already scarce resources. The end does indeed not justify the means. Such statements by such important bodies send resounding messages to people who will look at themselves as not being fully recognized for what they are; that

their type necessitates elimination because of burdensome costs, or merely because parents, who are having less children, have a right to a 'perfect baby'. What has been discussed here may be a road to see 'the other' in a child they wish to eliminate.

Another problematic area of genetics is databases. The protection of genetic information is nowadays subject to data protection acts. In Europe this has become enforced also by an overall directive. Yet there are many areas which need clarification and understanding. Insurance companies argue that genetic tests should be revealed to them if done because they are part of the overall assessment of risk of the individual. Yet genetic tests are only predictive in nature and if not done by everybody, one may have an unfair disadvantage just because he or she wanted to know their genetic status in order to use any precautionary methods available. Insurance companies conversely seem to have stopped following an ethos of pooling in money for the benefit of the sick; rather they will exclude insurance to someone with a genetic condition for the condition itself and anything which can be said to arise out of it. Rather than work out a new statistic for people with the condition, they fear fraud (someone could insure oneself in order to take advantage) and therefore the good suffer along with the potential abusers. A clear dialogue of understanding is needed both to insure people with genetic conditions and also whether insurance should have access to predictive genetic tests. Arguments of genetic essentialism may not be enough to stop insurance companies from requesting such tests.

The question of databases raises the issue of proper informed consent for genetic databases to be used for research purposes and also who shall give that consent in instance of vulnerable populations. Consider, for example, orphanages. The law usually recognizes the custodian of the orphans as the person who is able to give consent for treatment on behalf of the individual orphans. Would this, or *should* this, hold if genetic research laboratories ask for genetic material from orphans. The custodian may indeed see a potential advantage or incentive for the whole institutions (or may be offered one); but the interests of the individual would not be protected. Allowing such cases to be resolved in a court room may not be the ideal outcome; rather one should resolve these issues on a dialogue table. The interested parties must have an ethic of putting their individual interests aside rather than arguing in favour of their request.

Obtaining informed consent has also raised the concern of researchers. Going back to individual people is not always practical; conversely, obtaining across the board consent for all types of research is not specific enough for people to know what their genetic material is to be used for. In fact, anonymization is not always enough as a person may have a moral objection, even on religious grounds, for his or her DNA not to be used for a particular research, even though one cannot identify the individual from the sample.

One can argue that all these issues can be resolved with other framework of ethics. However to date they have not been as effective and it is unfortunate that legislation is taking the place of moral choices. A law will bind individuals more to the extent of not allowing for a moral choice to be done on pain of breaking that law. Conversely, pragmatic or principle-based ethics have not resolved such

issues as one can argue either way based on which principle he or she give more precedence to.

## Conclusion

The field of bioethics has been a field of moral debate since its birth. The debate it has encouraged thus far however is one of conflict between fundamental beliefs and attitudes. Conversely, philosophies which prescribe compromise have been too pragmatic in their approach to be endeared by all, especially those of strong values. Yet it has been argued that the challenge even to religions with long-standing traditions, like Catholicism, is to embrace pluralism and dialogue, not merely in a figurative manner of speaking, whilst in reality seeking only to defend one's fundamental ideals, but in a way of seeking true alternatives.

The principles of kenosis and perichoresis embrace an outward attitude which is open to true dialogue. This essay has looked at the thoughts of scholars within the Roman Catholic tradition, in particular Cambon and Coda. Whilst applying these issues to biomedical ethics still needs considerable work in each area, it can be envisaged that a departure from fundamentalism which embraces pluralism, interdependence and inequality of ideas, within the Catholic tradition may be a great breakthrough in bioethical thought. We live in a pluralistic society and the threat of relativism concerns Catholic scholars. A Trinitarian approach is a lived experience of ethics which faces and accepts pluralism as a condition which is essential to the human condition (Commissione Teologica Internazionale, 1973, pp. 367-369). Conversely Trinitarian praxis *has* to start with different views, or else it would not be Trinitarian at all. **E&M**

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## Endnotes

- 1 This paper discusses part of the spirituality of the international Roman Catholic Focolare movement, founded by Chiara Lubich. The theology discussed here is approved by the Roman Catholic Church.
- 2 Besides a return to profound modern Catholic theological studies to rediscover truths in Trinitarian theology as applied to the modern world (Baggio, A.M., 1998; Castellano Cervera, J. 1998; Coda P, 1998; Zak, L., 1998; Macek, W.M., 2000; Coda, P., 2000; Alessandrini, L., 2000; Brena, G.L., 2000), others have reworked this theology into the philosophies of their particular areas: in economics (Calvez, J.Y., 1994; Baggio, A., 1996; Ferruci, A., 1992;), in industry (Araujo, V., 1997; Lubich, C., 1984; Sorgi, T., 1998, p. 122), in culture (Salvati, G.M., 1990; Bague, R., 1983), in humans rights issues (Sobrinho, J., 1987; Sapienza, R., 1996), in Justice (Caso, G., 1987 and 1990); in public health (Caretta, F. & Petrini, M., 1991; Fratta A., 2001) and even in art (Pochet, M. 1996), philosophy and science (Picozza, P., 2000; O'Hara, P., 2000; Pettorossi, A., 2000; Rondinara, S., 2000). (References, listed at the end, from Gambon)

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# EUTHANASIA VERSUS LETTING DIE: CHRISTIAN DECISION-MAKING IN TERMINAL PATIENTS

DENNIS SULLIVAN, M.D.

*Not everyone is a physician, but everyone is a metaphysician.* —Peter Kreeft.

## Abstract

Utilitarianism and quality-of-life considerations have increased the pressure to devalue life in terminal situations, leading to ethical confusion among caregivers. Where is the balance between a commitment to life and a common-sense willingness to “let go” when the time comes? This paper explores this balance, using a case history of a man with respiratory failure. This provides an opportunity to define and discuss some commonly misunderstood concepts related to end-of-life care. The ethical principles of terminal care are presented from the viewpoint of both secular and Christian ethics.

## Introduction and Background

The care of terminal patients is often difficult and ethically challenging. The standards of competent and compassionate care that characterized a previous generation seem to be wavering, replaced by a post-modern *mélange* of newer conflicting theories and ethical values.

A shift from deontological principles to utilitarianism has occurred in the past thirty years, corresponding with the rise of the modern bioethics movement (Rae & Cox, 1999). Many members of an increasingly aging population are denied their autonomy on the basis of mental incompetence. The most common cause of the loss of competence is Alzheimer’s disease, which may afflict up to 50% of individuals 85 years and older (*Alzheimer’s Disease*, 2003).

Decisions to withdraw treatment are often based on a lack of higher mental functioning as evidenced by self-awareness and self-control. On such utilitarian ideas of bioethics, there are degrees of personhood as though it were a quantity that one individual could have more of than another. To lose these physiologic parameters means to lose something vaguely called the “quality of life.” Such “physiologic personhood” ignores a patient’s personal history, and the fact that she has existed for more than a moment of time. Dependency and irrationality, with decisions made by others, would often deny such an individual the right to live.

Utilitarian considerations have even led to a “duty to die” in public discourse, a general sentiment that the elderly should “get out of the way” of the

young. A report from a recent medical journal is chilling in this regard: An 85 year-old minister with dementia was abusive and irrational, posing a problem for caregivers in a nursing home. The minister's wife and children agreed that he was "without quality to his life." Therefore, they and the physicians decided to simply turn off his pacemaker to cause his death. In favoring this practice, the authors of the report made a purely utilitarian argument. Their act was convenient for the family, rather than based on any intrinsic value or personhood of the patient (Rymes, McCullough, Luchi, Teasdale, & Wilson, 2000).

The Christian thus faces a unique dilemma in today's health-care environment: How should he commit to compassionate and competent medical care within the current establishment, yet take a stand for the sanctity of life and respect for human dignity? Where is the balance between a commitment to life and a common-sense willingness to "let go" when the time comes? This paper will explore this balance, utilizing a case history from the author's personal experience.<sup>1</sup> This will provide an opportunity to define and discuss some commonly misunderstood concepts related to end-of-life care.

## **Case Study**

Mr. M., a 72 year-old retired accountant, presented to the emergency room in severe respiratory distress. He had a history of heavy tobacco use, having smoked two packs per day for 50 years. Though he completely quit smoking two years before this admission, he remained chronically short of breath. Mr. M. had three hospital admissions for respiratory failure in the previous year, two of which required short periods of mechanical ventilation. During the four months prior to this admission he required supplemental home oxygen. Three days before admission, Mr. M. began to notice an increase in his usual shortness of breath, a dry cough, and fever. On the day of admission, these symptoms grew worse and Mr. M. was brought to a nearby emergency room by ambulance.

On physical exam, Mr. M. was a thin, anxious, chronically ill appearing man in respiratory distress. His blood pressure was 140/80, respiratory rate 36/minute, and his heart rate was 124/minute. His temperature was 101.4 degrees Fahrenheit.

Admission laboratory studies revealed normal serum electrolytes, except for a slightly elevated potassium level. His serum bicarbonate was elevated at 36 mEq/l. His blood hemoglobin was normal. The white blood count was elevated at 14, 500 per cu. mm. Arterial blood gases (on supplemental oxygen by nasal cannula) were as follows: pH 7.34, pO<sub>2</sub> 46 mm Hg, pCO<sub>2</sub> 66 mm Hg. A chest X-ray showed a flat diaphragm, with hyperinflation of both lung fields and an infiltrate in the right lower lobe.

In the emergency room, Mr. M was orally intubated, and he was placed on a ventilator. He was admitted to the medical intensive care unit with a diagnosis of chronic emphysema, with superimposed right lower lobe pneumonia and acute respiratory failure. Over the next several days, physicians treated Mr. M. with antibiotics for his pneumonia. The lung infiltrate improved, and the patient's temperature and white blood cell count became normal. However, multiple attempts to wean him from the ventilator failed. Off the ventilator, he



became restless and agitated, with severe shortness of breath.

The primary physician, a specialist in the intensive management of respiratory diseases, discussed the various options with Mr. M. and his family. All agreed that continued long-term reliance on the ventilator was burdensome, and that his condition was terminal. Mr. M. was fully alert and competent; he and his family understood fully the implications of his illness. A “do not resuscitate” (DNR) order was entered in the chart, with the agreement of Mr. M. and his wife. After a night of rest, the physician removed the endotracheal tube and had the ventilator taken from the room. A strict “do not intubate/do not resuscitate” order was given, and the patient was left on supplemental oxygen.<sup>2</sup>

Twelve hours after discontinuing ventilator support, and with his family present, the patient died.

## Questions

1. Was the cessation of therapy for Mr. M. justified?
2. Could this be an example of assisted suicide or of euthanasia?
3. What ethical principles are involved here?
4. What insights can be applied from a Christian perspective?

## Definitions

This discussion will be more clear by first defining some important terms. A *terminal condition* is a disease or process that will result eventually in a patient's death, no matter what treatment is given. Of course, this may include cases where death is inevitable but far off, as in patients with cancer who live for years with their disease. On the other hand, the expression *imminent death* is used when death is expected within a short time, usually days or weeks (Kilner, 1992). The word *euthanasia* comes from two Greek roots: *eu* for “good,” and *thanatos* for “death.” Thus the term means a “good” or “gentle” death (Feinberg & Feinberg, 1993). *Active* euthanasia is the overt, deliberate killing of a patient, e.g., by injecting an overdose of morphine or by giving potassium chloride to stop the heart. *Passive* euthanasia refers to the withdrawing or withholding of treatment, while the disease process takes its course to cause death (Kilner, 1996). In other words, the distinction is between killing and letting die, but the *intent* in both is the patient's death.

Most would condemn active killing. The biblical command is “You shall not murder” (Exodus 20:13, NASB). The term “murder” refers to the taking of innocent human life and therefore does not include acts performed during a justified war, self-defense, or capital punishment. The intuitive nature of the injunction against taking life goes beyond the Decalogue to a shared consensus of the secular community as well (Budziszewski, 2003). Furthermore, this principle has been an integral part of the Hippocratic Oath from the fourth century B.C.: “I will not give poison to anyone though asked to do so, nor will I suggest such a plan” (Cameron, 2001, p. 27).

The proscription against the taking of innocent life is so compelling as to admit of no exceptions, even if requested by a patient. Leon Kass has said that “killing patients – even those who ask for death – violates the inner meaning of the art of healing” (2002, p. 250). Whether performed by a physician or a common thug, active killing is always wrong.

“Letting die” may seem to be more acceptable, though it can be just as unethical as active killing. James Rachels gives the following illustration: two men stand to benefit from a large inheritance if their six-year-old cousins die. The first drowns his cousin in a bathtub of water. The second sees that his cousin has hit his head on the edge of the tub, and has fallen in the water face down. He stands by and watches the boy drown. Both men committed murder, one by an act of commission, the other by an act of omission (Rachels, 1978). By analogy, Rachels would thereby argue that there is no morally relevant distinction between active and passive euthanasia.

However, this oversimplifies the reality of medical care. “Letting die” can be morally justifiable in medicine if a particular intervention is truly futile, or if a patient or her authorized surrogate refuses it.<sup>3</sup> In other words, the analogy to murder is unwarranted. Thus, the medical cause of death does have moral relevance, though not in and of itself. Beauchamp and Childress have said: “Killing, of course, may be wrong and letting die only rarely wrong, but, if so, this conclusion is contingent on the features of particular cases” (2001, p. 141). As discussed later, the term *passive euthanasia* has only added confusion to the ethical debate.

Another way to look at euthanasia involves three categories: voluntary, nonvoluntary, and involuntary. *Voluntary* euthanasia is the act of bringing about a competent patient’s death at his request. *Nonvoluntary* euthanasia means ending the life of an incompetent patient, usually at the request of a family member, as in the Karen Quinlan case. In 1975, the New Jersey Supreme Court granted Miss Quinlan’s father the right to authorize removal of the respirator in his permanently comatose daughter (*Karen Quinlan*, 2003). *Involuntary* euthanasia means taking the life of an competent patient who does not wish to die (Beauchamp & Childress, 2001). A moment’s reflection will demonstrate that these are not morally helpful distinctions. As mentioned earlier, the active taking of a patient’s life is usually considered wrong, even if a patient requests it. The focus here is on the agent who gives consent, rather on the ethical merits of the act of killing or letting die. *Physician-assisted suicide* is a variation of voluntary active euthanasia, where the agent that causes the death is the patient herself, with means provided by the physician.

Finally, the omission v. commission argument is frequently cited in making a distinction between *withholding* treatment, i.e., not starting it, versus *withdrawing* treatment, i.e., stopping an intervention already begun. Historically, the latter has always been more difficult in medicine than the former, though this is probably more psychological than real. Beauchamp and Childress call the distinction “both irrelevant and dangerous” (2001, p. 121).

## Was Cessation of Therapy Justified?

With these definitions in mind, consider the case study presented earlier. Was the cessation of therapy for Mr. M. justified? Yes, in that this is the withdrawal of *futile care*. The patient's condition was terminal, and his death was *imminent*. There is no reason to second-guess the physician's judgment here. There is no doubt that he was in respiratory failure and ventilator-dependent from an irreversible disease process (emphysema). He had received the best of aggressive medical therapy. This assumes medical competence on the part of the physicians, and assumes that the patient was maximally cooperative with his treatment.

One reason that this case seems difficult is that the doctors withdrew an already utilized treatment (the ventilator) as opposed to withholding it. Some might argue that the doctors in the emergency room should never have intubated Mr. M. and placed him on a ventilator in the first place, yet this would have been a denial of any attempt to treat him, and clearly inappropriate. Having established that further ventilator support was futile, the decision to withdraw it seems justified.

It is worth noting that medical personnel may abuse the concept of medical futility, often on arbitrary or utilitarian grounds. For example, treatment may be withdrawn because of a vague perception that there has been a loss of personhood (as in the case of the 85 year-old minister cited earlier). However the case of Mr. M. is an example of the best kind of doctor-patient relationship. Out of respect for his personhood and aware of his dire medical condition, the physician communicated openly with the patient and his family. Full and informed consent was sought and given by all parties. Ethicist Christopher Hook has expressed it well:

The real source of power in medicine . . . is in the relationship, the coming together of the afflicted and the healer, the blending of needs and goals with knowledge and skill, so that they may come to as good an outcome as possible. There can be no true healing without this relationship (Hook, 1996, p. 92).

## Assisted Suicide or Euthanasia?

Could this be an example of assisted suicide or at least of "passive euthanasia"? The answer is no to both questions. First of all, this was not physician-assisted suicide because the agent was the physician, not the patient. Is this therefore "passive euthanasia"? Not at all, because the *intent* was to relieve suffering, not to cause death.

An important guide in this instance is the *principle of double effect*. This is the concept that intentions have great weight in moral decision-making. For example, caregivers are obligated to preserve life and at the same time to relieve pain. If a physician were to inject a massive overdose of morphine into a terminally ill cancer patient, with the intent of active euthanasia, this would be morally wrong.

However, a physician should endeavor to treat the pain of a suffering patient with adequate doses of analgesics, even narcotics. This assumes that other medications have failed, and that *imminent* death makes addiction irrelevant. If such treatment hastens the death of the patient, but this was an unintended consequence of the intent to relieve suffering, then the act may be morally permissible (Jochemsen, 1996).

This principle applies to the case of Mr. M. As stated earlier, neither the patient nor his physicians intended his death. They did, however, intend to relieve him from a burdensome and futile treatment; his death was an unintended consequence. According to the principle of double effect, the action was justified.

Robert Orr and colleagues would not even call this act euthanasia: "Withdrawing or withholding treatment or artificial means of life support in someone who is dying is not euthanasia at all—not even 'passive' euthanasia—but acceptable, humane, and an often necessary part of everyday medical practice" (Orr, Schiedermayer, & Biebel, 1990, p. 152). More succinctly, Jochemsen has said: "Stopping disproportional medical treatment has always been good medical practice" (Jochemsen, 1996, p. 166).

The term *passive euthanasia* is confusing and should be discarded from medical ethics discussions.

## **Ethical Principles**

What ethical principles are involved here? The classical general principles of bioethics are autonomy, nonmaleficence, beneficence, and justice. The actions in this case are certainly compatible with these principles.

The principle of autonomy can be stated as follows: Rational people should be allowed to be self-determining and to make their own decisions (Munson, 2000). Contrast this with *paternalism*, where health-care providers make decisions independent of the patient and his family. In the case of Mr. M., full consultation with him and his family respected his autonomy.

Autonomy is not absolute, however. Patients must respect the integrity of the medical profession, and the ability of caregivers to say no to unreasonable requests for inappropriate or futile treatment (Hook, 1996). Patients who disagree with available treatment options are free to seek a second opinion.

Nonmaleficence means that a physician should never "by carelessness, malice, inadvertence, or avoidable ignorance" do anything to cause harm to a patient (Munson, 2000, p. 32). This principle is one of the oldest in medicine, and relates to the covenant between physician and patient. It dates back to the time of Hippocrates: "As to diseases, make a habit of two things — to help, or at least to do no harm" (Strauss, 1968, p. 625).

Certainly, assisted suicide and active euthanasia would violate this rule. The utilitarian case for physician-assisted death requires that "harm" be equated with the continuation of life. Such a claim seems difficult to justify, especially in view of new treatment modalities to cope with pain and suffering. According to Stoddard, it is a false assumption "that seriously ill people must

expect agonies and humiliations from which death itself is the only merciful release" (Stoddard, 2000, p. 241). Death with dignity does not require that physicians overtly intervene in a natural disease process.

However, this principle does require that burdensome treatments not be imposed on the terminally ill in whom death is imminent. In the case of Mr. M., further treatment was futile. Keeping the patient on a ventilator against his will would have been maleficent and hurtful, thus violating the principle.

The principle of beneficence is the moral obligation to act in the best interest of others (Munson, 2000). It is difficult to claim that euthanasia accords with this principle. So how does the cessation of ventilator support fulfill it? In the case of Mr. M., the physicians went beyond mere nonmaleficence and were overtly concerned about his benefit. Their compassionate interaction with the family and patient was consistent with beneficent intent.

Admittedly, the idea of beneficence would be more difficult to prove if the patient or family had opposed the treatment plan suggested by the physicians. However, even that eventuality would not violate beneficence if the case for futility were strong enough. As Beauchamp and Childress point out, "A justified claim that a medical procedure is futile removes it from the range of otherwise beneficial acts among which patients or their surrogates may choose" (2001, p. 192). Beneficence would also be suspect if the care team had acted out of strictly utilitarian concerns, e.g., "We really need this ventilator for the guy in 2B, so we ought to let Mr. M. die." Such a cold calculus would go against the Hippocratic tradition of medicine.

The principle of justice has at its heart the idea that "similar cases ought to be treated in similar ways" (Munson, 2000, p. 38). While this is not quite as important for Mr. M in the immediate context, terminal illness should be handled equitably for all patients. This assumes, for example, that medical staff members have thought through the implications of terminal respiratory failure. This is just good medical practice and ensures that an "ethical standard of care" is followed with all patients who enter the intensive care unit.

## Christian Principles

From a Christian perspective, three principles for end of life care seem evident:

### *Principle #1: Human life is sacred*

Psalm 8 is David's lofty hymn of praise to the Creator God: "You (God) have made him (man) a little lower than God, And You crown him with glory and majesty." This wonderful valuing of man is expressed in creation as the "image of God," described in Genesis 1:26-28. Man resembles God, yet not in any physical or visible characteristics. Though there has been considerable historical debate over the meaning of this concept, it is clear that this is some quality or aspect whereby created man is like God. This makes man distinct from animals, for the Bible declares that only man is made in God's image.

A thorough discussion of the image of God is beyond the bounds of this discussion. There is, however, a great danger in attempts to derive a list of characteristics that define the image of God. This may open up a real temptation to declare some human beings “non-persons” when they cannot fulfill all the elements of such a list. On the contrary, the image of God in man must surely be an *intrinsic* feature, wrapped up in the very essence of what makes him a person, and not separable from his humanness.

Therefore, there is no such thing as a “loss of meaningful personhood,” or a “loss of human dignity.” No matter how much they suffer, human persons have an inherent worth and dignity conferred by God. Christian caregivers must always be mindful of this dignity and act accordingly.

### *Principle #2: God is sovereign over life and death*

Death is the curse (Genesis 3:17-19) brought about by Adam’s sin. Therefore, it is never to be welcomed; it will always be the ultimate enemy. Christians should never *intend* death, for God is sovereign over such matters (Deut. 32:39). On the other hand, Christian physicians and their patients may *accept* death, bowing to God’s sovereignty, with peace and the joyous hope that good will come out of it (Kilner, 1996). After all, death is a conquered enemy (1 Cor. 15:50-58).

What about those patients who do not know the hope of Christ? This is a wonderful opportunity for ministry. Some of this author’s most precious memories as a physician are those where God’s Spirit led a dying AIDS patient or terminal cancer victim to the Savior. Though it cannot be the only goal of compassionate care of the dying, Christian physicians can share their joyous hope with others.

As already shown, patient autonomy, both in accepting suffering and in choosing one’s own moment of death, must yield to God’s sovereignty. In 1 Cor. 6:19-20 Paul states that a person’s body belongs to God, for he was “bought at a price.” On this principle, patients must recognize that God is in control.

This does not deny, however, that feelings of “losing control” cause many problems for the dying patient, often contributing to psychological depression. As much as possible, care givers should help patients to make their own choices, even in the smaller day-to-day issues. This will help them to feel a little more “in control.”

### *Principle #3: No patient is beyond Christ’s compassion*

Robert Orr has said: “No treatment is mandatory except two: *comfort* and *company*” (2001). In this, Dr. Orr has rightly emphasized two great shortcomings of modern technological medicine.

The first is a failure to adequately manage suffering. Competent palliative care requires a well-integrated approach to supporting the patient. This means adequate use of analgesics, including narcotics as needed, for clearly addiction is not a concern. Adequate doses must be used to control pain, even if an unintended side effect is to speed up the dying process, as discussed earlier on the principle of double effect (Pellegrino, 1996). The modern hospice movement

recognizes such an enlightened view, and has helped to promote the concept of a “good death”. Unfortunately this is still the exception rather than the rule (Twaddle, 1996).

The second great failure of modern medicine is abandonment. As ventilators, intravenous lines, feeding tubes, and monitors multiply, the actual patient seems somehow lost amidst all the technology. Caregivers can be so busy managing the devices of life support that they fail to even greet the patient as they walk in the room. This should not be.

Emotionally, dealing with death is difficult for both caregivers and families alike, and a tendency to distance one’s self from a loved one is understandable. Many may think, “I don’t know what to say.” But it is not always necessary to say something; mere presence can comfort. In the book of Job, commentators criticize Job’s counselors for their lack of insight, but they did some things right. For example, when they first arrived, they silently joined him in his suffering: “Then they sat down on the ground with him for seven days and seven nights with no one speaking a word to him, for they saw that his pain was very great” (Job 2:13). In the same way, caregivers must be present with patients and loved ones. A simple hug or the holding of a hand is not a departure from professionalism, and such actions may be more valuable than words. The shedding of a tear may be priceless.

## Conclusion

This paper has explored the issues of euthanasia, futile care, and letting patients die. The case of Mr. M., tragically afflicted with end-stage lung disease, provided the backdrop for a discussion of secular and Christian principles of compassionate care at the end of life.

Christians must remember that they should not grieve as those who have no hope (1 Thess. 4:13-14), “for if we believe that Jesus died and rose again, even so God will bring with Him those who have fallen asleep in Jesus.” The Christian caregiver has a great privilege and responsibility: to compassionately care for those who are facing eternity. **E&M**

*The author would like to express appreciation to Steve Burdette, MD (Clayton, Ohio) for valuable suggestions in the preparation of this paper.*

## Notes

- 1 For the interest of health care students, certain technical details and laboratory values are included. However, a grasp of these particulars is not necessary to deal with the ethical issues.
- 2 For simplicity, this discussion has not included the use of CPAP (Continuous Positive Airway Pressure) or BiPAP (Bilevel Positive Airway Pressure). For more information on newer management modalities, see (Rappard, 2000).
- 3 The standards for determining who may be a surrogate decision-maker vary considerably from one jurisdiction to another (see for example Orr, 2004).

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## BOOK REVIEW

### Historical and Philosophical Perspectives on Biomedical Ethics

Andreas-Holger Maehle and Johanna Geyer-Kordesch, Editors  
Burlington, VT: Ashgate, 2002

ISBN 0-7546-1529-4, 159 PP., HARDCOVER, \$69.95, £42.50

This volume is a contribution to the 'Ashgate Studies in Applied Ethics'. Drawing largely on papers presented to a conference in the United Kingdom (Durham) in 1998, it falls roughly into two unequal parts. The first consists of five essays focusing on historical accounts. Three of these (by Andreas-Holger Maehle, Lutz Sauerteig, Cay-Rudiger Prull and Marianne Sinn) concern Germany in particular: the emergence of medical professional ethics there, the ethics of its sickness insurance system, and the 'Problems of Consent to Surgical Procedures and Autopsies' in the twentieth century. They more or less illustrate transitions from more paternalistic or professionally self-interested medical ethics towards practices that reflect the social emergence of increasingly autonomous agents. These essays are flanked by an account of the work of the Central Ethical Committee of the British Medical Association in the first half of the twentieth century (Andrew Morrice), again illustrating the emergence of autonomy against the background of increasing interest in human rights. A fifth essay (Ulrich Trohler) describes the path from national to international regulation of human research, with the important conclusion that the development of protection of participants in research on human beings has been lamentably slow.

This account of the first five essays is bland, but the essays are not so, and convey very useful information. Only those experts in the particular areas will be able to judge their detailed merits, but the arguments are consistently well-researched and plausibly presented. The logic has to be carefully scrutinised, of course, as in the case when general conclusions are drawn about early twentieth century German pathologists' greater interest 'in using the human body for medical science than in acknowledging lay views on respecting the dead' (p.78). The conclusion itself is manifestly probable, but it is hard to argue that the particular case cited 'clearly' demonstrates it (p.77). The essayists draw out effectively the significance of their research. The first essay raises the question of what has constituted 'medical ethics' over time; the second asks what Nazism has to do with the connection between medicine and public welfare; the third offers conclusions on the lack of connection between mortality rates and health care expenditure; the fourth compares the relative historical immunities of surgery and pathology against public criticism; the fifth indicates what is unsatisfactory about the development of the code of ethics of the World Medical Association. So these contributions may be generally commended for study, with the proviso that experts in the various areas must assess the detail.

## *Ethics & Medicine*

Relatively little space is then devoted to Bryan Jennett's discussion of 'Ethical Aspects of Life-Saving and Life-Sustaining Technologies', Susan Lowe's argument that patient autonomy can not justify euthanasia and physician-assisted suicide, and David Cooper's asseverations on "The Frankensteinian" Nature of Biotechnology'. Bryan Jennett is characteristically succinct and superficially persuasive in outlining both the clinical and ethical issues involved, stating our proper aim as the promotion of 'compassionate care' and the 'respect of the wishes of competent patients' (p.127). But many will question whether some of its implicit or explicit lines of argumentation will survive detailed and rigorous scrutiny. Indeed, Susan Lowe's following essay indicates just why that may be the case; it is generally a good, if again brief, check on arguments from patient autonomy. David Cooper's essay is, again, quite short. In describing our need to take seriously people's visceral concerns about interventionist technology in the area of genetics, he is helpful. But although he manifestly believes in the possibility of rigorous moral argument in this area, and occasionally signals what that might be, he risks giving the impression that sensibility and suspicion are the main reasons for halting certain kinds of biotechnological advance. In sum, I wish that the same amount of space had been given to later essays on ethical issues as has been given to the earlier, more empirically-oriented, ones.

Having said that, conference productions allied to independent essays are seldom easy things to manage, and we have here a useful collection for which we must thank the editors. But it is exorbitantly priced.

**Stephen N. Williams, Union Theological College, Belfast, UNITED KINGDOM.**

## BIOTECHNOLOGY UPDATE

### MARCH 2005

#### **The Image of God in All People: A Sermon Regarding Inheritable Genetic Modifications in Human Beings**

AMY MICHELLE DEBAETS

##### *Genesis 1:26-31 (author's translation)*

And God said, "Let us make humanity in our image, with our resemblance, and let them have dominion over the fish of the sea and over the birds of the sky, and over the cattle, and over all the land, and over all the creeping things that creep upon the earth." So God created humanity in his image; in the image of God he created them. Men and women, he created them. So God blessed them, and God said to them, "Be fruitful and increase; fill the land and subdue it. Rule over the fish of the sea and over the birds of the sky and over every living creature that creeps upon the earth." The God said, "Behold, I give you every plant that bears seed upon the face of all the earth, and every tree which bears seeds in its fruit. They will be yours for food." And to all the beasts of the field and to all the birds of the sky and to all the creeping things upon the earth - everything that has in it the breath of life - I give every green plant for food." And it was so. The God saw all that he made, and behold, it was very good. And there was evening, and there was morning, the sixth day.

##### *Phillipians 2:2:5-11 (NRSV)*

Let the same mind be in you that was in Christ Jesus, who, though he was in the form of God, did not regard equality with God as something to be exploited, but emptied himself, taking the form of a slave, being born in human likeness. And being found in human form, he humbled himself and became obedient to the point of death - even death on a cross. Therefore God also highly exalted him and gave him the name that is above every name, so that at the name of Jesus every knee should bend, in heaven and on earth and under the earth, and every tongue should confess that Jesus Christ is Lord, to the glory of God the Father.

As we have just read the account of the creation of humanity by God, we will consider the potential implications of that passage and other Christian concepts and principles to look at a very specific issue that is quietly becoming important in the life of the church and the future of humanity. That issue is the use of inheritable genetic modifications in human beings, also called germline genetic engineering.

Inheritable genetic modifications sound a bit like science fiction, but in the field of genetics and assisted reproduction, it is far more a case of science than of fiction. It is the idea of manipulating and changing a person's genetic structure

so that the modifications that are made are passed down to that person's children and to all subsequent generations. For instance, let's say that I have green eyes, but I want my children to have brown eyes. Using assisted reproductive technologies like IVF, I could develop an embryo in a lab, as is common today. I could then isolate the gene for eye color in that embryo and change it, essentially swapping out the DNA so that the child who was born would have brown eyes instead of green. Because the genetic change was made at the early embryonic stage, it exists throughout all of the cells of the child's body, including the eggs or sperm that the child might someday produce. If my child then had children, all of those children would receive the gene for brown eyes, because I had chosen to change my child's genetic structure permanently.

Now I've chosen a simple trait, eye color, which is controlled by a single gene, and is relatively unimportant in terms of either therapy or enhancement of my child. Such genetic changes, of course, could involve much more complicated manipulations, such as avoiding certain genetic predispositions to disease or trying to make the child more intelligent, a better basketball player, or a more talented musician. In all of these cases, I would have introduced into the child some kind of genetic change that would be permanently a part of his or her genetic structure, and all of that child's children would have the same genetic structure.

Most of what we know of as gene therapy today is not this kind of genetic alteration. It is known as somatic gene therapy, and it involves treating the particular genetic conditions of a person who is already born, such that the genetic changes made are not passed down, but simply serve as a form of medicine for that person, not unlike a drug therapy or a helpful virus. Germline engineering is quite different, not primarily in its intentions, but in its effects. With germline, even a modification that is intended to be therapeutic alters the child's genetic structure in ways that cannot be taken back, regardless of any additional unintended consequences.

Let us look now at our passage for this morning - the creation of humanity in the image of God - and then consider how an understanding of this passage may apply in the case of germline interventions. As we see here, human beings were created in the image of God. The bearing of this image was inclusive of all people, regardless of gender or status. This was a decision made by God, to create people in God's own likeness, and the creation of humanity as humanity was called "good" by God. We as human beings were given the gift of life by God, with all of the privileges and responsibilities that came with being human. As creatures made in God's image, we have a special relationship to God as covenantal creatures, and we also have a special relationship of stewardship and guardianship over the rest of creation. Our passage today says that humanity was given dominion over the other creatures made by God — the beasts, birds, and fish, but not over one another. This creation of human beings in the image of God and our relationship of stewardship within creation are key points to remember as we move forward in looking at how Christians might consider using technologies such as germline engineering.

In tying our understanding of human beings as creatures with a special relationship to God and to the rest of creation, there are some other theological considerations that I think we ought to keep in mind as we look at the specific

case of inheritable genetic modifications. In looking at technologies that have the capacity to substantially alter the form and meaning of humanity, we must keep the incarnation in mind as well as creation. We must also remember our vocational calling as Christians — what it is that we are to value and to do in our lives as we seek to follow Christ. There are three vocational tasks that we are to keep in mind. The first is the call to care for and protect “the least of these” — the weakest among us, who cannot protect themselves. We are to support them and help them to thrive, and not to undervalue or destroy them. In Matthew 25:40, Jesus declares that “Truly I tell you, just as you did to one of the least of these who are members of my family, you did to me.” The second is the call to care for the poor. It is the given task of the community of God throughout scripture to care for the poor in love and respect. The third call is the Christian call to love one another. We are to treat people as people, and not as products of our own devising. This call includes the generations to come as well, and not simply those of our own time.

Keeping these vocational callings in mind, as well as the doctrines of creation and the incarnation of Christ, let us now look at how they might apply in the case of using technology to effect inheritable genetic modifications in human beings. As people created in the image of God, God has made us, and we have not made ourselves. God called the creation of humanity “good,” including all people, whether genetically “superior” or not. Even as the good creation of God, we are also fallen and sinful people, and we have no way to become perfect on our own. No technological fix can cure our sinfulness; no genetic manipulation will make us perfect. It is only in Christ that we may have the hope of restoration to who we were created to be, and even that will not be perfected in this life. Likewise, as human beings, we have a responsibility to protect and care for creation, including one another. We are given by God a unique status as guardians of the creation, but this allows us power within limits, and does not give us dominion over one another, including our children’s genetic makeup.

In looking at the incarnation of Christ in the world, we see the way in which God chose to come to redeem our fallenness. Jesus Christ came into the world as a human being. He took on the weaknesses of human flesh in order to redeem us. The pain of suffering and death in this world is the result of sin having come into the world, and so the only way by which suffering and death might be overcome is through the conquering of that sin, which could only be accomplished in Christ. Just as our humanity is not reducible to our genetic makeup, so no “fix” of the genetic structures of humanity could ever cure the human condition of finitude, sinfulness, and mortality, nor their effects in human suffering and disease. There is no way for us, apart from Christ, to perfect humanity, to overcome our mortality, or to ultimately fix the problem of the human condition. It is part of our task as Christians to alleviate the plight of people in distress from the harmful consequences of sin in this world — through medicine, justice, and care — but we are looking at the root of the wrong problem if we try to fix who people are apart from Christ.

Let us now look again at our three vocational callings as Christians that were mentioned earlier. The first calling was to care for the least among us. In the parable in Matthew 25, Jesus specifically mentions those who are hungry,

thirsty, naked, strangers, the sick, and those in prison. We are to care for those who are in need, including those who have genetic structures we would consider to be defects. It is our responsibility to use our time and resources to love and care for them, not to decide who needs to be "fixed" in order to be considered worth living.

The second calling was that of caring for the poor. Technologies such as germline engineering create a class differential that is not merely monetary. Futurist Lee Silver has looked ahead to the future of genetic technologies and envisioned a world in which those who can afford it, genetically modify their children to give them perceived advantages, including ones not available to any human beings today. The vast majority of the human community, of course, would never be able to afford such changes and would be left in the genetic dustbin. Silver has termed those with the changes the "Gen Rich," and considers the move to this type of society to be one that we ought to pursue. The division of humanity into rich and poor on a basic, genetic level, is far out of line with the Christian calling to care for the poor and to avoid their exploitation by those with the power and resources to transcend their own humanity.

The third and final calling to consider when looking at technologies of genetic change is that of the Christian calling to love one another. This means that we must prophetically seek to avoid the creation of a genetic wealth or poverty among human beings, and we must also avoid the tyranny of a single generation over all subsequent generations. The generation of people who are about to become parents has the opportunity to determine the genetic future of all humanity, and once changed, the decision of who we are as human beings is lost for all other times. We have the power to instill our flawed and culturally conditioned genetic preferences and values in the next generation and so exercise a tyranny over all future generations of human beings. This, I believe, flies in the face of our calling to love one another, including the subsequent generations, who we ought to treat with respect and care, instead of turning them into the genetic products of our own devising.

What does all of this mean for us? What can we do about this as people in the church? The first and best thing that can be done is for us all to be informed about germline genetic engineering, its status, availability, and implications for the future of humanity. We must think through this issue and related issues theologically so that we can be prepared to speak in the public arena when the issue of genetic modifications arises. We have the opportunity to be a prophetic voice in the world, to help others to consider the implications of these types of changes to human beings, and to not simply listen to the hype that so often accompanies new scientific possibilities like this. Most of all, we can pray, for one another, for those in positions of having to choose whether to utilize such technologies, and for the leaders of this nation and of all nations when they determine legislation regarding changes in the genetic futures of all humanity. Amen. E&M

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## IN THE NEWS

### *UN passes declaration favoring human cloning ban*

The United Nations recently passed a declaration opposing all forms of human cloning as "incompatible with human dignity." This declaration was supported by the United States and led by Costa Rica. The declaration passed in the General Assembly upon the recommendation of the Sixth Committee by a vote of 84 in favor, 34 against, and 37 abstaining. The declaration does not have the force of international law, though it does make a strong international statement against all forms of human cloning, including research cloning.

<http://www.un.org/apps/news/story.asp?NewsID=13576&Cr=cloning&Cr1=&Kw1=human+cloning&Kw2=&Kw3>

<http://www.un.org/News/Press/docs/2005/ga13271.doc.htm>

<http://www.washingtonpost.com/wp-dyn/articles/A18205-2005Mar8.html>

<http://www.un.org/News/Press/docs/2005/ga10333.doc.htm>

### *Somatic Stem Cell Advances*

Major scientific and therapeutic advances continue to be made in the field of research utilizing somatic (adult) stem cells. Stem cells derived from patients' bone marrow may be a key in the treatment of Alzheimer's. Stem cells that can develop into cardiac muscle have been found in the hearts of human newborns, and cardiac patients who received injections of stem cells from within their bodies showed significant improvement in their conditions. Additional stem cells have been found to exist within umbilical cords, which have already been found to be a rich source of stem cells.

<http://news.ucf.edu/UCFnews/index?page=article&id=00240041998c09010172bc803800783d&mode=news>

[http://www.webindia123.com/news/showdetails.asp?id=66078&n\\_date=20050211&cat=Health](http://www.webindia123.com/news/showdetails.asp?id=66078&n_date=20050211&cat=Health)

[http://www.eurekalert.org/pub\\_releases/2005-02/uocf-usc021005.php](http://www.eurekalert.org/pub_releases/2005-02/uocf-usc021005.php)

<http://health.myway.com/art/id/523894.html>

[http://www.thestar.com/NASApp/cs/ContentServer?pagename=thestar/Layout/Article\\_Type1&c=Article&cid=1107903011703&call\\_pageid=970599119419](http://www.thestar.com/NASApp/cs/ContentServer?pagename=thestar/Layout/Article_Type1&c=Article&cid=1107903011703&call_pageid=970599119419)

<http://www.washingtonpost.com/wp-dyn/articles/A55369-2005Feb1.html>

<http://www.reuters.com/newsArticle.jhtml?type=healthNews&storyID=7428791>

<http://www2.netdoctor.co.uk/news/index.asp?id=117815&D=18&M=2&Y=2005>

<http://health.myway.com/art/id/524154.html>

<http://www.fortwayne.com/mld/newssentinel/living/11015097.htm>

### *Human-animal hybrids*

Experiments continue in the United States and elsewhere toward the creation of various forms of human-animal hybrids. A recent University of Nevada study injected human embryonic stem cells into fetal sheep, with the resulting sheep growing organs that were part-human. A similar experiment was reported in 2003 using pig fetuses. Bioethicists across the spectrum of opinion are asking at what point such experiments end, including questions about genetic crosses between humans and animals and children who are "mostly human."

<http://www.cbsnews.com/stories/2005/02/24/eveningnews/main676424.shtml>

### *Risks to women in embryo cloning*

Some of the risks inherent in human cloning have been little considered either by scientists who support research cloning or by many bioethicists in considering the ethical implications of such a practice. The risks to women who would serve as donors for the eggs needed to carry out such experimentation are now being brought to light, including the risks involved in taking Lupron, which stimulates the body to produce extra eggs and the surgery required to harvest them.

[http://www.boston.com/news/globe/editorial\\_opinion/oped/articles/2005/02/25/risks\\_to\\_women\\_in\\_embryo\\_cloning/](http://www.boston.com/news/globe/editorial_opinion/oped/articles/2005/02/25/risks_to_women_in_embryo_cloning/)

[http://www.boston.com/yourlife/health/diseases/articles/2005/03/10/cloning\\_sparks\\_concern\\_over\\_egg\\_donors/](http://www.boston.com/yourlife/health/diseases/articles/2005/03/10/cloning_sparks_concern_over_egg_donors/)

### *FDA suspends gene therapy experiments*

After recent reports of cancer and death associated with gene therapy experimentation, the United States Food and Drug Administration has halted a number of gene therapy trials. The field of gene therapy has been thought to hold enormous promise for patients with genetic disorders, but the number of treatments resulting from gene therapy experiments have been few in comparison to the number of failures, which have come to be associated with the development of various forms of cancer. It is unknown if or when the trials will resume.

<http://www.washingtonpost.com/wp-dyn/articles/A3926-2005Mar3.html>

### *Federal lawmakers move to expand embryonic stem cell research funding*

New bills in the US House and Senate that have been recently introduced would alter President Bush's policy on federal funding for embryonic stem cells. The current policy provides federal funding to researchers using embryonic stem cell lines created prior to August 2001, and the bills would expand the scope of lines available for federal funding.

<http://www.washingtonpost.com/wp-dyn/articles/A30588-2005Feb16.html>



### *Fight in Massachusetts over cloning policy*

Massachusetts Governor Romney has proposed to ban human cloning research within the state, a move that has caused much debate and discussion in the biotech-heavy state. The move upset researchers at Harvard who have been working toward human cloning experimentation, but the Governor stated that he could not “justify the creation of life for experimentation and destruction.”

[http://www.boston.com/news/nation/washington/articles/2005/02/16/kennedy\\_rips\\_romney\\_over\\_stem\\_cell\\_policy/](http://www.boston.com/news/nation/washington/articles/2005/02/16/kennedy_rips_romney_over_stem_cell_policy/)

<http://www.baltimoresun.com/news/opinion/oped/bal-op.thomas16feb16,1,15217.story>

<http://www.nationalreview.com/script/printpage.asp?ref=/lopez/lopez200502110936.asp>

### *Missouri moves to ban human cloning*

The Senate Judiciary Committee in the state of Missouri has approved a bill that would ban human cloning for research. Senate Bill 160 passed the committee by a 7-2 vote, but Republican Governor Blunt has threatened to veto it if it passes.

<http://www.stltoday.com/stltoday/news/stories.nsf/sciencemedicine/story/D5B368D43F2272FC86256FA9001B0ACF?OpenDocument&Headline=Ban+on+some+stem+cell+work+moves+ahead>

<http://www.thekansascitychannel.com/politics/4197176/detail.html>

### *US refuses to issue patent on human-animal hybrid*

The US Patent and Trademark Office has chosen not to issue a patent to Dr. Stuart Newman for a human-animal hybrid, indicating that such an invention would be too close to a human being to be considered patentable. Newman had applied for the patent in hopes that it would set a legal precedent under which human-animal hybrids, also called chimeras, would be considered unpatentable under US law. A recent article in National Geographic also highlights the issue of human-animal hybrids within the world of emerging issues in biotechnology research and policy.

<http://www.washingtonpost.com/wp-dyn/articles/A19781-2005Feb12.html>

[http://news.nationalgeographic.com/news/2005/01/0125\\_050125\\_chimeras.html](http://news.nationalgeographic.com/news/2005/01/0125_050125_chimeras.html)

<http://www.weeklystandard.com/Content/Public/Articles/000/000/005/204bqkvl.asp>

### *Dolly cloner receives license to clone human embryos*

Ian Wilmut, the researcher most well-known for his research that led to the development of Dolly, the cloned sheep, has applied for and been approved for a patent to conduct cloning experimentation in human beings. The Human Fertilisation and Embryology Authority (HFEA) of the United Kingdom approved the request for human cloning research, and the experiments to look at motor neurone disease are expected to begin soon.

<http://www.washingtonpost.com/wp-dyn/articles/A9118-2005Feb8.html>

<http://news.scotsman.com/latest.cfm?id=4105125>

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Amy Laura Hall, Duke University

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