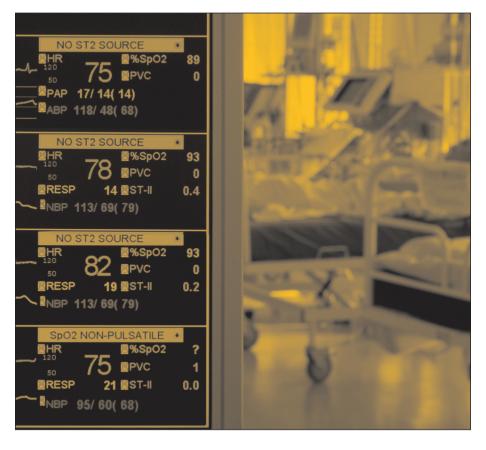


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# Ethics Medicine

An International Journal of Bioethics

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### EDITORIAL

# **GENETICALLY ENHANCING ATHLETES?**

### C. BEN MITCHELL, PHD

Readers of both the academic and popular literature in bioethics will be well aware that genetic and other forms of so-called human enhancement are clearly on the drawing board. No one knows how long it will take to develop these technologies, but they are most certainly coming. Already, of course, through the use of preimplantation genetic diagnosis, human embryos are screened for undesirable genetic traits and embryos with those traits are not transferred to a woman's uterus—they are discarded or used in embryo-destructive research. This is not enhancement, but negative eugenics.

Soon, however, we will be able to direct our DNA to make ourselves different. I say "different", because it is unclear to me that having keener than normal eye sight is necessarily a good to be desired. Likewise, I hardly think that being able to choose one's eye color is something worth the cost of genetic intervention. And, while I suppose 10 additional IQ points would be nice, I am quite certain that merely having them will not make people nicer. Finally, physical immortality, it seems to me, is something only some of the well-healed would want.

The venues for the most rapid development of genetic enhancement will not (and are not) in the medical sector, but in the military and athletics. Competitive advantage means a great deal on both battlefields. For instance, articles in *Scientific American* (July 2004) and the *New York Times Magazine* (January 18, 2004), pointed out that athletes are already trying to access genetic intervention for enhancement purposes. More efficient killing machines (a.k.a. soldiers) and a speedier fast pitch seem to be "goods" for many people. But are they?

News junkies could not help but read about Marion Jones' tearful plea for forgiveness as she returned her Olympic Medals because of her past steroid use. In response, Olympic javelin bronze-medalist Kate Schmidt maintained that athletes take enhancement drugs because of the expectation of fans and that doping is so pervasive it ought to be made acceptable. Olympic officials are loath to do so not only because most of these drugs have deleterious side-effects, including sudden death, but because doing so would fundamentally alter the nature of competitive sport. Even presumably safe enhancements would give unfair advantage.

Happily, without nearly as much publicity the U.S. Congress passed legislation at the end of last year banning "gene doping" in the United States. HR 6344 was signed into law on December 29, 2006, defining gene doping as, "the nontherapeutic use of cells, genes, genetic elements, or of the modulation of gene expression, having the capacity to enhance athletic performance." "At its best, athletics celebrates remarkable human achievements that result from hard work, dedication, not from hypodermics and DNA labs," said Jaydee Hanson, Director for Human Genetics Policy for the International Center for Technology Assessment. "This ban represents an important milestone for human dignity in the fight against a new eugenics that ultimately intends to engineer all human life."

Keeping amateur athletics amateur athletics is especially important with the 2008 Olympics in China just around the corner. The bill states that "The United States Anti-Doping Agency shall . . . ensure that athletes participating in amateur athletic activities recognized by the United States Olympic Committee are prevented from using performance-enhancing drugs or performanceenhancing genetic modifications accomplished through gene-doping . . . (and) permanently include 'gene doping' among any list of prohibited substances adopted by the Agency."

This is not only good news for amateur athletics, but good news for our humanity.  $\mathbf{E}\&\mathbf{M}$ 

#### GUEST COMMENTARY

# How Do Doctors Become Killers?

RONALD PIES, MD

My earliest recollection of doctors and doctoring is of a kind man with a large, bulbous head and thick, horn-rim glasses, peering down at me as I lay sick in bed. I can still feel Dr. Gerace's warm fingers palpating my neck and under my chin, checking (I now know) for enlarged lymph nodes. My mother did not have a great deal of trust in doctors—to her dying day, she would usually take only about half of whatever the doctor had prescribed—but she trusted Dr. Gerace. He was our family doctor, and he saw my brother, sister and me safely through our childhood illnesses. He was also someone I aspired to become: a gentle and thoughtful healer. In a thousand times a thousand years, I could never conceive of someone like Dr. Gerace doing deliberate harm to another human being.

We do not yet know who is guilty of the recent terrorist attacks in Britain, but news reports leave no doubt that most of the prime suspects are doctors or medical personnel.<sup>1</sup> As a physician, I feel a mixture of outrage, shame and incomprehension at this turn of events. How can those solemnly sworn to "do no harm"—indeed, to heal one's fellow human beings—collude in such heinous acts?

Yet, hard as it is to accept, history tells us that physicians are all too easily drawn into acts of evil, often in the service of a totalitarian regime. In his classic study, *The Nazi Doctors: Medical Killing and the Psychology of Genocide*, psychiatrist Robert J. Lifton cited several instances of physicians carrying out acts of state-sponsored evil. Examples included doctors in Chile serving as torturers and Japanese doctors performing medical experiments on prisoners during the Second World War. Then there was the shameful participation of Soviet psychiatrists in the incarceration of political dissidents. But to explain the satanic brutality of Nazi doctors, Lifton had to dig deeper into the psychology of genocide. He developed the concept of "the healing-killing paradox". Nazi doctors convinced themselves that they were "killing Jews in order to heal the Nordic race". In effect, for these physicians, killing became an act of redemptive purification. Once they could assimilate these ideas into the medical paradigm—*heal, sterilize, purify*—these doctors could move with relative comfort into the otherwise unimaginable realm of torture and murder.

We do not know yet that all the physicians now being held in Britain are guilty of terrorist acts. Nor do we know yet that their justifying narrative is similar to that of the Nazi doctors. But we do know that the rhetoric of religious extremism is almost always filled with allusions to "purity"—purity of race, purity of blood, and purity of practice. Those who do not fit the approved criteria of purity quickly become "infidels" or are reduced to "vermin", as the Nazis characterized their victims. The world must be "swept clean" of those with impure blood or impure faith. Among some terrorists, this lust for purity is fused with a dream of re-establishing some idealized theocracy.

Allusions to purity, to be sure, are found in many legitimate faiths. But when ideas of purity become merged with fanatical religious nationalism, the result is often brutal. As Prof. Michael Sells has observed, "Religious violence frequently justifies itself through ideologies of purity."<sup>2</sup>

Nazi doctors justified their acts of torture and murder with the twisted rationale that they were carrying out acts of healing and purification. I will venture to suggest that, when more is known, we shall discover a similarly perverse paradox underlying the beliefs of the doctors now being detained in Britain. If so, we must find ways of immunizing physicians—and all of us—against such disturbed thinking. After all, if healers can be turned into killers, what does that bode for the rest of humankind? E&M

### Endnotes

- 1 Addendum 10/9/07: Eight people were initially held over the failed car bomb attacks on central London and Glasgow. Three men—all physicians—are still facing charges. A fourth man (a physician) was arrested in Australia, but the charge against him was later withdrawn. Two men (both doctors in training) and a woman have been released without charge, and one man died from his injuries in hospital. Detailed updates may be found at: http://news.bbc.co.uk/2/hi/uk\_news/6264230.stm [Last updated: Friday, 5 October 2007].
- 2 Sells M: Lecture notes for Religion 305: Religion, Ethics, and Society. Accessed at: http://www.haverford.edu/relg/ sells/courses/rel305\_02.htm

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GREY MATTERS

# IN THE TWILIGHT OF AGING, A TWINKLE OF HOPE

WILLIAM P. CHESHIRE, JR., MD

Our brains are seventy-year clocks. The Angel of Life winds them up once for all, then closes the case, and gives the key into the hand of the Angel of the Resurrection.

Oliver Wendell Holmes<sup>1</sup>

The arrival of grey hairs can signify both the attainment of wisdom and the accumulation of age. In the words of Solomon of old, grey hair "is a crown of splendor; it is attained by a righteous life." (Proverbs 16:31, NIV) Grey hair is also a visible reminder of the uncertainty of maintaining mental faculties in old age. For many people, the prospect of deterioration in brain function is feared more than any other ailment of aging. Joints may give way and vision dim without eroding personal integrity. The brain, however, is essential to who we are. Its grey matter is the centerpiece of the living tapestry of personal identity.

Some neurological diseases cause sudden loss of brain function, while others bring about slow disintegration of cognitive faculties. Depending on the site and extent of disease, the loss of neurons and their connections can impair one's ability to participate mentally and physically in the world. Cognitive disorders may erode creative expression, wipe away biographical memories, disrupt language, and render the patient increasingly dependent on caregivers. Age is the primary risk factor for developing neurodegenerative diseases. An estimated 4 million Americans have Alzheimer's disease, which is the most common type of dementia. Its prevalence is expected to grow to 14 million by the year 2050. An estimated 12 million Americans have milder forms of cognitive impairment that may precede the development of dementia.<sup>2</sup>

Subtle cognitive decline occurs also in normal aging. Brain volume decreases at a rate of 0.1-0.2%/year during middle age and even more rapidly at a rate of 0.3-0.5%/year over the age of 70 years.<sup>3</sup> Physiologic aging in the brain is characterized by a loss of synaptic connectivity and neuronal apoptosis. Some of the factors responsible for neuronal aging include oxygen free radical damage, mitochondrial calcium dysregulation, and a host of genetic, dietary, and environmental influences, many of which remain to be fully defined.<sup>3</sup>

Our finite brains are winding down. There are, of course, some notable countercurrents. Mental engagement<sup>4</sup> and physical fitness<sup>5</sup> have been shown to improve cognitive function. Drugs that increase the level of acetylcholine in

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the brain provide symptomatic benefit in the treatment of Alzheimer's disease.<sup>6</sup> The discovery that neuronal progenitor cells in the adult brain proliferate and differentiate in the subventricular zone and dentate gyrus has overturned the long-held view that neurons, once lost, cannot be replaced.<sup>7</sup> Such findings have encouraged research into enhancing the brain's ability to repair and regenerate damaged areas.<sup>8</sup> These lines of research are praiseworthy, provided that they are pursued ethically.

Gains in cognitive function, though worthwhile, are partial and temporary. Completely rejuvenating or preserving the brain indefinitely is not simply a problem to be solved by better biomedical engineering.<sup>9</sup> Even if neuroscience were to achieve the capability to grow new neurons or replace whole sections of human brain, the replacement tissue would not reestablish exactly the original labyrinth of neuronal interconnections. The brain patch could not know what the original tissue knew. Inevitably, the brain must yield, after its brief moment in the universe's billions of years, to the cold rule of time. The body likewise must surrender to mortality.

And yet, despite the certainty of death, human history abounds with expressions of a longing for permanence. Authors and composers pen works that they hope will endure. Scientists test theories that they hope will not be disproven. Philosophers expound ideas that they hope will stand the test of time. Individuals and families leave legacies. Virtually all religions speculate on an afterlife. Considering the evidence from history and culture, C. Ben Mitchell observes that, "the impulse for immortality is a deeply human impulse."<sup>10</sup>

The impulse to immortality is distinctly human in that nonhuman animals do not exhibit this inclination. Natural appetites such as hunger, thirst, and the desire for shelter, and natural instincts for survival and procreation all seek after what is seen or known. While analogous to basic biological drives, the longing for immortality transcends them. It looks to what can be glimpsed only through faith.

The spiritual longing that looks beyond mortality is common to all people. This longing often finds expression through religious faith. Christians believe that the answer to this longing lies in a personal relationship with Jesus Christ, in whom is life (John 1:4, 14:6), and who as God incarnate in human form, bridges the terrible divide between deity and humanity. For the Christian, eternal life is to know the one true God (John 17:3), and faith in the hereafter is united with belief in God as Creator, Redeemer, and Sustainer. Christian faith in restoration beyond death is "being sure of what we hope for and certain of what we do not see" (Hebrews 11:1, NIV). Our hope in Christ is premised on the understanding that we, as individuals, are incomplete, that our communal human story is unfinished, and that suffering and injustice in this life are not absurd but will find meaning when, in the fullness of time, evil is banished and the creation is renewed. Jesus says of himself, "I tell you the truth, whoever hears my word and believes him who sent me has eternal life and will not be condemned; he has crossed over from death to life." (John 5:24, NIV).

The impulse to immortality also influences secular decisions regarding the application of science. It comes as no surprise, in an age when science has triumphed over so many of the conditions of nature that diminish or threaten life, that society would apply the tools of technology to serve the human impulse to surpass the limits of mortality. In place of oral tradition, modern civilization also utilizes printing, video recording, digital archiving, and other durable media to pass its story along to later generations. In place of the stone carvings of antiquity, modern technology has planted a flag on the moon and sent into deep space Voyager's Golden Record inscribed with pictures and sounds of life on Earth. Modern medicine, sanitation, and public health measures have greatly extended life expectancy by reducing preventable early death. Modern biotechnology can now rewrite genomes, permanently altering the genetic code of all subsequent progeny.

The human impulse to transcend the brevity of human life is both personal and communal, spiritual and technological. The comedian Woody Allen famously remarked, "I don't want to achieve immortality through my work.... I want to achieve it through not dying." His words strike a common chord in the human spirit. Hence, the quest for immortality has placed its faith in all manner of emerging technologies. Occasionally the ambition of these pursuits is immoderate. Anticipated prospects, for example, for precise reengineering of tissue at the molecular level have inspired nanotechnology pioneer Robert Freitas to declare that, "Natural death is an outrage" to be overcome through technology.<sup>11</sup>

So deeply human is the impulse to immortality that futurist Ray Kurzweil's hyperbolic prophesy of uploading the brain into a computer and living forever in cyberspace has attracted a curious popularity. According to Kurzweil,

At that point the longevity of one's mind file will not depend on the continued viability of any particular hardware medium (for example, the survival of a biological body and brain). Ultimately softwarebased humans will be vastly extended beyond the severe limitations of humans as we know them today. They will live out on the Web, projecting bodies whenever they need or want them, including virtual bodies in diverse realms of virtual reality, holographically projected bodies, foglet-projected bodies, and physical bodies comprising nanobot swarms and other forms of nanotechnology.<sup>12</sup>

Such prospects remain, for now, distant to technology's reach. Extrapolating from the rate of acceleration of computer processing speed, which historically has doubled every 18 months, once computational power exceeds human intelligence, and provided that it were even possible to copy the information content of a human brain to an electronic medium, it is not clear that such a process would preserve the continuity of personal identity. An intelligent computer would be a different entity that would only disappoint the desire for living forever in the subroutines of endless cyberspace.

For those whose anticipated life expectancy falls short of Kurzweil's predicted date for the "Singularity," when computers might rescue human minds by replacing them, or for those who have a preference for continuing in

human form, there is cryonics. In the heart of the Sonoran Desert, an Arizona company has developed the means to suspend the body in an ultra-cold tank until such time as future medicine develops the hypothetical technology to reverse the cryonic procedure, revive and reconstruct the frozen tissue, and restore the person to health. The cryonic intervention has many of the appearances of a medical procedure. Immediately following the moment of cardiac cessation and medicolegal declaration of death, but before the brain has undergone irreversible hypoxic damage (an unproven claim), the body's water is surgically replaced with cryoprotectants such as glycerol to inhibit the formation of ice crystals, and then the body, or in many cases just the severed head, is immersed in a tank of liquid nitrogen at a temperature of minus 120 degrees Celsius. Cryonic practitioners hold to the astonishing hope that, "The emerging science of nanotechnology will eventually lead to devices capable of extensive tissue repair and regeneration, including repair of individual cells one molecule at a time ... [and] theoretically recover any preserved person in which the basic brain structures encoding memory and personality remain intact."<sup>13</sup> In contrast to the ancient Egyptians, who preserved the bodies of their pharaohs after discarding their brains, which they thought to be unimportant, a common practice in cryonics is to preserve just the brain of the patient, leaving the brain's accompanying head intact "as a practical matter."<sup>13</sup> According to the cryonicists, "Brains are compact, inexpensive to store, easy to move, and are a single organ for which cryopreservation protocols can be completely optimized."13

The search for prolongevity attracts both sound science and charlatanry. Compelling arguments could be offered that limited medical resources ought first to be directed to the treatment and prevention of illness before being spent on efforts dramatically to extend life expectancy or to store fading brains in suspended animation. The purpose of this essay is not to judge matters of scientific credibility, but rather to take notice that the impulse for immortality finds universal expression. In the marketplace of ideas there is a continual demand for promising pathways to abundant, lasting, even eternal life. Ideas, moreover, have neurobiological correlates in the brain. Why does the human brain by its nature yearn for eternity? That the brain would imagine and long for something that its sensory inputs can neither see nor feel is to neuroscience a persistent puzzle. That the mind intuitively knows to reach for something completely beyond its earthly experience is to philosophy a timeless enigma. This same deeply human longing echoes in George Herbert's verse, "O that Thou shouldst give dust a tongue to cry to Thee."<sup>14</sup>

The neurobiological correlates of the longing for immortality are unknown. They likely involve many areas of the brain in cooperation. Neuroimaging studies have shown that thoughts

of hope engage brain regions involved in cognition, language, perception, vision, audition, and emotions.<sup>15</sup> Envisioning an immortal future is also likely to draw considerably from past experience. Neuropsychological and neuroimaging studies have revealed that the neural substrates for recalling the past have a parallel role in envisioning the future. Constructive episodic memory allows

individuals to remember past experiences as well as simulate or imagine future experiences, events, or scenarios.<sup>16-18</sup> Interestingly, patients with amnesia who have bilateral damage to the hippocampi and have lost the ability to recollect past events are also unable to construct new imagined experiences.<sup>19</sup> Thus the brain, despite its remarkable capability for prospection, cannot fully imagine an afterlife because its thoughts draw from and are constrained by past experience. A genuine immortal future surpasses earthly imagination.

Whereas natural biological drives can be localized to specific structures and circuits within the brain, the human longing for immortality is a spiritual longing. As such, its relationship to brain structures may be best described metaphorically. Pascal knew this when he wrote of the God-shaped void within us that can be filled only by a relationship with the inscrutable and infinite.<sup>20</sup> In the prayerful words of Augustine, "Thou hast made us for Thyself, and restless is our heart until it comes to rest in Thee."<sup>21</sup>

William Hurlbut's observation about ethics at the beginning of the 21<sup>SL</sup> century holds true also for speculations about immortality: "We are at the outer edge of the expanding universe of ethics. No one has ever been here before."<sup>22</sup> The factual record of history contains valuable lessons to guide neuroethical decisions but alone does not specify the purpose of life or the destiny of humanity. It is necessary to look beyond the past trail of human failures to the promise of a future in which all things are new (Revelation 21:5).

What science cannot explain, the most powerful technology cannot satisfy. Technology in the hands of fallible humans is a two-edged sword. Its gains provide but transitory optimism, and its harms, whether intentional or unintentional, disappoint, and in so doing, only intensify the materially insatiable human impulse to immortality. Recognizing that the impulse to immortality reflects a true yearning, during this twilight prelude to eternity, it matters which promise we believe and where we place our faith. For, to quote Solomon once more, in time, "the dust returns to the ground it came from, and the spirit returns to God who gave it." (Ecclesiastes 12:7, NIV). **E**&M

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### CLINICAL ETHICS DILEMMAS

# IS IT PERMISSIBLE TO SHUT OFF THIS PACEMAKER?

FERDINAND D. YATES, JR., MD, MA, AND ROBERT D. ORR, MD, CM

The following consultation report is based on a real clinical dilemma that led to a request for an ethics consultation. Some details have been changed to preserve patient privacy. The goal of this column is to address ethical dilemmas faced by patients, families and healthcare professionals, offering careful analysis and recommendations that are consistent with biblical standards. The format and length are intended to simulate an actual consultation report that might appear in a clinical record and are not intended to be an exhaustive discussion of the issues raised. In this case, analysis and recommendations were sought from two ethics consultants.

### Case

Dorthea is a 69-year-old woman who was well and active until about five years ago when she developed diabetes. She was admitted to the hospital 18 months ago with recurrent fainting and was found to have an intermittent transient heart block<sup>1</sup>. She reluctantly consented to insertion of a permanent pacemaker.

Three months ago her kidney function was found to be diminished to about 10% of normal, probably caused by her diabetes. It was expected that she would soon require dialysis. However, her kidney function has since improved so that dialysis will not likely be needed for some time. She has since said she would refuse dialysis even if it were needed, and she has refused treatment of her profound anemia. She did consent to a colonoscopy last month to see if she had cancer (malignant change was found in one small area, presumably cured). She is now asking that her pacemaker be turned off so that she can die.

The ethics consultant met with the patient and two of her daughters. Dorthea says she wants to die now because (a) she misses her husband who died three years ago after 45 years of marriage; they were very close, did everything together, and she says she can't live without him; (b) she can't stand to live in their home (memories), but refuses to move; and (c) she wants to "set her children free." She has resisted attempts by her three daughters who have encouraged treatment, including grief counseling, and have even offered for her to live with them. She has guns in her home and knows how to use them, but she says she is unwilling to take her own life. She is an inactive Methodist. She says her only pleasure is having her children, grandchildren and great-grandchildren visit, but she feels her misery is also making them miserable.

The patient says she was told when the pacemaker was inserted that it could be shut off whenever she didn't want it. It is her impression that she will die quickly without it, however, her cardiologist expects this would not be the case. Though she demonstrates no intrinsic rhythm when the rate of the pacer is turned down to 30 beats/minute on testing, most patients do develop some rhythm after several seconds of not beating at all. Thus she might not die, but could suffer symptoms of congestive heart failure with an unknown outcome. She says she is miserable, is not eating (though her weight is down only 5-10 pounds), and cannot care for herself or her home, but she doesn't want treatment for her anemia or her grief. When asked, she said she did not have the colonoscopy last month in order to protect her life. The only reason she consented to the procedure was that she hoped it would show she had cancer that would end her life.

Her daughters have run out of ideas for helping her, and are now supportive of her request. They believe "she wants quality of life over quantity of life," but they recognize that she is refusing treatment which could enhance her quality. They realize she has not dealt with her grief, but are convinced that she never will.

The patient's primary care physician requests an ethics consultant to address the question of whether this patient's pacemaker may be shut off.

### Consultant #1 (Yates)

### Discussion

This 69-year-old patient is dealing with many of the issues impacting chronic illness in our current health care system – a medical organization that has much to offer, variability in function of the organ systems as the body ages, the profound loss of a loved one, ambivalence, indecision, and depression. In addition the patient apparently has a supportive family structure that offers appropriate care and assistance as well as joy. However, as is common with many elderly patients with chronic illness, this patient does not wish to be a burden to her family.

A patient is generally allowed to make her own treatment decisions if she appears to have 1) knowledge of the medical issues, 2) decisional capacity to make a healthcare decision, and 3) the ability to make a decision without coercion. With respect to her decisional capacity, the family and physicians need to be assured that Dorthea understands (and can express her understanding of) the medical situation, and that she is able to weigh the various aspects of the decision to be made. In the current situation, the patient appears to satisfy these criteria, though it is not yet clear whether she understands the outcome of stopping the pacemaker. It is reasonable to assume that she understands that refusal of dialysis (if needed) and refusal of blood transfusions (which would probably improve her well-being) will ultimately lead to a terminal event.

Since pain and mental illness can significantly affect decisional capacity, it is imperative that these issues be addressed in any patient. In this case, whereas the issue of depression may not be adequately treated from a medical and psychiatric perspective, it has certainly been appropriately addressed from a family and social perspective. Furthermore, the family is clearly attempting to offer the patient care and concern in addition to allowing her to engage in medical decision-making that is free from coercion. There is some question whether she was coerced into accepting the pacemaker in the first place by being told that it could always be removed at her request. Pain does not seem to be an issue at the present time for this patient. Many believe that a pacemaker may be regarded as any other medical treatment, and it may be treated as any other medical life-sustaining treatment (given the parameters outlined above). Using this reasoning, turning a pacemaker off may be ethically justified if 1) continued treatment is inconsistent with patient goals, 2) death is imminent from either cardiac or non-cardiac medical complications, and 3) the patient is refusing or has refused other forms of life-sustaining treatment. However, others believe that, because of implantation into the chest cavity and the necessary wiring to an internal section of the heart, an implanted pacemaker becomes an integral part of the cardiovascular system, similar to an aortic graft or a cardiac valve replacement. Using this latter conceptualization, it becomes ethically problematic to render a pacemaker non-functional. Thus, many cardiologists are reluctant to turn off a pacemaker if a patient is not imminently dying.

In this case, the pacemaker is providing stimulation for the heart to continue beating. However, if it is turned off, the patient may not die; her heart may continue to beat on its own. Her cardiologist predicts that without artificial pacing, the patient's cardiac condition will deteriorate and she may suffer from considerable cardiopulmonary complications.

### *Recommendations*

- 1. It is imperative that her physicians confirm that the family and patient are aware of the complete medical condition, specifically that they know her condition may deteriorate if the pacemaker is stopped.
- 2. Even though the patient's religious base has been described as 'inactive', spiritual care assistance should be considered as there may be some unexplored information in need of discovery and discussion.
- 3. Psychiatric evaluation is mandatory as (a) it is important for all concerned to know whether the patient's depression is impacting her decision-making capacity and (b) such an evaluation may direct who has decisional authority.
- 4. It is ethically permissible for the pacemaker to be turned off if it is apparent that the patient is imminently dying from either a cardiac or non-cardiac medical condition. In addition, if the patient is not imminently dying, the patient's request to turn off the pacemaker may be honored in light of the principle of autonomy if (a) she persists in her request, (b) she (and her family) thoroughly understand her condition, and (c) there are no new considerations evolving from other preceding recommendations.

### **Consultant #2 (Orr)**

### Discussion

Patients have a right to refuse any treatment, even life-sustaining treatment. It may rarely be ethically permissible to force some treatment on unwilling patients who are a danger to themselves or others. Though a patient may be involuntarily hospitalized to prevent suicide, only rarely is it felt justified to seek court authorization to enforce antidepressant medication. When a patient refuses effective and nonburdensome life-prolonging treatment, it is critical to understand the reason behind the request, and then to try to address that reason before considering acceding to the request.

There is no moral or legal difference between withholding and withdrawing a treatment. Thus it is permissible to stop a ventilator or dialysis if it is (a) no longer

achieving its purpose, (b) causing intolerable symptoms, or (c) merely sustaining life with an intolerable quality. While it would be permissible for a patient to refuse pacemaker insertion, it is an unresolved question whether it is permissible to shut off a pacemaker which is sustaining life without causing intolerable symptoms. Some would argue that it is permissible because it is artificial technology, comparable to a ventilator. Most would argue that it is not permissible because the pacemaker, once inserted, becomes part of the person, and shutting it off is akin to assisting in a suicide.

In this case, the patient has not allowed her reasons for refusal to be addressed. In addition, her request, if followed, would probably not achieve her goal of being quickly dead and might even cause her greater physical distress for an unknown period of time.

### Recommdations

- 1. It would be ethically troublesome to turn off this patient's pacemaker at this time. At a minimum, she should have adequate treatment for her anemia and her depression before it can be concluded that she has an intolerable quality of life.
- 2. If she does not respond to an adequate trial of treatment, most physicians would remain unwilling to turn off her pacer either because (a) this would be too close to active participation in the patient's suicide, or (b) it might result in worsening her quality of life without actually ending her life. Others might be willing to honor her request, though they should have clear contingency plans for what will be done if she slips into heart failure or unconsciousness, but does not die quickly.

### Follow-up (editor)

The patient's primary physician explained the likely outcome of stopping the pacemaker. He then told Dorthea and her family that he couldn't consider stopping the pacemaker until she had had full treatment for her depression and her anemia. Two weeks later she consented to nursing home admission and beginning an antidepressant. Her appetite and mood improved, and inexplicably, so did her kidney function. She stopped asking about turning off the pacemaker. **E**&M

### Endnote

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Heart block is a dysfunction of the electrical conduction pathway in the heart. It can lead to a slowing of heartbeat, and occasionally to temporary stopping for several seconds. Treatment may require the use of medication or a pacemaker.

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# USES OF BIBLICAL, THEOLOGICAL, AND RELIGIOUS RHETORIC BY CLONING ADVOCATES: A CRITIQUE

DENNIS L. DURST, MDIV, PHD

# Abstract

Religious and theological language is commonly found in the arguments utilized by opponents of human cloning-to-produce-children. Less well-known is the use of religious and theological language in the rhetoric of the proponents of reproductive cloning. This essay examines both blatant and subtle instances of religious and theological rhetoric in the public discourse of cloning proponents. Particular attention is paid to offering a critique of the term "created co-creators" in reference to those who would engage in human cloning.

# Introduction

In 2000, Theologian Philip Hefner addressed his own denomination, the Evangelical Lutheran Church of America, on the subject of cloning. His rhetoric was by historical standards nuanced, cautious and subdued.<sup>1</sup> Nevertheless, for many engaged in the bioethical conversation today, the following words are jarring: "Nature comes to us today under the form of human co-creating activity, under the forms of what humans can make of nature, the forms of genetic engineering and cloning. This means that God's creation comes to us under these forms, as well."<sup>2</sup>

It is commonly believed that if religious rhetoric is inserted into the cloning debate, it is there because Protestant Evangelical or Catholic essayists have done the inserting. Yet this is an inaccurate belief. We find politicians, scientists, bioethicists, and theologians who favor cloning-to-produce children who are willing to engage in religiously-based arguments or at least to employ common religious tropes in their overall argument strategies. For some, cloning has become a religious ideal, or perhaps an ideology. In this essay, I make a distinction between *blatant* instances of cloning as a religious ideology and *subtle* instances of religiously-motivated cloning. The blatant instances will be readily apparent to the reader and dismissed (perhaps too easily) as the mere arena of cranks and frauds. More troubling are the subtle forms of cloning as a religious ideology because of their more persuasive qualities for those yet undecided.

### **Blatant Cloning-as-Religion**

During his pilgrimage to a radical reinterpretation of the Judeo-Christian story of human origins and progress, a French-born author and racecar driver first known as Claude Vorihon underwent a name change. As the prophet Rael, he has claimed to be one of a long line of humans inspired by alien guides who have periodically visited earth to check on their project of enhancing human evolution. One way that the Raelian version of the human race makes its great leap forward is through human cloning. Even Jesus gets into the act via Raelian theology: his resurrection was really a successful cloning experiment, conducted by these benevolent space aliens, known as the *Elohim* (in a bizarre appropriation of the ancient Hebrew term for Almighty God). The Raelians are convinced that the cloning of Dolly the sheep in 1997 is the harbinger of an expansion of this cloning/resurrection nexus.<sup>3</sup> Life on earth derives from other planets—only for the Raelians, this was planned by a super-species of aliens.

The chief pro-cloning spokesperson for the Raelians' cloning ambitions is their star "bishop" and biochemist, Brigette Boisselier. As CEO of the "brand name" (not a company, according to Boisellier), "Clonaid," that has come under a federal investigation, the blending of religion and cloning could not be more obvious or theatrical. The Raelians believe in extraterrestrials and defend their enthusiasm for cloning as a chance for "eternal life" for the cult's adherents. Exploiting the pain of infertile couples, as well as the pocketbooks of wealthy grieving parents, the Raelians are widely criticized even by those scientists who favor cloning research.

The on-again, off-again promises of clone babies has eroded whatever minimal credibility Clonaid may have had. Still, Mark Hunt, the wealthy former West Virginia legislator who openly sought Clonaid's help in cloning his dead 10-month-old son, shows the interplay of mainstream and fringe figures in the pro-cloning movement. Hunt's public statements show how biblical rhetoric has been used and abused in the case for cloning. "We didn't know what to do and I couldn't accept that it was over for our child," Hunt lamented, adding that "For the first time in human history, I didn't accept death as the end. Not since our Lord and Saviour, Jesus Christ, spoke to Lazarus and told him to 'come forth' from the grave has a human being (been) able to bridge the great gulf of death."<sup>4</sup>

When scientist Richard Seed rashly announced his intention to clone a human being shortly after the 1997 cloning of Dolly the sheep, he couched it in biblical terms. Seed asserted that God supports his cloning activities because God wants us to be like God, and God gave humans the power to clone.<sup>5</sup> The mixture of bold claims in the name of an often-misunderstood science, wealth, media coverage, emotional appeals, and oblique references to scripture and to religious freedom all feed the blatant cloning-as-religion fervor of the cloning entrepreneurs. To what degree such figures will be mainstreamed or further marginalized remains to be seen. Clearly, the excesses of once reputable figures like South Korea's Hwang Woo-Suk, whose faked cloning research led to an

international scientific and human-rights scandal in late 2005, may dampen for a time the enthusiasm of the cloners.<sup>6</sup> Yet, it would not do to rest easy on this news, as more subtle, and ostensibly more moderate voices, continue to press for the legalization of human reproductive cloning.

### Subtle Cloning-as-Religion

More important than such blatant forms of cloning as religious ideology are its subtle forms. In the decades following World War II, the ability of our government to impose eugenic (literally "good birth") solutions on unwilling others under the banner of "the greater good" has been curtailed in significant ways. The rise of informed consent, the exposition of the horrors of human experimentation, and a greater sensitivity to the inherent dignity and the positive contributions to our society of the disabled, have eroded the power of eugenics as a social policy movement. Even the term eugenics itself has only a few proponents, and it is seen as a word to be avoided by most in the fields of social service, genetics, and medicine. Still, the goal of producing good births, through (for example) reducing incidences of birth defects remains a significant impetus in research and clinical application. The impulse to manipulate good births leads physicians into problematic practices like the selective abortion of Downs Syndrome babies.<sup>7</sup> Germline interventions and both cloning-to-producechildren and cloning-for-biomedical-research are other areas where eugenic thought-patterns hold a lingering, if more subtle, sway. Such biotechnological developments are usually defended on the grounds that they utilize biological material derived from actions voluntary in nature, such as excess embryos from in vitro fertilization, and are not imposed by any governmental entity. The problem with eugenics, so say these researchers, was that it was shoddy as science, and it was undemocratic and coercive as social policy. The science is clearly more exacting today, and the social policy has been grounded afresh in the supposed democratic terms of consent and choice.

Choice and freedom are key terms in the early twenty-first century defenses of "good birth" interventions. Panayiotis Zavos, associate director of the Kentucky Center for Reproductive Medicine and IVF in Lexington, Kentucky, gave testimony before a U.S. House subcommittee on May 15, 2002. The historical context was a larger debate on Capitol Hill on whether or not to ban human reproductive cloning. Zavos testified in opposition to such a ban. Much of Zavos' testimony focused on the claim that cloning shows compassion toward infertile couples. His core assumptions included the following: 1) any fear of cloning can be traced to "an illogical transient fear of a new technology;" 2) the criminalization of cloning would merely drive it underground or out of the country, thus making it less safe and more expensive for the infertile; 3) human reproductive cloning is inevitable and thus laws against it are futile; and 4) granting reproductive cloning federal legalization is the only way to regulate it.<sup>8</sup>

Zavos appealed to religious and even Judeo-Christian rhetoric in his argument for cloning-to-produce-children. This rhetoric reveals the easy blurring that takes place between human making activity and the more fundamental act of divine creation as perceived by some outspoken cloning advocates:

We are law abiding citizens of the great Nation of ours, but we are a compassionate group of people that wish to help our fellow man and woman have the gift of life. The gift of life that most of us have been so fortunate to have, enjoy and take for granted. Let us not be so uncompassionate and so insensitive to tell those people that we are not willing to listen to them and unwilling to help them. This is not what our country's constitution and principles are based on. We believe in creating families, not preventing them. In God we trust!<sup>9</sup>

In framing the opponents of cloning as lacking compassion, as spurning the gift of life, as insensitive, and as unwilling to hear and help infertile couples, Zavos appealed to the values that remarkably mirror pro-life values (perhaps to gain the ear of the reproductive cloning ban's chief sponsor, Sam Brownback, pro-life Senator from Kansas). In a plea for a prerogative of freedom to create twenty-first century families, Zavos took on the mantle of Godhood, while still asserting "In God we trust." The irony that this phrase is also stamped on American currency is not lost on those of us who find such utopian rhetoric utterly detached from the grisly path that would be the inevitable concomitant to a successful human cloning procedure and is only thinly veiling the vast monetary incentives well-known to observers of a barely regulated infertility business.

Moments later in his testimony, Zavos tried to align himself with President George W. Bush by agreeing with the President's statement that "Life is a creation, not a commodity" after which the President issued a warning about the commodification of children. "We agree with President Bush and uphold the sanctity of human life," Zavos cried, urging that little moral difference exists between the procedure of cloning and standard procedures common in IVF. "Reproductive cloning is nothing more than another modality for the treatment of human infertility in giving the gift of life to a childless couple that have exhausted all other choices for having a child" Zavos glibly claimed, adding the plea, "What is so wrong about this?"<sup>10</sup>

What is so wrong about this is aptly surveyed in the unanimous opposition expressed by chapter five of the report of the President's Council on Bioethics.<sup>11</sup> The specter of manufactured humans is not just an irrational "Bio-Luddite" nightmare.<sup>12</sup> A regime out to create a master race by controlling human heredity is not science fiction, it is the well-documented history of science in the twentieth century. Given that attitudes about the "inevitability" of cloning reveal a brazen willingness of its proponents to flout most proposed regulations of the practice, citizens who see the manifold flaws in the pro-cloning rhetoric have ample cause for alarm.

Gregory Pence comes across as the most level-headed of the advocates of human cloning, and even himself expresses irritation that the Raelians, "Dick" (Richard) Seed, and Panos Zavos garner so much public attention. Still, Pence's opposition to the anti-cloning arguments is rooted in his transhumanist and atheist agenda. Though he would doubtless dispute the inclusion of transhumanism and atheism under the rubric of religion, it has never been completely clear why such positions are not religious. They are ideologies that partake of ultimate concern (Paul Tillich's definition of religion, cited often by the Supreme Court in strict separationist arguments), even if they limit ultimacy to the confines of human history and this-worldly aspirations of humanity. Pence re-states "a series of statements intended to be reductio ad absurdums" that he nonetheless accepts as true, namely, criticisms of a new eugenics which includes human cloning. Pence quotes R. Albert Mohler, professor of Christian theology and president of Southern Baptist Theological Seminary in Louisville, Kentucky. One of the statements with which Pence admits ironic agreement is the following:

If there is no divine Creator, no Maker of heaven and earth, then we will have to take creation into our own hands. The eugenic temptation is so powerful that only the Christian worldview can restrain it. Scripture alone reveals our creaturely identity, our sinfulness, and the limits of our authority and responsibility. We are not the creator, and the responsibility to assume control of the universe is not ours. . . [In contrast] the very notion of moral limits is foreign to the secular mind.<sup>13</sup>

Pence is loathe to modify his transhumanist philosophical naturalism even to make peace with non-theists or progressive theists who have qualms about human cloning. He sees their resistance as either residual religious prejudice, or as a cloaked religion masked by natural law argumentation. "Liberal Christians and pro-choice theists will not like Professor Mohler's message and will probably ignore it, seeking some compromise," Pence predicts. With refreshing candor he continues: "But I believe Mohler is correct: either we believe that a God exists and sets limits or we reject it in favor of the idea that humans determine their own limits and their own destiny."<sup>14</sup>

One of those liberal Christians who turns out to be a cloning ally is Philip Hefner. Far from arguing against the relevance of theology to the cloning debate, however, Hefner offers his own theological grounding and justification for cloning. Hefner strives to remove some in-principle theological objections to cloning. The main theological or religious term giving ethical space for cloning is Hefner's description of humans as "created co-creators." Much in the work of Hefner and his followers is fruitful, worth reading, and necessary to an informed discussion of such matters. Still, the notion of humans as "created co-creators" may constitute a subtle form of cloning-as-religion re-entering the discourse surrounding our desire for good births. Thus, the phrase "created co-creators" will be critiqued below on both theological and exegetical grounds.

Philip Hefner is a leading theologian in the effort to bridge the unwieldy and mutually wary realms of science and theology. As editor of *Zygon*, a journal dedicated to this project, and as author of numerous books and articles over more than 30 years, Hefner's pronouncements carry weight among both theologians and scientists. His 1993 book, *The Human Factor: Evolution, Culture and Religion*, sets forth the notion of humanity as co-creators with God. Hefner's core claim reads as follows:

Human beings are God's created co-creators whose purpose is to be the agency, acting in freedom, to birth the future that is most wholesome for the nature that has birthed us—the nature that is not only our own genetic heritage, but also the entire human community and the evolutionary and ecological reality in which and to which we belong. Exercising this agency is said to be God's will for humans.<sup>15</sup>

For the most part, Hefner applies this notion to the widely-acknowledged observation that humans are creative beings in general, and more specifically, that humans are creators of culture. Culture, for Hefner, is one of two fundamental evolutionary forces, of which the other is our genes. When the notion of humans as created co-creators must be applied to experiments on the genetic materials of humanity itself, Hefner has recently paused to urge a measure of caution. However, his caution has more to do with the excesses of entrepeneurism and the narcissistic mentality of "self-help" in American culture than with any ethical problem he has with the act of cloning itself.

Hefner disagrees with the perspective of those who see cloning as morally suspect because it is unnatural. He cites farms and agriculture, cities, electronic communications and computers as examples of "unnatural" interventions via technology we take for granted. Yet Hefner hesitates to prohibit even those forms of genetic engineering that include cloning, because such are expressions of human creativity, which he roots in the classic Judeo-Christian doctrine of the image of God. Even his acknowledgement of the potential abuses of the technology does not lead Hefner to prohibit the act of cloning itself, as he writes:

Genetic engineering and cloning may be carried out in blasphemous and perverse ways, but they are rooted in our deep-down desire to fulfill the image of God within us and our fellow human beings. How that truth can be clarified is the task of Christian reflection, devotion, and action.<sup>16</sup>

Even if cloning turns out to be a sinful activity, such activity fits with seeming ease into Hefner's interpretation of the classic Lutheran statement that we are justified and yet sinners at the same time. Hefner's understanding of sin departs from the classic Lutheran sense of sin as tragic, however, and sees sin as a natural part of biological evolution, rather than a deep rupture in the fabric of creation to be overcome and healed. He writes:

The assertion of Original Sin says this—it says that sin is what we do in sinful acts, but it also says that sinful acts flow from our created nature. The creatures who have been made in the image of God are also sinners. For our topic, we may say both that the capability for genetic engineering and cloning are good, since they flow from the distinctive human nature hat God has created, and that they are never without sin, however, because the engineers and the cloners are never without sin. Our cloners are saints and sinners at the same time, and so also our ethical precepts concerning cloning will be both saintly and sinful at the same time. There will never be a perfect code of ethical guidelines for cloning. The question is how this insight can be rendered effective in the actual practice of genetic engineering and cloning.<sup>17</sup>

### Critique of "Co-Creator" Language

As an initial critique, an examination may be necessary of the exegetical elements of the biblical terminology of creation, which deserve more prominence in unpacking the rights and limits of so-called creative human activity. In the Hebrew Bible (the Christian Old Testament), different terms are normally used for the creative act of God and the initiatives of human beings. The Hebrew verb  $b\hat{a}r\hat{a}$ ' is only used of humans four times (note that these usages refer to the action of cutting down of trees, use of the sword as symbolic of judgment, or of gluttony, cf. Josh. 17:15, 18; 1 Samuel 2:29; Ezek. 21: 19; and 23:47). The Hebrew verb  $b\hat{a}r\hat{a}$ ' is applied to God nearly fifty times, and bespeaks God's creation from nothing (*creatio ex nihilo*), to create decisively, effortlessly, and with a flourish.<sup>18</sup>

In an extensive study of the uses of this term, Thomas J. Finley identifies two key dimensions of the verb in the OT literature: *construction* (physical, sociological, ethical and spiritual) and *performance* (especially focused on God's unique power and unparalleled glory).<sup>19</sup> The implications of both dimensions should constrain our enthusiasm for notions of humans as "created co-creators." On the construction side, human cloning has implications ranging far beyond the prowess to manipulate human physiology. The sociological, ethical and spiritual dimensions of this activity are of greater importance, and all show how little "control" we really have over the consequences of our technological choices. On the performance side, God must be glorified as the source of life, which frankly remains an awe-inspiring mystery, despite the great strides we have made in unveiling the genetic code. God will not yield his glory to another; God is the one who will make all things new.

The Hebrew verb 'asâh is used of God and of human beings and refers to making or fashioning something by using pre-existing materials. Calling humans "created co-creators" illegitimately applies the same English root word for creativity to both the *origins* of humans and the subsequent *activities* of humans. This rhetorical move fails to uphold the theological distinction embedded in the underlying Hebrew text. God's creative activity is unique, in that only God creates from nothing. Accompanying this view is the conviction that God alone has ultimate prerogative for determining the uses to which his created elements and created agents are put. Humans by contrast always use pre-existing materials. Thus they are under obligation to act as *stewards* of those pre-existing materials in ways that acknowledge gifted quality of the materials with which they are working. When humans come up with a human biotic entity they have created *from nothing*, then they will have the right to do with that being as they please, because that being will be their property. Until then, there are inherent ethical limits in what ought to be done with human or potential human beings.

A second critique of the created-co-creators approach to cloning comes from attention to stewardship. The notion of human *dominion* means stewardship over the rest of the created order, but not an ownership of humanity, or even the genetic code itself. Though both Old and New Testaments permitted slavery, for example, as a concession to human weakness, it was never described as unregulated use of another human person. Strict rules were put in place so that, at least in principle, slaves could not simply be reduced to the status of inanimate chattel property. Slaves were to be offered manumission on a regular basis, slave families were to be left intact, and slaves were offered opportunities for participation in religious life of the community. They were not merely means to an end, and were seen as having value as persons. The long history of slavery contains important analogies to the cloning debate and is an area that needs to be mined by historians and ethicists.

Thirdly, the tenor of the Bible militates against the "self-made (wo)man" myth that drives much of American individualism in general and much of the pro-cloning movement in particular. Various self-aggrandizing motives come into play: the wealthy businessman who wants his look-alike, the scientific racist who wants a super-race, the homosexual couple who wants to "naturalize" their relationship with the introduction of children. Yet self-mastery and radical autonomy are theologically, as well as sociologically, poisonous ideas. Elsewhere Hefner disavows some of these applications of cloning, but it is difficult to see how his resignation in the face of the biological sinfulness of human nature can erect any robust ethical barriers against such abuses.<sup>20</sup>

A biblical story treating human creative autonomy is found in the book of Daniel, chapter 4, in a colorful critique of the "self-made man," Nebuchadnezzer. Looking out over his city of Babylon, he boasted "Look how great Babylon is! I built it as my capital city to display my power and might, my glory and majesty." Upon this boast, the text indicates that God punished Nebuchadnezzer by taking his sanity, and banishing him to live with the animals for seven years. It is difficult to see how, if humanity's status is that of Hefner's created co-creators, he could fault Nebuchadnezzer for seeking the accolades that so often accompany human creative achievement. Yet it was such creative or engineering activity Nebuchadnezzer assumed to validate his godhood. As it turns out, he ended up actually in a condition less-than-human, or beastly, as the fitting punishment for his pride.

### Conclusion

We are in our ultimate origins made by God, while in our nearer origins we are, as bioethicist Gilbert Meilaender and others have pointed out, "begotten, not made."<sup>21</sup> Procreation is indeed a divine concession to us, a gift. It is not "creation" in the fullest biblical sense. We do encounter limitations upon our "making" capacity, namely, that the biological elements we use in biotechnology

really are not created by us, but are merely reshaped, harnessed, and sometimes exploited. For the clone, the doctrines of informed consent do not apply, and the freedom of being begotten, not made, of being cherished as a gift, not a commodity, is jeopardized by his or her status as clone. To be truly free is to be aware of our dependent status, to experience peace in the realization that God takes ultimate responsibility for the unfolding and flourishing of human history.

This is not to justify any mistreatment of clones, should they tragically come into existence. Protection of their full human rights as persons should be anticipated as policy that all compassionate persons should accept. This is the only consistent position, given our advocacy of the humanity of those cloned blastocysts routinely destroyed in biomedical research.

The desire to help the infertile couple is indeed a strong and admirable desire. At a practical level, both church and state must do a better job of making adoption a more appealing and viable option for hurting infertile couples. The belief that only "biological" offspring are adequate to fulfill the drive toward parenthood is a narcissistic belief that can and should be gently and sensitively challenged. To construct oneself as a co-creator with God leaves little room for the ethical checks and balances needed for a just social order, and leads too easily, if not inevitably, to a "might makes right" mentality for the bioengineer.

It was a theologian named Paul who insisted our status as adopted children of God has elevated us to the pinnacle of being "co-heirs" with Christ. The term "co-heir," with its implicit stress on grace and mercy, has more the ring of humility than does the term "co-creator." Such a realization of our place in the divine economy offers a chastened definition of the inheritance that really matters most. E&M

### Endnotes

- 1 For instances of harsher pro-eugenics religious rhetoric, see my "Evangelical Engagements with Eugenics, 1900-1940," *Ethics & Medicine* 18 (Summer, 2002): 45-53.
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- 11 Readers are encouraged to read this for themselves in the final report as well as the deliberations leading to it at www.bioethics.gov.
- 12 "Bio-Luddite" is Gregory Pence's favored ad hominem term for opponents of reproductive cloning, used repeatedly in his recent book (see subsequent note); On the trans-Atlantic nature of eugenics in the pro-Nazi effort to control human reproduction, see text and documentation in Edwin Black, War Against the Weak: Eugenics and America's Campaign to Create a Master Race (New York: Four Walls Eight Windows, 2003), 261-318.
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- 16 Hefner, "Cloning."
- 17 Ibid; cf. Hefner's *Human Factor*, 123-42 for his extended argument for "naturalizing" original sin.
- 18 Stanley L. Jaki, Genesis 1 Through the Ages (London: St. Thomas More Press, 1992), 295
- 19 Thomas J. Finley, "Dimensions of the Hebrew Word for 'Create'," Bibliotheca Sacra 148 (2001), 409-423.
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# DIFFERENCES BETWEEN BEHAVIOURS OF FEMALE PATIENTS FROM POLAND AND BELARUSSIA AFTER NATURAL MISCARRIAGE AND INDUCED ABORTION

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# Abstract

Obstetric failures and their sequels account for approximately 15-20% of the female population in the reproductive age. The aim of the present study was to explore the failure-terminated pregnancy experience of women, as well as to find out whether and how this type of failure affects further procreation and what differences exist between behaviours of female patients after natural miscarriage and induced abortion. The study found significant statistical differences between behaviours of female patients after natural miscarriage and induced abortion, especially with respect to religious belief/activity, self-esteem, view of the fetus, attitude toward conception and sexual intercourse, secondary infertility, desire for a child, emotional bond with the child prior to abortion, and relationship with the biological father. Based on the study, it is conluded that induced abortions usually leave permanent scars in the minds of women. They frequently express a negative opinion of gynecologists and more frequently have no procreation plans. In contrast, natural miscarriage did not have extra negative effects on the woman's relationships within her closest social environment. Women in this group were emotionally attached to the child, did not avoid conception, but some even had future procreation plans. Generally, the woman's relationship with God grew deeper as well. Of course, the study's limitations preclude drawing definitive conclusions, but the findings do suggest the need for additional cross-cultural research on this issue.

Key words: procreation failures, trauma, procreation plans, attitude of women

# Background

Obstetric failures can be basically divided into two different groups. One group includes idiopathic or non-committed failures, independent of patients' or doctors' will (natural miscarriage, preterm labor).<sup>1,2</sup> The other group (induced abortion) comprises conscious failures, voluntarily chosen by patients or due to pressure or even compulsion from the woman's closest milieu.<sup>3,4,5</sup> Clinical observations and increasing scientific evidence show that abortion leads to mental and physical disorders related to posttraumatic stress. Abortion can be followed by two types of disorders: PAD (post abortion distress) and PAS (post abortion syndrome), which affect women, family members, friends,

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and medical staff involved in the event.<sup>6,7,8</sup> Reports suggest that in making a decision to terminate pregnancy, the mother suppresses her own feelings and natural maternal reactions and dehumanizes the child. Through strong denial or rationalization, the mother thus attempts to give the child features of an unidentified person.<sup>9,10,11</sup> These two groups of obstetric failures and their sequels account for approximately 15-20% of the female population in the reproductive age.

## Purpose

The aim of the present study was to explore the failure-terminated pregnancy experience of women and the adaptation processes in their families, as well as to find out whether and how this type of failure affects further procreation and what differences exist between behaviours of female patients after natural miscarriage and induced abortion. Another related objective was to search for supports for parents after the loss of a child as well as counseling that would efficiently bring the mother back to normal functioning in the family and in society.

# **Material and Methods**

The study involved 103 randomly selected women aged 28-68 years. 33 women came from Grodno, Belarussia, and 70 from Białystok, Poland (Out-patient Department of Gynecology). The study lasted for two years (2004 and 2005). The questionnaire was applied in a face-to-face interview during medical examination in a separate room in the Out-patient Department of Gynecology. Retrospective data were collected using the Coping Orientations to Problems Experienced (COPE) in Polish modification by Wrze niewski (1996). The data were evaluated using the Statistica 6.0 pl and Excel programs. The Chi-square test, Student's t-test, and Fisher's exact test were used for statistical analysis.

The research method was anamnesis combined with elements of open psychological talk (referring to women's recollections). Some of the questions (in the obstetric anamnesis) were closed. The anamnesis consisted of two parts: personal questions and precise obstetric inquiries exploring mothers' recollections of obstetric failures.

Patients	Total	Bialystok		Grodno	
Conditions	N	N	%	N	%
Education, statistical result* p< 0.	001	•			
higher	11	9	81.8	2	18.2
uncompleted higher	10	7	70.0	3	30.0
secondary	44	30	68.2	14	31.8
after primary	12	5	41.7	7	58.3
primary	26	19	73.1	7	26.9
The marital status, statistical resul	t p < 0.05				
unmarried	5	5	100.0	0	0
married	91	61	67.0	30	33.0
widowed	7	4	57.1	3	42.9
The financial status, statistical res	ult p < 0.001				
Very good	9	5	55.6	4	44.4
good	24	16	66.7	8	33.3
average	40	29	72.5	11	27.5
bad	30	20	66.7	10	33.3
Age, statistical result p < 0.05					
18-28	34	21	61.8	13	38.2
29-38	27	24	88.9	3	11.1
39-48	22	20	90.9	2	9.1
49-58	13	3	23.1	10	76.9
59-68	7	2	28.6	5	71.4
The number of children, statistical	result p < 0	.01			
lack of children	19	16	84.2	3	15.8
one child	59	40	69.0	18	31.0
Two and more	26	14	53.8	12	46.2
The attitude to religion, statistical	result p < 0.	01			
religious and church goers	50	34	68.0	16	32.0
religious but not practicing	20	16	80.0	4	20.0
not religious	33	0	0.0	33	100.0

Table 1. The social and demographic conditions of patients

\*One and two or more induced abortions have been evaluated together in the statistical analyses.

The women (aged 28-68), from Belarussia and Poland together, were divided into two groups according to the type of failure. The first group consisted of 50 women after natural miscarriage, and the other group contained 53 women after induced abortion. All the women in the latter group had abortion in the first trimester and all because of social and/or financial status. There were no therapeutic abortions. Eleven patients had university education, 44 had secondary, and the rest had basic technical or primary education (p<0.001, Table1). Except for seven widows, five were unmarried, and the rest were married. Their financial status varied: nine women considered their status "very good"; 40 "average"; and 24 "good" (p<0.001, Table1). The remaining women had "poor" life conditions. Their attitude to religion was also investigated: 50 were religious and church-goers; 20 were religious but not practicing; the rest (33) were not religious, including one who declared attachment to family tradition. Again, the data were evaluated using the Statistica 6.0 pl and Excel programs. The Chi-square test, Student's t-test and Fisher's exact test were used for statistical analysis.

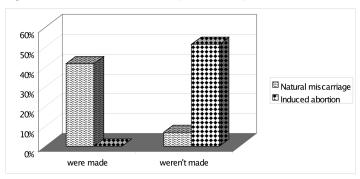
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## Results

### Natural Miscarriage

In the group of women after *natural miscarriage*, failure terminated the first pregnancy in 19 patients, the second in 18, and the third in 13 patients. The miscarriages took place either in the first trimester or at the beginning of the second—two, six or ten years before the study. The feelings accompanying this event included: breakdown, anxiety, the feeling of grief and loss, disappointment, unfulfilled expectations, and unrealized aim. Except for seven women, all were emotionally attached to the child before miscarriage (Figure 1, p < 0.0000).

Figure 1. Emotional relationships with the fetus



Seeing the baby on the ultrasonograph screen was a crucial moment. Sikorski<sup>12</sup> also notes the positive effect of fetus visualization on the emotional bond between the mother and the child. Emotional bonds with the child most frequently manifested themselves in joy and happiness and even in name-giving to the child.

The failure had no negative effect on the woman's closest relational environment (Figure 2, p < 0.01). The women were asked how the experience of failure affected their family relation, and in seventeen patients (34%) the couples became "concentrated around a desire to have another baby", "talked about future procreation", and "the husband became more thoughtful" or "sensitive".

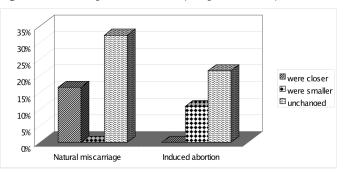
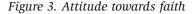
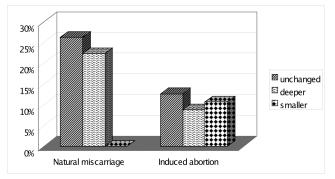


Figure 2. The couples' relations after procreation failures

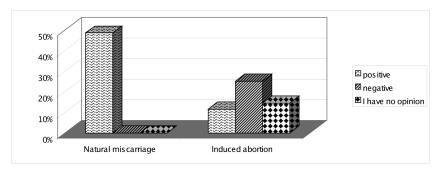
Reported relationships with God grew deeper in 23 women (46%). They prayed more frequently for another child (Figure 3, p < 0.05). All the women (100%) needed psychological and spiritual support. Religion, according to the women, exerts an enormous effect on the way they experience the failure—"what comes from God brings peace" or "I was peaceful, I trusted God".





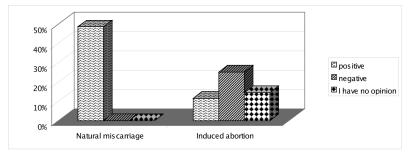
In 19 patients (38%) with the first pregnancy, natural miscarriage had an influence on their decision to have a baby in the future, while in the remaining patients who had already had children, this event had no distinct effect on procreation plans (Figure 4, p < 0.005).

Figure 4. Procreation plans after procreation failure



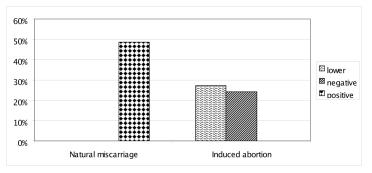
All the patients in this group (100%) positively evaluated their contact with a gynecologist: "he/she gave frank information, was honest, thoughtful all the time, supportive in difficult moments" (Figure 5, p < 0.001).

Figure 5. Contact with a gynecologist



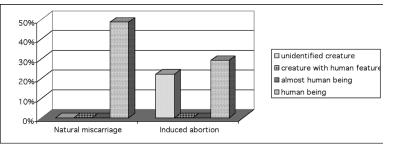
Self-esteem in this group was positive in 50 women (100%) (Figure 6, p < 0.0000). Five women needed one-year leave to recover after the loss of child. The patients who had a baby after natural miscarriage revealed after labour: "I was fully aware of the happiness I experienced" and "Never before had I experienced such an intense feeling of happiness".

Figure 6. The patients' self-esteem after procreation failures



All the mothers (100%) agreed that the conceived child was a complete human being (Figure 7, p < 0.001). The patients were asked if they treated a child as "a human being", an "almost human being", a "creature with human features" or a "unidentified creature" from the very beginning (conception). Twenty-two women still had the feeling of attachment to the child; four of them said that "the child is in heaven"; these women experienced longing and had fond recollections.

Figure 7. Status of the child from conception according to women's opinions



# Induced Abortion

The other group consisted of women *after induced abortion*, who were examined in the Outpatient Departments of Gynecology in Grodno and Białystok. Fiftythree women after one or two abortions were examined. They had one or two children. Most of them (39) had one sibling and only 14 had two or more brothers or sisters. Thirty-three (62.4%) declared being unreligious—one unreligious declaring attachment to family tradition (from Grodno); four (7.5%) were believing Christians but not church-goers; 16 (30.1%) declared being practicing believers. They had induced abortions because of social and/or financial status 2-40 years before the study. In each case, abortion was accompanied by fear of having the next child, avoiding sexual intercourse, and anxiety of the technical procedure itself. Usually after a few years these feelings changed: eight patients experienced a feeling of peace as a result of a resolution to the problem; 13 women began to regret their decision (Table 2, no,1,2,3,5,6,15); 17 experienced a strong feeling of committing a mortal sin; and the remaining 15 did not express any feelings. The patient forced by her husband to have an induced abortion said: "I have a grudge against the whole world that I had to do this, no words for it" (Table 2, no 4,10). None of the women had emotional bonds with the child before abortion (Figure 1, p<0.0000). Thirty women (56%) who felt sorry or were aware that they had done ill acknowledged the child's full humanity (Figure 7, p<0.001).

Twenty-three women (43%) who had two abortions and expressed no feelings toward them treated the child as an unidentified creature (Figure7, p < 0.001). Nearly half of the patients (25; 47%) had low self-esteem (Figure 6, p < 0.0000), (Table 2, no 7). The remaining patients (28; 52.8%) tried to find an excuse (Table 2, no 8). Eleven patients (20%) admitted that they walked away from God, their religious bonds weakened (Table 2, no 9) as well as their interpersonal relations (Figure 3, p < 0.05). No alterations were observed in the other five women (9%). Two of them expressed being still full of rancor and even hatred toward their husbands because of the pressure and compulsion exerted (Figure 2, p < 0.01). Among the women with reduced self-esteem, 25 (47%) admitted the influence of a philosophy of life or religion (Table 2, no11). Lack of qualms of conscience corresponded with a declaration of being unreligious. Nine women (16%) pray more now and talk to their priests. The years of life experience that have passed since abortion triggered some reflections in only half of the patients (Table 2, no12). However, the women whose life experience had no effect on their point of view stated that their decision would still be the same. Thirteen (24%) could not have more children; 32 (60%) did not want to have children and avoided conception and sexual intercourse (Figure 4, p < 0.005). Only eight (15%) had children later. Twelve (22%) had a positive interaction with a gynecologist; 26 (49%) had a negative contact (Table 2, no13); still others had no opinion (Figure 5, p<0.001). Twenty-eight patients (52%) believed that medical and psychological information would not have changed their attitude. In the questionnaire, patients defined their present feelings as follows (Table 2):

Table 2. The expression of the feelings of women after induced abortion

Nr.	Descriptive data from individuals who aborted
1.	"I am very unhappy, it may have been a daughter to take care of me, the only son is an alcoholic"
2.	"these negative feelings persisted and were not going to vanish as the scar is too deep"
3.	"when the pain, spiritual and mental, gets stronger I kneel at the altar prepared in my flat or lie prostrate crying loudly; time doesn't matter then and it brings a relief"
4.	"I have a grudge against the whole world that I had to do this, no words for it"
5.	"If I could repeat my life I would never do it", "I am thinking of how old my children would be now"
6.	"It's a great burden, I have no words to express my pain"
7.	"I strongly accuse myself", "I can't forget" , "I can't have more children"
8.	"I had no way out, I would do the same if the situation repeated again"
9.	"I have no qualms of conscience"
10.	"I won't give him anything to eat", because of the pressure and compulsion he exerted on her
11.	"I had the feeling of violating the God's law"
12.	"man looks at it more wisely", "I wouldn't do that", "I would teach my children not to do that"
13.	"doctor did not care that I was going for slaughter"
14.	"the life began to break into pieces, only to tie a blindfold and get drowned"
15.	"spiritual and emotional trauma", "empty soul" and "deeply engraved scar".

# Discussion

The patients in this study were selected randomly. They were investigated only after they had seen the questionnaire and had given consent to the talk. They were asked for consent to enrollment in the study during visits at the doctor's after revealing procreation failure experience. The difference related to the patients' origin (from Grodno or Bialystok) lies mainly in mentality: Belarussian women talk about induced abortion openly, casually, with friends; for Polish women it is an embarrassing issue. Most of the examined women from Grodno declared themselves unreligious, while in Bialystok most of the women were religious. Overall, according to Rue<sup>14</sup> and Vikhlayeva,<sup>13</sup> the predictors of positive and negative outcomes associated with induced abortion differ between the two cultures.

Lack of procreation plans in the group of women after abortion may be associated with the absence of emotional bonds with the child and feelings of dislike, anxiety, or even hostility—"if the situation repeated I would do the same". Hettie,<sup>15</sup> making a profound analysis of procreation plans, noted that women after child loss (especially due to induced abortion) were burdened with subsequent losses (habitual abortions). These patients treated their children as "unidentified creatures". Lack of reflection and awareness of having terminated their own baby led to subsequent abortions. Such attitude may result from defense mechanisms used to justify the act of abortion and to deny the child's humanity from the moment of conception. Shaap et al.<sup>16</sup> observed unconscious grief caused by child's loss more frequently in a group of parents after abortion. Conscious mourning turned out to be crucial to prevent irreversible effects that cannot vanish with time. Therefore, the author encourages parents to express the feelings of grief and sorrow, especially on the child' death anniversary, when negative emotional reactions can be intensified. Also Astrachan<sup>2</sup> describes harmful effects of unattended feelings in families who were remorseless after the child's death. Engel<sup>17</sup> has defined certain attitudes resulting from the lack of proper mourning:

- expulsion and rejection of death as a psychotic response when death is not acknowledged,
- the use of substitutes as a projection of features of the dead onto another object.

Solnit and Stark<sup>18</sup> report that the feelings of prostration and disappointment predominate in mothers suffering stillbirths.

The obstetric failure experience may determine the doctor-patient relationship. Some women after the loss of a child show vague attitudes towards the gynecologist. According to Peretz<sup>22</sup> these difficult emotional conditions may involve rejection of the doctor. Bondless relation with the child, accompanied by lack of mourning, was strictly connected with negative procreation plans in women in the abortion group. Dunlop<sup>20</sup> does not advise another conception unless the child has not been mourned.

Statements of some of the women that abortion had no effect on relations with the closest relatives or on the woman herself seem rather astounding. According to Lillford and Bibring,<sup>21,23</sup> these responses may result from deeply engraved injury.

Many other authors<sup>24,25,26,27,28,29,30</sup> emphasize the existence of medical and psychological effects on post-abortion women.

#### Conclusions

*Induced abortions* usually leave permanent scars in the minds of women. Women after an abortion differently perceive the conceived child, more frequently express a negative opinion of gynecologists and have no procreation plans, as compared to those after natural miscarriage. The major findings in the group of induced abortion can be summarized as follows:

62% of these women reported being unreligious;

47% had low self esteem post abortion, 53% tried to find an excuse;

43% reported the fetus as an unidentified creature;

60% avoided conception and sexual intercourse,15% had children later;

24% suffer secondary infertility;

0% had emotional bonds with the child before abortion.

*Natural miscarriage* had no negative effect on the relations with those in the woman's closest environment. Women in this group were emotionally attached to the child. The patients did not avoid conception, but after this event some of them still had procreation plans. The woman's relationship with God also deepened through this experience. The major findings in this group after natural miscarriage include:

68% of these women declared being religious and 32% religious but not practicing;

0% had low self esteem;

100% reported the fetus as a complete human being;

38% decided to have a child in future;

86% had emotional bonds with the child;

34% had close relations with their husbands.

While study limitations preclude drawing definitive conclusions, the findings do suggest some important differences between the effects of induced abortions and natural miscarriages and thus indicate the need for additional cross-cultural research on this important issue. E&M

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Advertisement



Who Has the Words of Eternal Life?, by Jennifer Lahl, National Director, Center for Bioethics and Culture Network

Danielle Egan over at the New Scientist writes about Transvision 2007 in her piece in October 2007, "Death Special: The plan for eternal life". Many of the transhumanist 'regulars' showed up for Transvision 2007, the ninth annual meeting of the World Transhumanist Association (WTA) which took place in Chicago this past summer. Ray Kurzweil, Nick Bostrom Ph.D. (co-founder of WTA), Aubrey de Grey of the Methuselah Foundation, were some of the usuals, but in the WTA's attempts to go more mainstream, they've added Hollywood celebrities to their line-up. This year, William Shatner and Ed Begley Jr. were both invited to give keynote presentations.

The three-pronged program,"Transhumanity Saving Humanity", was structured as:

- \* Innerspace: Transforming ourselves
- \* Metaspace: Transforming humanity
- \* Outerspace: Beyond the planet

This platform supports the WTA agenda to develop and integrate technology into our humanness, which will improve on humanity by giving us better minds, better bodies and better lives. The ultimate goal of the transhumanist movement is living better than well: transhumanists are by and large averse to suffering – they seek to avoid suffering at all costs, by any means necessary.

You might wonder, "What's wrong with an agenda to avoid suffering?" Well, not much and a whole lot. The answer depends on your anthropology. Transhumanists take as foundational the view that "the human species in its current form does not represent the end of our development but rather a comparatively early phase". To that end, eternal life and immortality are driving forces behind their technological imperative for progress and advancement. Within the transhumanist community, the views on ethical limits and restrictions, and governmental regulation vary, which makes conversations with transhumanists lively and diverse, not to mention full of disagreement among their membership.

Staunch libertarian, Marvin Minsky, co-founder of the Artificial Intelligence lab at MIT, and speaker at Transvision 2007, is quoted as saying, "Ordinary citizens wouldn't know what to do with eternal life (emphasis added)," and "the masses don't have any clear-cut goals or purpose." And he offers his wisdom on the pursuit of scientific inquiry: "Scientists shouldn't have ethical responsibility for their inventions; they should be able to do what they want . . . you shouldn't ask them to have the same values as other people."

Some from within this movement argue for ethical standards and administration that would distribute justly access to technology for all, regardless of their economic or social status; the same argue for the rights of all people to enhance or not enhance without fear of discrimination. However, it's clear that the most important debates are taking place within a small, elite (and predominately white, upper-middle class, educated men) group who will be setting policy. As Kurzweil states, "I don't recall when we voted there would be an internet."

The technological pursuit to alleviate human suffering and the quest for immortality are not new to the human condition. Transhumanism falls short on many counts.

- \* Naively believes perfection is attainable or should even be pursued as an end
- \* Denies the advantage of caring for and serving the weak and vulnerable
- \* Fuels the insatiable desire to always improve vs. fostering a spirit of contentment

Within a framework of techno-realism, the CBC invites you to engage with these debates!



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# CONTEMPORARY MEDICINE: APPLIED HUMAN SCIENCE OR TECHNOLOGICAL ENTERPRISE?

SYLVIE FORTIN, PHD, FERNANDO ALVAREZ, MD, GILLES BIBEAU, PHD, AND DANIELLE LAUDY, PHD

# Abstract

This article takes as point of departure the quality of the doctor-patient relationship to consider contemporary medicine's often compromising commitments to both technological enterprise and applied human science. The authors argue that this relationship is located within a tension at the heart of the clinic, between the demands of cutting-edge medicine (and ever-advancing technology) and the demands of a medical tradition long sworn to hold patient wellbeing in the highest regard. As members of a pluridisciplinary research team (anthropology and medicine), the authors carry out ethnographic research in a third-line pediatric hospital in Montreal, Canada. Involving interviews, informal exchanges, and observation with practitioners, patients, and families in clinical spaces, the ongoing research project broadly addresses humanism and medicine. Mainly drawing on interview material with clinicians and observation, we examine here the importance attributed by the specialists to human dimensions of the clinical encounter and the sometimes problematic relation between the cure and care aspects of medical practice. Technological and medical progress in recent years has given rise to tremendous scientific advancements that are engaged daily in the hospital context. But can knowledge in itself hold meaning beyond the life of the patient? Is medicine an applied human science or is it a technological enterprise? Is there necessarily an opposition between these premises? The authors call for the promotion of a humanist approach to medicine, in which relationships, involving multidimensional exchanges between different actors, may better serve patient interests.

*Key words:* doctor-patient relationship, pediatric hospital, technology, humanism, cure and care.

# Introduction

As members of a pluridisciplinary research team (anthropology and medicine),<sup>1</sup> belonging to both pediatrics and anthropology departments, we are currently carrying out an ethnographic study in a third-line pediatric hospital in Montreal, Canada. This university health center plays a prominent role in coordinating the network of pediatric and perinatal health services in Quebec and in the training of tomorrow's pediatricians (and pediatric specialists). The facility counts more than 500 physicians and 18,000 patients hospitalized annually, 185,000 out-patients and 65,000 emergency consultations.<sup>2</sup> A number of phenomena

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characterize this hospital setting, notably the diversity of its clientele, with a high rate of families born outside Canada using the services,<sup>3</sup> along with the evolution of a clinical practice.

Our main argument here is that the response of patients to treatment is individual and depends on biomedical and pharmacologic case management. This response also depends on the consideration given to the social and cultural dimensions of any clinical encounter, and more widely on the humanization of healthcare conditions surrounding birth, illness, and death (2). Medical anthropology distinguishes between biomedical notions of being unwell in its pathological aspects (*disease*), in its subjective and experiential dimensions (*illness*), and the representations that these inspire or the social construction of health problems in a given milieu (*sickness*).<sup>4</sup> The clinic, taken as a place of care and of interaction between healer and patient, implies an incursion into this simultaneously biological, social, and cultural universe.

The quality of the human relation (often called "alliance") between patients and their families on the one hand, and the healthcare team on the other, is central to the progression of an illness and the extent to which patients and their families follow or negotiate prescribed treatments (3; 4). This alliance enhances patients' health outcomes and increases satisfaction for both patients and healthcare professionals (5).<sup>5</sup> From this perspective, 1) the bond between clinician and patient becomes an active component in the therapeutic process; 2) in the pediatric context, this relation is triadic, as it involves the patient's family as an integral part in decision-making and the care trajectory; 3) this relation is located within a tension at the heart of the clinic, between the demands of cutting-edge medicine (and ever-advancing technology) and the demands of the project of medicine itself, i.e. the welfare of the patient and his/ her intrinsic confidence in this project (6).

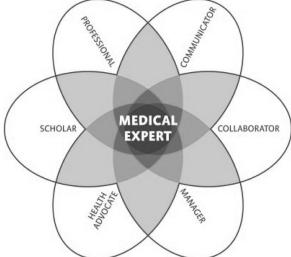
#### **Urban Contexts and the Hospital**

The hospital where we are conducting research and clinical work is located in a multiethnic neighborhood, with an immigrant population of over 43%. This is one of the most pluralistic areas in Montreal, a city where nearly 27% of the population is of immigrant origin (8). In fact, 90% of all immigrants who come to this part of Canada (that is, Quebec) choose to live in Montreal, where approximately 30,000 to 40,000 immigrants from 100 different countries land each year. This creates a cosmopolitan urban environment characterized by a multiplicity of languages and religions. The hospital, as "an open-door to the city" (9) is not immune to such diversity.<sup>6</sup>

In addition to this pluralist context, the hospital is affected by the evolution of clinical situations linked to the increase in complex chronic pathologies (10) and technological progress (11). While health care units are configured around 'acute care', complex patients require 'chronic', long-term care (what many call "chronic/acute illness"). At the same time, because of the quality of care in specialized and superspecialized environments, the hospital tertiary care context promotes the proliferation of caregivers at the patient's bedside, to the point that the notion of 'treating doctor' is often unclear. Furthermore, the reform of the Canadian public health care system has also transformed the space of treatment, most markedly by promoting patient care outside the hospital. This has had the effect of increasing "heavy burden cases" in the hospital, with the "lightest cases" leaving the institution, making room for more complex and often heavier cases in terms of care. In turn, this divides the time allotted to a doctor-patient relation because the patient is rapidly redirected towards other health care services outside the hospital.

As a matter of fact, the doctor-patient relationship is frequently disregarded due to both structural constraints (and lack of resources), and the progress of medical science itself, which is sometimes detrimental to this relationship so central to the therapeutic process. And subsequently, several studies carried out in recent decades have identified deficiencies among healthcare professionals in regards to communication and relational competencies in clinical interactions (15). A patient's illness and his or her vulnerability create a need for security as well as trust in biomedical knowledge, as confirmed by the concerns of the Royal College of Physicians and Surgeons of Canada (16) and the Accreditation Council on Graduate Medical Education (17). These organizations, through the development of a competencies program,<sup>7</sup> are mandated to promote an approach to medicine that (re)unites expert knowledge, central to the classical biomedical model, and relational competencies (Figure 1). The latter, and more particularly doctor-patient communication,<sup>8</sup> are at the foreground of a patient-centered approach to care.





## Outline

Technological and medical progress in recent years has given rise to tremendous scientific advancements. These are engaged daily in the hospital context (for both research and education), where technical competencies and knowledge assisted

by leading technology prevail. Every means is taken to advance and preserve expert biomedical knowledge. But what does medical knowledge signify beyond the healthcare link? What importance does the specialist attribute to the human dimensions of the clinical encounter? Is medicine an applied human science or is it a technological enterprise? Is there necessarily an opposition between these premises?

Drawing on ethnographic research underway, we will examine this relative dichotomy, and more generally, the complexification of the medical profession. After outlining the methodological approach of this study, and briefly discussing the relational aspects of the clinical encounter, we will examine this complexification with a focus on the growing importance of technology, which can at times be detrimental to a humanist approach to care. Examination of this 'tension' in the clinical environment promotes the exploration of diverse therapeutic approaches that often illustrate the prospective or budding relationship of expert knowledge with communication and inter-relational competencies, as put forth by the Royal College of Medicine. To conclude, we offer a reflection on the 'medicalization of the medical profession' and the humanism central to the medical project.

#### **Methods**

Ongoing since 2005,<sup>10</sup> this research has taken place in different units, including hemato-oncology, palliative care, and two spaces dominated by pathologies that are referred to as complex,<sup>11</sup> one offering curative care and the other longterm palliative care. It is within this setting that we examine clinical practices, particularly those of physicians, with a special interest in the caregiver/patient/ family relationship. Our approach is ethnographic, comprising observation in pluridisciplinary clinical spaces and informal exchanges with diverse practitioners, patients, and families (spaced out over a one-year period); forty individual interviews with physicians (semi-structured, lasting between 90 and 120 minutes); and eighteen case studies with patients and their families. The latter were chosen according to the healthcare team's availability, as well as on the basis of unfulfilled expectations by the healthcare team or the patient/ family, such as adherence to treatment, the involvement of parents, expressed therapeutic expectations, and so forth. For their part, the physicians of various specialties were initially recruited (but not exclusively) because of their presence in one or another of the observed units.<sup>12</sup>

We have chosen a triple investigative method in order to document physicians' daily practices, and in parallel, those of the other healthcare professionals concerned; the world of the patients and their families; and the relational dynamics among clinicians, patients, and their families. We are interested in all that concerns the trajectory of care, decision-making processes, and the biographies of patients and clinicians. The present article draws on interviews and observation of the latter.

# **Results and Discussion**

Clinicians and clients sometimes draw upon different referential frames in order

to understand illness and deal with the therapeutic (and decision-making) process. Many healthcare practitioners admit that an approach centered *a priori* on the organic or biological aspects of a disorder is limited in its ability to discern the diversity of the Other\_(19). And in fact, it is worth noting that, after several years in practice, a number of physicians, confirmed specialists, have come to declare that listening to and being present for the Other is now, for them, the foundation of all clinical encounters: *"It's more through listening that confidence is established, less in what we say"* (physician, pediatric specialist, 20 years professional experience). This vision enhances an approach guided by the sole evidence of measure in the alignment of the care trajectory: *"Madam, you can think what you like, you can say what you like, [but for] me it's written there"* (physician, pediatric specialist, 6 years professional experience). Can knowledge in itself hold meaning beyond the life of the subject?<sup>13</sup>

# The Complexification of Medicine

Medicine is becoming increasingly complex, as knowledge, pathologies, and treatment offer diverse alternatives for care. This complexification is dual, linked to both technological progress and its resulting expertise. An ever-increasing body of medical knowledge is generating a specialization and division of medical practice into specific fields of expertise. In neonatology, for example, while technology allows for the eventual detection of certain foetal anomalies, and as such the prevention of stillbirth or morbidity, prematurity may entail a series of so-called complex pathologies (successive, multi-systemic, or chronic...). These require a multiplicity of expertise, since general pediatrics alone cannot meet all the healthcare needs of these patients. Numerous healthcare professionals become involved, each offering expertise on a very specific aspect of treatment, according to the institutional structure of healthcare itself, and often without knowledge of the problem as a whole:

[...] the team is mainly oriented towards scientific things, protocol, it's more of an assembly-line—there are a lot of patients. It keeps going and going and going. There are a lot of doctors. It's sometimes difficult to know which doctor is involved in a given situation [with a particular child] (physician, pediatric specialist, 10 years professional experience).

This complexification of knowledge and specialties stands as a measure of the undeniable evolution of medicine. This progress seems, nonetheless, to shape its own alterity, to the detriment of the 'human' dimension of healthcare, troubling generalist and specialist alike, all the while legitimized by its positive effects.

# **Tensions within the Clinic**

This search for humanism translates into willingness on the part of certain clinicians to include or to reaffirm the social and cultural character of the medical vocation and its relational and qualitative aspects. Technology, then, elicits reflections regarding the growing absence of these dimensions from medical practice. When asked about current challenges in clinical practice, many of the physicians interviewed affirmed the existence of a dichotomy between *cure* (scientific competence, knowledge, expertise, technical skill) and *care* (attitudes, as well as personal, relational, and communicational qualities).<sup>14</sup> This preoccupation conveys a core interrogation of biomedicine:

I find that medicine has become detached from the very idea of health, with respect to life and other daily preoccupations that can be political, economic, and social in nature. It has become something entirely separate (physician, pediatric specialist, 4 years professional experience).

"Evidence-based medicine" in the clinic is the guarantee of expertise based on experience and scientificity, fundamental characteristics of biomedicine (22). *"That's medicine,"* some clinicians would tell us. Expert knowledge is first and foremost:

[In my area of practice, we find] the sickest patients. We treat everything, the liver, intestines, lungs. What interests me is basic science, [...] the medical side, the investigation more than the relationship" (physician, highly specialized, 13 years professional experience).

More popular in units where technological investment is important, this approach to medicine is described by some, nevertheless, as homogenizing, both for medical practice and for the patient who must conform to it:

You've got to understand that when we're facing a patient, all this 'evidence-based medicine', it's just one of many chapters in our head, there's a lot more than just that. And [convincing data] supply us with ideas for specific treatments but that's all.... Medicine goes a lot farther and is much more vast than simply diagnoses and treatment [...]. [...] even in groundbreaking specialties, such as my own, we don't have an enormous need for techniques or science for the care of patients, because there are no medications, or at least not at the moment. Often [what is important] is communication, establishing confidence (physician, paediatric specialist, 30 years professional experience).

#### A Diversified Practice

Biomedicine and its practitioners do not make up a homogeneous body (23; 24). In spite of a relatively consistent medical ethos, intensive care and the oncology department are areas that generate a different kind of praxis than that of general paediatrics or the field of long-term complex pathologies. Be it acute or chronic care, curable illnesses or those under constant supervision, treatment techniques, teams of specialists, biomedical practice and treatment situations are equally variable. This said, the different ways of being a doctor are tied to the context of institutional politics and more broadly, of systems of care (25). This is similarly the case of interdepartmental and inter-specialty practices.

A number of doctors call for a clinical approach in which theoretical and relational competencies intersect, but actual practice is often otherwise. With the exception of palliative care, in which relationships among healthcare professionals and between them and their patients are regularly discussed topics, team meetings involving clinicians in other units usually discuss treatment choices and pharmacological needs—the more technical aspects of care. Several physicians evoke the double standard of a care structure wherein the acquisition of 'scientific' competencies and the effective practice of medicine are valorized, but wherein humanization of the field is also advocated. Relational qualities translate into transversal capabilities. Recognized by the Royal College of Doctors and Surgeons of Canada (the Canadian medical accreditation institute), they become explicit issues in professional training. The quality of the therapeutic relationship, of patient/physician communication, and more broadly, the clinical encounter, become objects of study that "add to" an already exhaustive degree program. For some, they are welcome, for others, superfluous.

Many of the clinicians interviewed recognize (to different degrees, depending on field of work, training, and the dynamics of service) the need to have both scientific and humanist competencies in a context where the human dimension is more easily relegated to an individual preoccupation. Yet, fundamental knowledge (so-called 'hard' knowledge) is as central to training as it is to clinical practice. It constitutes an essential element of medical prestige. But as physician and ethicist Pellegrino (26) reminds us: "Who does the physician serve—the good of the patient, the success of the team that pays his salary, or his own infatuation with athletic success?"

I am becoming less and less comfortable with the way medicine is evolving. It is evolving very poorly. It has lost its symbolic function. It is no longer an art. [Before, there was] a scientific side and a very important human side. The evolution of medicine gives primacy to the scientific and technological side in relation to the other side. Medicine has fallen in with this technological evolution to the detriment of the human evolution of people. More and more, it's computers, robots, technology. People (patients) no longer come to see a doctor, they come to see a guy to find out if he will use a laser or (...). We haven't mastered the technological evolution... in any case, we haven't put it to the service of humanity. Universities have also been excessively impressed by scientific and technological development and have put a lot of energy into it, to the detriment of human development. As physicians, we are increasingly becoming technicians, scientists and less and less a human consultant who has decisions to make.

(physician, highly specialized, over 30 years in professional practice).

## Conclusion

Social research in healthcare, along with an increasing number of clinical experiences, reveal the need to reunite medicine's dimensions of *cure* and *care* under a single banner, or, as some would say, to promote the humanist approach central to medicine's initial project.<sup>15</sup> The "medicalization of medical practice" is a product of the refinement of biomedical knowledge. These advances generate

a proliferation of competencies and the categorization of knowledge, sometimes to the detriment of biomedicine's initial project in which care and competence are complementary. Such care implies a relationship, a context of multi-facetted exchanges among the various actors, in all their complexity.

If physicians were at one time powerless to fight disease due to insufficient means, today they are sometimes powerless because of these means. They are also often faced with choices that some years ago did not yet exist.

So long as we have no clear sign from society, setting our limits, we must do everything (physician, highly specialized paediatrics, 15 years professional experience).

Or again:

One of our biggest challenges today is, in 2006, to know how to use technology properly and [the question of] the allocation of resources. [...] What should we do when many patients are left waiting? [...] Because ultimately, this is also a challenge... to come back to the patient and decide... how far should we go with... this or that technology? And even when potential criteria are present, is it reasonable? Is it correct? Are we really making the best decision for the patient? (physician, highly specialized paediatrics, 5 years professional experience).

And here we can ask: Is technology an asset to medical practice or is practice at the service of technology? However, room must be left for nuance, as our research site is a leading-edge institution, removed from preventative medicine and primary healthcare services. As well, we must take into account the cultural heterogeneity and diversity of care perspectives within a given specialty or a same departmental unit.

Anthropologist, Margaret Lock (27) affirms that it would be an error to locate the current medicalization of biomedicine solely among physicians, pharmaceutical corporations and their private interests. Undoubtedly, many scientists are motivated by the ever-retreating technological horizon, but patients (clients) are also buying into it...<sup>16</sup>

In the words of one medical colleague, a paediatric specialist with thirty years professional experience:

The challenge in years to come, from the paediatric point of view, is to try to strike a balance between action and reflection, between science, technology and humanism, and what is individual and collective. I think we are far from such a balance. [...] Society itself fluctuates like a pendulum, swinging from back and forth. Rarely does it stop in the middle.<sup>17</sup> E&M

#### Endnotes

- 1. With the exception of D. Laudy, ethicist, S. Fortin, F. Alvarez and G. Bibeau are members of the Inter-Cultural Pediatric Unit at Sainte Justine Hospital.
- 2. The hospital also has 1,300 nurses, 970 professionals, 160 researchers, 400 paraprofessional employees, 400 volunteers, and over 2000 interns and students from all fields (for 2005). It comprises eight departments: Anaesthesiology and Resuscitation, Biochemistry, Ophthalmology, Pathology, Pediatrics, Pharmacy, and Psychiatry.

- 3. In a pilot study, Gauthier et al. (1) found that more than 40 % of the institution's clientele were of immigrant origin. These were mainly Arab, Caribbean, South-American, and Asian populations.
- 4. See Kleinman (7).
- 5. This alliance also decreases risk for malpractice litigation (5).
- 6. Elsewhere we address challenges posed by pluralism in the medical milieu and the diversity of norms and values in the clinical context (12; 13; 14).
- As an initiative to improve patient care, the "CanMEDS" framework (for those in the Canadian program) insists on the following competencies needed for medical education and practice: medical expertise (central to the physician role); communication; collaboration; management; health advocation; scholarship; professionalism (see Figure 1).
- 8. "[As Communicators], physicians enable patient-centered therapeutic communication through shared decisionmaking and effective dynamic interactions with patients, families, caregivers, other professionals, and other important individuals. The competencies of this role are *essential* for establishing rapport and trust, formulating a diagnosis, delivering information, striving for mutual understanding, and facilitating a shared plan of care. Poor communication can lead to undesired outcomes, and effective communication is critical for optimal patient outcomes" (16).
- 9. Source: http://rcpsc.medical.org/canmeds/index.php
- The research team for this study includes S. Fortin, G. Bibeau (anthropologists), F. Alvarez (pediatrician), D. Laudy (ethicist) and research assistants M.E. Carle, G. Davis, E. Laprise and N. Morin. Funding has been granted by the Canadian Institute for Health Research (2005-2008) and the Inter-Cultural Pediatric Unit of the Sainte Justine University Hospital Centre (18).
- 11. By complex pathologies, we mean illnesses that are serious, chronic, evolutive, eventually debilitating, and sometimes fatal.
- 12. All participation was voluntary. More widely, the study protocol was peer reviewed and met the requirements of the Ethics Research Committee of the Hospital where our research is underway.
- 13. See Le Blanc (20).
- 14. Good and DelVecchio Good (21) also tackle this theme.
- 15. The Hippocratic Oath promotes a medicine that serves the sick, practiced benevonently. It avows to achieve the patient's well-being, and in order to do so, the maintenance of expert competence.
- 16. Due to limited space, we do not address this question here. It remains that the evolution of the role of patients is just as pertinent, as it is a question of relational dynamics in the midst of the clinical exchange.
- Funding for this research has been granted by the Canadian Institute for Health Research (2005-2008), the Fonds de Recherche en Santé du Québec (2004-2008) and the Inter-Cultural Pediatric Unit of the Sainte Justine University Hospital Center.

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# FINDING ETHICALLY ACCEPTABLE SOLUTIONS FOR THERAPEUTIC HUMAN STEM CELL RESEARCH

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# Abstract

Katrien Devolder offers a compromise solution for the derivation of human embryonic stem cells that is designed to appease those who consider the killing of human embryos immoral. She proposes to build on a gradualist view of embryonic development in which the embryo merits special respect as human but does not possess ultimate value. Respect for the embryo must be weighed against other values, such as the desires of potential parents and the medical needs of patients who could benefit from stem cell therapy. Devolder also contends that William Hurlbut's "altered nuclear transfer" (ANT) proposal will not satisfy those who hold that the beginning of human life occurs at conception. In my critique of Devolder's position, I discuss why ANT and "oocyte assisted reprogramming" (OAR) are ethically questionable, and then review the epistemological value of the hylomorphic view of the human embryo, as well as the ethical importance of potentiality and intentionality. Finally, I argue for an expanded research effort in the area of adult stem cell therapy, which obviates the ethical dilemma associated with the manipulation or destruction of human embryos.

# Introduction

Katrien Devolder offers a compromise solution for the contemporary debate over whether it is ethically licit to derive pluripotent stem cells from human embryos. The most controversial issue for those who advocate the harvesting of human embryonic stem (hES) cells is to take into account the special moral worth the immature human being possesses in the eyes of many people. While only a few authors claim that the human being is a person from the moment of conception, several Christian ethicists defend the human identity of the embryo and its unique moral status. Devolder points out, however, that numerous individual scientists and governmental agencies have developed intermediate positions on this question in order to foster promising research with hES cells for therapeutic purposes. These individuals generally argue that this line of investigative activity offers the possibility of alleviating the debilitating effects of numerous diseases if it is vigorously fostered and adequately financed.<sup>1</sup>

While a variety of new techniques for deriving hES cells have been proposed recently, Devolder reminds us that these methods are not all acceptable to everyone on ethical grounds. In this article I expand on her assessment of "altered nuclear transfer" (ANT), extending that critique to "oocyte assisted reprogramming" (OAR), suggesting that, in the final analysis, these two methods could actually be morally equivalent. I then offer some critical observations of her own compromise solution, suggesting that it is faulty in several critical respects. As an alternative, I briefly discuss the possibility of pursuing additional research into the therapeutic use of adult stem cells, such as those that can be derived from bone marrow and cord blood, an approach that avoids the ethical problems associated with hES cell use.

#### In Search of Compromise

Katrien Devolder describes a proposal advanced by Howard Zucker and Don Landry in which hES cells are taken from surplus embryos produced by *in vitro* fertilization (IVF). She correctly concludes that this proposal is just "a redundant compromise" meant to appeal to those who already accept the morality of IVF. While one could make a distinction between the morality of IVF for reproductive purposes and for the procurement of stem cells, I point out elsewhere how IVF tends to de-personalize human conception, trivializes marital sexuality, and often entails the destruction of some embryos.<sup>2</sup> Similar reservations apply to the establishment of colonies of hES cells derived from single-cell blastomeres obtained from two-day-old pre-implantation embryos.<sup>3</sup> While the researchers who developed this technique report that it spares the embryo, in fact, embryos were destroyed in the study. Moreover, given the fact that the blastomere could be totipotent, even if an embryo were not destroyed, scientists could be disrupting the development of a new embryo.

An alternative to deriving hES cells from (the destruction of) blastocysts would be to harvest these cells from the entity created by "altered nuclear transfer" (ANT), a variation on somatic cell nuclear transfer cloning. Here a technician alters a particular gene in a donor (somatic) cell nucleus, and then combines it with an enucleated oocyte, thereby creating an ANT entity (or "ANTity") that does not mature to the embryonic developmental stage and yet produces pluripotent hES cells. According to Dr. William Hurlbut, the original architect and principal advocate of ANT, deriving hES cells from the inner cell mass of these "embryoid-like entities" is ethically acceptable because the ANTity is a "limited cellular system that is biologically and morally akin to a complex tissue culture."<sup>4</sup> Markus Grompe subsequently proposed a modification of ANT, "oocyte assisted reprogramming" (or OAR), which produces hES cells *directly*, that is, without forming an intermediary ANTity. Here a gene (e.g., *nanog*) is overexpressed in the host oocyte, which reprograms the donor somatic cell genome to produce a pluripotent cell.<sup>5</sup>

#### What are ANTities and OARites?

Both ANT and OAR are premised on the idea that the identity and function of every cell of the human body depends on which genes in the nucleus are switched on or off. ANT preemptively alters the epigenetic state of a somatic cell by silencing a particular gene in the nucleus (e.g., *Cdx2*) prior to transferring its genetic material into a host "ooplast" (the organic sac of cytoplasm left after

the enucleation of an oocyte). According to one proponent of this procedure, "the gene sequence is not what is responsible for determining cellular identity, since the DNA is identical in nearly every cell in the human body. Rather it is the programming of the gene sequence that distinguishes cell types."6 Critics contend that ANT amounts to creating a badly disabled human embryo, for the epigenetic state of a cell does not define the ontological identity of an organism.<sup>7-9</sup> Actually, something similar could be said about OAR, since the nanog gene holds the "OARite" in an undifferentiated state of development.<sup>10</sup> Devolder points out that if we were to disable an implanted embryo so that it could not develop beyond eight weeks of gestation, it would be hard to justify that procedure in the minds of most people. Concerning Hurlbut's argument that his proposal shifts the ethical debate from *when* an embryo should be considered a human being to *what* component parts and organized structure constitute a human being, Devolder contends that the meaning of some expressions he uses (e.g., "integrated organismal existence" and "a self-sustaining and harmonious whole") are far from clear.

In the opinion of several authors, ANT creates a defective embryo that is prevented from developing into a blastocyst, with the ANTity progressing through developmental stages that are identical to a normal embryo. The OAR method, in contrast, creates an entity that is defective from its inception, with the genetic material of the donor reprogrammed to overexpress the *nanog* gene in order to maintain pluripotency and prevent differentiation. While the OARite seems to share no developmental stages with a normal embryo, it does share the initial stages of development seen in cloned embryos, including the process of nuclear reprogramming that occurs after the adult nucleus is introduced into the oocyte. This has led a couple of authors to conclude that the only difference between the OARite and the ANTity is that the developmental path of the former is shorter than the latter.<sup>11</sup> In the end, OAR could be morally equivalent to ANT, simply representing an innovative attempt to overcome the "time-delay" inherent in the ANT technique.

#### To Be or Not to Be: Is that an Embryo?

While Hurlbut claims that the ANTity has no inherent principle of unity, because it does not form a trophoblast and embed in the uterus, the failure to form a trophoblast does not necessarily mean the ANTity is not an organism.<sup>12</sup> Furthermore, the failure of an embryoid body to become a true blastocyst is the consequence of an *intentional* act, not the result of a random genetic mutation or a cytological defect, and it is clearly immoral to intentionally cause a defect in a developing embryo. In addition, since the product of ANT has a complete human genome (i.e., with the material constituents accounting for functional unity), the "silencing" of the gene responsible for triggering differentiation of the trophectoderm leaves the suppressed gene intact. Even if this gene were deleted, seriously altered, or damaged in some way, that would not signal the emergence of a new kind of organism, much less the absence of a human organism.

Some authors contend that the ANTity is not a genuine human being at all, because its developmental trajectory resembles that of an ovarian teratoma

or a hydatidiform mole, entities that arise when a blastocyst divides prior to implantation and recombines with placental tissue. However, ovarian teratomas (or ovarian dermoid cysts) are wholly *maternal* in origin, arising from the spontaneous (i.e., parthenogenic) activation of an oocyte, whereas an ANTity has both maternal *and* paternal genes. Similarly, the parthenote is not really an analogue of an ANTity either, since it has a full complement of chromosomes derived only from the female. Hydatidiform moles, which can be complete or partial, are composed exclusively of *paternally*-derived genes; further, partial moles have 69 rather than 46 chromosomes, being the result of two sperms jointly fertilizing one egg. In sum, the comparison of the ANTity to teratomas, parenotes and hydatidiform moles fails, and so the argument that the ANTity is not really human fails as well.

#### Does silencing gene expression alter speciation?

Although nearly every cell of the human body carries the entire genome, not all genes are expressed in all tissues, or even at every point of development. Genes are normally turned on and off at different developmental stages, with the expression of one gene affecting the overall pattern of gene expression in the organism. The coordination of cell divisions takes place by a process of methylation in which some genes are "silenced" and others are "turned on" so that development can proceed to the next stage.<sup>13</sup> Over against Hurlbut's claim that the ANTity has no inherent principle of unity because it does not carry out certain functions, the process used to produce an ANTity mimics the initial phase of a natural pregnancy, except that a technician artificially prevents pregnancy.

The *Cdx2* gene has been advanced as a possible genetic control switch for ANT because it is not expressed until the 16- to 32-cell stage of embryonic development, and it plays a critical role in the formation of the trophectoderm (which gives rise to the placenta). If this gene is "silenced" (by inserting a gene encoding an RNA that inhibits *Cdx2* expression), the resultant embryoid body will not embed in the uterine wall. Besides the fact we do not know whether human  $Cdx^2$ -deficient pseudo-embryos die at the same stage as mouse pseudo-embryos, it is possible that the hES cells taken from ANTities could develop in unpredictable ways.<sup>14</sup> Moreover, since the pseudo-embryo's Cdx2 gene can be reactivated,<sup>15</sup> a true embryo was probably present all along. In reality, gene "silencing" is similar to the situation of persons with genetic predispositions for Huntington's disease, Alzheimer's disease, or breast cancer. And so, in the words of W. Malcolm Byrnes, "one could argue that ANT-derived embryos (which are perfectly normal in every respect during the initial stages of development, except that they have genes knocked out of their genomes) are indeed human embryos."<sup>16</sup> In sum, it appears that both ANT and OAR create a genetically disabled embryo, which is intentionally prevented from developing in a normal manner by artificially silencing the gene responsible for trophoectoderm formation.

# When Does Human Life Begin?

Irving Weismann insists that the key issue in the hES cell debate is *when* human life begins, and this cannot be determined by science alone, but calls for recourse to philosophical reflection.<sup>17</sup> David Schindler alleges that the proponents of OAR fail to recognize that the beginning of life is shrouded in mystery, and their reduction of life's origins to empirically observable facts fails to take into account the ontological dependence of all life on something other than itself. "[D]etermination of the presence of life *in its most subtle beginnings* is precisely *not* obvious in the manner of a positivistic fact, but always involves philosophical mediation (even if only unconsciously)."<sup>18</sup> This is especially true of human beings, who are the source of their thoughts and actions, yet cannot be the ultimate source of their own spiritual life.<sup>19</sup>

# Ontological individuation, rational ensoulment, and human potentiality

Some authors allege that the dominant view in ethics supports the instrumental use of the pre-implantation embryo because this entity has a relatively low moral status.<sup>20</sup> One reason cited in support of this interpretation is that monozygotic twinning is possible up to 14–15 days after fertilization. Since the zygote or early embryo could divide up to the point of gastrulation, with any embryonic cell capable of becoming an individual human being, Thomas Shannon and James Wolter allege that the early conceptus has not completed ontological individuation. "While the zygote is the beginning of genetically distinct life, it is neither an ontological individual nor necessarily the immediate precursor of one."<sup>21</sup> Of critical importance to this argument are the loss of cellular totipotency in the zygote/embryo and the restriction of its developmental possibilities to that of a single human being. However, just because the zygote/ embryo could possibly divide into integral twins before implantation does not necessarily mean it is not an ontological individual.<sup>22</sup> Shannon and Wolter assume that embryonic individuation comes from something *added on* to the pre-implantation embryo, which ensures a level of development and integral function that prevents the emergence of another individual. The fact that a zygote could divide before implantation does not preclude it from being an ontological individual, although once it matures beyond the age of twining any division would result in only body parts (and not new organisms).

#### The hylomorphic theory of ensoulment

Since all living creatures have an animating principle of life, the notion of a soul is not limited to human beings. Moreover, the philosophical concept of "form" (or soul) explains the very nature (or essence) of animate things, being the ultimate principle of the organization and continuation of any life form (not simply the genetic structure of a material body). According to Thomas Aquinas' hylomorphic description of the soul–body (form–matter) relation, all animated beings are composites of "matter" (*hylē*) and "form" (*morphē*). The form or soul is the animating principle of a living substance, for it actualizes and configures the matter (or body) to which it is united. The rational soul of a

human being is unique vis-à-vis the vegetative and sensible souls of plants and non-rational animals in that its faculties are not reducible to matter. That is to say, by its very nature, the rational soul transcends matter and is not confined to the limits of a body.<sup>23</sup> Rose Koch-Hersehnov believes that hylomorphism has exceptional explanatory power for modern embryology, and she suggests that a hylomorphic account of immediate animation could explain why the "forced twinning" of human embryos has been unsuccessful to date. If twinning were simply a matter of splitting the chromosomes of one organism into two sets of chromosomes, the simple action of dividing an embryo in a material manner would always result in two organisms. So, in her estimation, the totipotency of pre-implantation embryos is merely a hypothetical possibility: "although published studies by no means provides evidence *for* an ensouled embryo, a review of studies on artificially induced twinning affords more plausibility to ensoulment at fertilization than is offered in philosophical literature on our origins."<sup>24</sup>

There is another potential difficulty with the theory of immediate animation which Koch-Hersehnov does not discuss. It would seem that if a human soul were present in a pre-implantation embryo, there would be evident human functions under its control. Specifically, given that the human being cannot carry out rational operations without a brain, it appears that a rational soul is not present in the early embryo (since the brain is absent). Actually, such a Cartesian concept of the soul-body relation overlooks an important feature of the soul's function, namely, its animation of a human body. In Gilbert Ryle's critique of Cartesian mind-body dualism, the human being is not simply a ghost in a machine. According to Ryle, Descartes made a category mistake by considering the mind as a substance, for mental activities really belong to the category of relations, not substance.<sup>25</sup> Those who allege that a rational soul could not be present in the embryo without a brain to sustain intellectual activity forget that the soul primarily acts as the animating principle of life, and only *secondarily* functions as the principle of rational and volitional operations, when requisite vital organs like the brain reach a mature functional state.<sup>26</sup>

Aquinas (1226–1274) held that during normal human development only a vegetative soul is present at first, followed by an animate soul, and then a rational soul. In contrast, Thomas Fienus (1567–1631) and Paolo Zacchia (1584–1659) argued that a rational soul is present from the moment of conception, and that this single soul directs organ development in the embryo.<sup>27</sup> While the embryo does not manifest rational functions, it has the *potential* to develop a nervous system, and this is ascribed to its form or essence. "This teleological function of the form not only distinguishes the hylomorphic soul from a Cartesian soul but can account for how we could have once been the 'undeveloped' body that is the zygote."<sup>28</sup> Indeed, philosophical theories of human growth that deny that the pre-implantation embryo is a human being offer no credible explanation for regular development of the unicellular zygote and the multicellular embryo, nor do they address the potential of the embryo to act in personal ways.

# The significance of embryonic potentiality and moral intention

The potential for the early embryo to develop into a mature human being with operations that should always and everywhere be recognized and protected is present from the first moment of its existence. After all, there is no substantial change in the embryo from conception to birth, or from conception to its first thought-the individual human being has the same essence or substance from conception to death. Devolder overlooks this aspect of the potentiality argument, simply accusing those who use it to defend the embryo's special moral status of failing to take into account the hopes of infertile (prospective) parents. "[I]t is not the embryo as such that will be the object of value, but the embryo that is intended to lead to the birth of the desired child."29 However, in a strict axiological sense, an existing embryo is not really comparable with a (possible) future embryo. Something that is merely possible does not presently exist and thus only has hypothetical value, whereas something that already exists possesses definite moral value hic et nunc. To focus one's attention on future possibilities, assigning greater value to them over real existents, amounts to living in a world of dreams. While what I want or desire in life reveals a motive for action, it lacks the impersonality required to serve as a suitable moral reason for action.<sup>30</sup>

Devolder admits that the greater value some people assign to a prospective child over the intrinsic value of an embryo is merely a *belief*, not something based on or derived from empirical facts or philosophical considerations. In reality, she argues that value is based on personal preference. The obvious problem with a preference–utilitarian approach to ethical inquiry is that people may be mistaken about their preferences, and they can be wrong for reasons that are not limited to what they consider would be most satisfying to them. Morality requires us to do more than seek personal preferences or subjective satisfaction; it demands taking into account justice, which entails the awareness of the rights and needs of others, calling for a non-arbitrary standard which will ensure that the basic values of all human beings are respected. A morally upright intention is another critical feature of good moral action, for the specific desires we entertain and seek to satisfy are not necessarily good, based solely on whether an act serves as an effective means for attaining a particular goal. This is not to say that intention is unimportant. Barry Miller points out that "the mere cutting of Plato's throat by Socrates is, in itself, neither morally good nor morally bad: it would be good if Socrates were intending to remove a tumour, bad if he intended to kill Plato, and neither good nor bad if he performed the act while sleepwalking."31 While the desire to have a child is morally good in the abstract, recourse to IVF is morally wrong in the judgment of many, and for a variety of more or less compelling reasons, as I briefly outlined above.

James Peterson questions the relevance of potentiality for the personal identity of an embryo, yet he mixes apples and oranges when comparing the potential of gametes to give rise to an embryo with the potential of embryos to display personal properties as they mature over time. "How can we let patients who are unmistakably people die to protect embryos that, even if implanted, may or may not turn out to someday become persons? We should not kill people to benefit others, but we should also not let people die to protect human tissue such as sperm or ova, though such gametes have great potential."<sup>32</sup> In actual fact, there are two kinds of potentiality dealt with in this statement, and neither one is a sustainable critique of the genuine potentiality of the embryo. First of all, comparing the moral value of adult human beings with the potentiality of embryos to act as persons is specious: one should either compare the moral status of the embryo with the moral status of an adult or compare the potentiality of the embryo to act as an adult human being with the potentiality of the embryo to act as an adult human being with the potentiality of the embryo to act as an adult human being with the potentiality of the embryo to act as an adult human being with the potentiality of a gamete to become an embryo is an egregious (biological) error, for the gamete is not an organism but a reproductive part of an organism.

Current embryological science indicates that the organism resulting from the union of a sperm and an egg is a genetically human individual from the moment of conception, and the development of this nascent human being involves a continuous process of maturation, moving from one developmental phase to the next, with only arbitrary points of demarcation separating one phase from another. Few authors would contest the fact that the human being is an ever changing work-in-progress, eventually coming to be and to act in more personal ways by virtue of his or her relationships and actions. When addressing the issue of the potential of human embryos to act as mature persons, bioethicists often fail to distinguish between perception and conceptual thought. Perception is the process of acquiring, selecting, and organizing sensory information, whereas conceptual thought involves the mind's intentional exemplification of, or formal identification with, things in the world by way of language, as well as the ability to judge that these things are as one takes them to  $be^{33}$  This distinction is not only important to keep in mind when comparing the sentient and primarily perceptive life of non-human animals with the rational operations of human beings, but it is also critical for evaluating the moral status of the immature human being. For example, the argument that rational ensoulment cannot occur until the cerebrum is sufficiently developed to support conceptual thought defies common sense, because to deny that an infant is a human being is patently absurd. In addition, the embryo is largely responsible for its own regular and complex development, including the inherent capacity for rational thought.<sup>34</sup> Furthermore, we do not find the rational soul in any specific body part or organ, because, as the animating principle of bodily matter, it organizes and is responsible for the integrated function of the entire organism.

#### **Finding a Happy Medium**

Devolder suggests that the best way to manage the dilemma surrounding the procurement of hES cells is two-fold: to recognize the fact that most people accord a gradual and variable moral status to the early embryo, and to accept the idea that a contested value should not restrict scientific freedom. Over against the first point, moral value cannot be ascribed to an organism based solely on an extrinsic principle, such as human convention or public opinion, or the extrinsic properties or qualities it possesses at a given point in time. Notice, when Jonathan Moreno's writes, "although embryos deserve respect, they are not morally equivalent to human beings," what he means is that certain properties must be present in a human being before we are compelled to respect it unconditionally.<sup>35</sup> Rather than evaluate nascent human life in terms of its (personal) properties, which are largely hidden, it is preferable to accept that the human embryo *is* human. Development of the embryo does not alter its ontological status, even though its perceived moral value may change in the minds of some as the embryo takes on more obviously human qualities. In short, one's moral stance toward the embryo should not depend on when its personal properties appear, but rather should be based on its human identity.

Devolder admits that the human embryo merits special respect, yet she alleges that we can sacrifice embryos for purposes of "highest importance," without explaining why one's personal desires outweigh the embryo's intrinsic moral worth. In effect, she applies a utilitarian calculus to public policy decision-making, without providing a convincing ethical justification for assigning greater moral value to alleviating suffering than to the intrinsic value of embryonic human life. There is a strong tendency here to focus on hypothetical benefits to justify the use of *any* means to achieve a desired result. What is missing in such thinking is an objective moral standard that would enable us to judge which options are good to employ as means to achieve the desired end. Any possible actions can be measured against one another in an ethical sense *only* if they have some shared property that can be evaluated by a distinct moral norm.<sup>36</sup>

The second element at work in Devolder's position is the belief that there are several legitimate views of the moral status of the embryo, and tolerance dictates that we never consider any one moral evaluation as simply true. Since the true moral value of the human embryo is not agreed upon, "a justification primarily based on a contested value is insufficient to restrict scientific freedom to such an extent."37 However, if freedom is limited to and is measured by what is, we can only act freely if we know the truth about things.<sup>38</sup> In the issue before us at present, the human embryo either is or is not a human being—these are the only two possibilities. Notwithstanding the opinion of Norman Ford, who, like Shannon and Wolter, holds that the "pre-embryo" (or "pro-embryo") is not an ontologically distinct human individual, the totipotentiality of cells in the early embryo is merely a hypothetical possibility (not an *active* potentiality). Indeed, if the totipotency of embryonic cells were active, *all* these cells would become individual persons *all* the time, not just when twinning takes place. For all intents and purposes, monozygotic twinning is a developmental accident, in which a new genetically identical individual arises by way of asexual reproduction (or self-cloning).39

Ironically, the avid interest in hES cells for regenerative stem cell therapy is driven in part by the great success of bone marrow transplants, in which hematopoietic stem cells collected from the peripheral blood of HLA-matched siblings are used to treat diseases like leukemia and lymphoma. It is not too surprising, then, to learn that there are embryonic-like stem cell populations in adult bone marrow, which could serve as a source of pluripotent stem cells for tissue regeneration.<sup>40</sup> Of equal interest, stem cells with pluripotent flexibility taken from umbilical cord blood and the placenta are beneficial in animal models of spinal cord injury, stroke, and Parkinson's disease.<sup>41</sup> In addition, a recent example of the value and efficacy of employing autologous stem cell grafts is the case of Ryan Schneider, who was diagnosed with cerebral palsy at 3 years of age. Fortunately, his parents had the foresight to save Ryan's infantile cord blood at birth, and so physicians were able infuse the child with his own hematopoietic stem cells, causing his condition to improve rather dramatically in a short period of time.<sup>42</sup> Unlike hES cells derived from the early embryo, which are not immunologically compatible with potential patients in need of cell transplants, using endogenous stem cells for therapeutic purposes avoids the risk of immunorejection.<sup>43</sup> Even adult human neural progenitor cells (AHNPs) from the brain are highly expandable in cell culture, and these differentiate normally when implanted into the lateral ventricles of the brains of nude mice.<sup>44</sup> So, even though many scientists have argued that hES cells are more promising than adult stem cells for regenerative medicine, one commentator quips: "if neurons are the goal, then harvesting AHNPs from a patient's brain, rather than going the somatic nuclear transfer route, seems [to be] a win-win situation."45

It now appears that there are stem/progenitor cells in more accessible areas of the body as well, which could serve as an effective means for providing regenerative cell therapy without using hES cells. For example, epidermal neural crest stem cells (EPI-NCSC) taken from hair follicles have a high degree of innate plasticity, and these cells can be isolated at high levels of purity and expanded *in vitro*. Perhaps the patient's own EPI-NCSC could be used for cell replacement/repair therapy, even for such intractable conditions as spinal cord injuries, avoiding a graft-versus-host rejection of the implant.<sup>46</sup> The most exciting new discovery in the field of adult stem cell research is the extraction of stem cells from amniotic fluid. These cells are not tumorigenic; they can be induced to differentiate into cell types representing all three embryonic germ layers; and they are truly pluripotent.<sup>47</sup>

In the final analysis, the primary benefit of studying human stem cells may be to serve as models of disease processes in individual patients, without having to destroy human embryos. For instance, a physician could take cells from a diseased patient and revert them to their embryonic form, in order to see how they mature and why their development goes awry. This would shed light on the basic cause of the disease as well as serve as a means of screening potential drug therapies.<sup>48</sup> So, while scientists often boldly assert that embryonic stem cell research should be pursued because these cells are more flexible and offer greater possibilities for future therapies, adult stem cells are not only more stable and less prone to tumorigenesis than hES cells, but autologous grafting of endogenous progenitor cells avoids immunorejection. These two considerations favor the pursuit of adult stem cell biology over experimenting with and the destroying human embryos, if medical therapy is the true goal of human stem cell research.<sup>49</sup>

#### Conclusion

Katrein Devolder maintains that the human embryo only deserves a limited level of respect because of its lack of ultimate value. The moral status of the embryo ought to be considered in terms of external and internal factors, weighing the former more heavily than the latter. This claim is apparently based on changing public opinions concerning the true identity of the embryo, with its intrinsic value being subordinate to and dependent on the intentions of others. However, if we were to set up personal preference as a legitimate ethical theory, no impersonal criteria for moral reasoning would be valid.<sup>50</sup> Having been strongly influenced by naturalistic ways of thinking, and having virtually eliminated the qualitative discrimination of values, we are left with nothing more than desire and the maximization of its fulfillment as a practical guide for action.<sup>51</sup> No wonder it has been so difficult to reach a consensus on the ethical probity of hES cell research. E&M

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# **BOOK REVIEWS**

#### Last Rights: Rescuing the End of Life from the Medical System

Stephen P. Kiernan. New York: St. Martin's, 2006. ISBN 0-312-34224-1; 275 PAGES, HARDCOVER, \$25.95

At the turn of the twentieth century there was a barrage of socially critical novels and writings condemning the evils of the American industrial age, so much so that a new genre was coined: the "muckraker." Upton Sinclair's *The Jungle* and Frank Norris's *The Octopus* are two notable examples that come to mind, addressing the evils of Chicago's meat packing industry and California's railways, respectively. It would be tempting to approach Stephen Kiernan's latest book, *Last Rights: Rescuing the End of Life from the Medical System*, as a modern-day example of the muckraking genre. As the subtitle suggests, this book does expose many of the evils, or more often incompetencies, of the medical system's current approach to dealing with gradual dying.

However, some notable differences between *Last Rights* and the muckraking novel might highlight the wisdom in taking a different approach to this book. First, though *Last Rights* does contain a couple of fictional stories, the majority of its accounts are unfortunately all too real. Second, though Kiernan is a journalist by trade, he takes a much more personal approach to this book than the sometimes dispassionate, objective journalism that is supposed to be a mark of the trade. He interviews countless individuals who have lost loved ones, even accompanying many to bedside visits and funerals. Finally, and most importantly, Kiernan's goal is not *merely* to expose the flaws of the medical system's approach to dying; instead he goes further by offering potential solutions and alternatives to the current status quo.

Last Rights is divided into seven parts. In part one, Kiernan explains that today people often take longer to die than in the past and argues that hospice and palliative care must accordingly become more viable options. Part two offers a glimpse into the nearly universal stages of gradual death, giving helpful advice for both family and caregivers. Problems with the way the medical system approaches dying are discussed in part three, including some of the many obstacles to change. In part four, Kiernan explores how the aims of the medical system and those of families often collide, explaining how beautiful it can be when the two come together. Then, in part five, he boils down these issues to a word: control. Part six expresses how dying offers an opportunity to learn and to "reaffirm all of life that is noblest, most compassionate, most courageous" (241). Finally, part seven offers a vision for reforming end-of-life care in America.

While Kiernan has a clear agenda in this book, the fact that his agenda is *clear* makes it trustworthy. And while written from a primarily secular perspective, *Last Rights* is highly sympathetic to the spiritual aspects of death and dying. It is an enthralling, quick, yet challenging read which is targeted primarily to the popular U.S. audience, though its insights would be of interest to medical professionals as well. *Last Rights* is thus recommended for those with elderly or terminally ill relatives or close friends, professionals in the medical system, particularly those in geriatrics or intensive care, and those who, like myself, anticipate dying at some point in the future.

**Reviewed by David C. Cramer,** who is currently finishing MDiv and MA (Philosophy of Religion) degrees at Trinity Evangelical Divinity School, Deerfield, Illinois, USA.

#### Hardwired Behavior: What Neuroscience Reveals about Morality

Laurence Tancredi. New York: Cambridge University Press, 2005. ISBN 10 0-521-86001-6; 226 PAGES, HARDCOVER, \$28.99

Is moral behavior determined by nature or nurture? This is the question addressed by Laurence Tancredi in his book *Hardwired Behavior: What Neuroscience Reveals about Morality.* Tancredi contends for a biological basis for moral behavior, but his evidence is inconclusive and unconvincing.

As a psychiatrist, lawyer and consultant in forensic psychiatry, Tancredi believes that the human brain, which evolved through natural selection, now shapes our moral responses. He colors this argument with fascinating anecdotes from his repertoire of experiences with criminal minds.

While acknowledging the complex relationship of nature to nurture in the arena of moral behavior, Tancredi attempts to demonstrate that nurture is subservient to our "hardwiring," thereby challenging traditional notions of moral agency. His arguments, though, are weakly substantiated and often bolstered by speculation as he establishes theories of normal functioning on isolated instances of aberrancy. For instance, he believes that lying is a hardwired product of natural selection, but then states "humans can't lie without some alarm going off" (p. 120), indicating that this behavior is not a hardwired "normality." He argues that moral difficulties involving the misuse of money are due to the "nature of money itself" and the "way the human brain responds to it" (p. 137), ignoring the fact that money is a social construct with no "nature" of its own. He distinguishes between mind and brain while never adequately defining that distinction. Moreover, his belief in hardwiring is inconsistent with his stated beliefs regarding neuroplasticity. Unsurprisingly, he treats the brain in isolation from the body, attributing the "flight or fight" response to the amygdala alone, ignoring the crucial role of the adrenal cortex, and distorting the reality of our bodily integrity.

The crux of his argument is found in his chapter "The Mad and the Bad," where he argues that current neuroscientific knowledge blurs traditional distinctions between madness (insanity) and badness (criminality) and, therefore, moral accountability. He believes we cannot legitimately hold one morally accountable for actions that are biologically determined; justice requires development of technologies that can make those determinations. This raises important bioethical questions concerning how we relate to those who refuse or are unable to conform to rules essential for the stability of our society.

In the final chapter, Tancredi presents a future "dystopia" where politicians attempt to legislate morality by requiring "therapy" (implants, transplants, stem cells) for anyone who falls outside the predetermined moral norm. Although Tancredi supports such possibilities on an individual and voluntary basis, he warns of the societal "costs" of biologically engineered morality. Due to our inherent interconnectedness, he argues that such interventional therapy may adversely impact other valuable aspects of the human personality.

Tancredi's fascinating book raises important bioethical issues, but his argument that our moral behavior is essentially hardwired is unconvincing, and may in fact support a quite different premise: that what is hardwired is the higher order capacity for moral reasoning, while actual behavior is "programmed."

**Reviewed by Susan M. Haack, MD, MA (Bioethics), FACOG,** who a consultative gynecologist at Mile Bluff Medical Center in Mauston, Wisconsin, USA.

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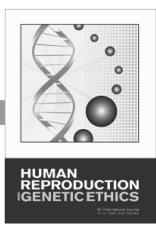
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