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EDITORIAL

## HUMAN DIGNITY AND BIOMEDICINE

C. BEN MITCHELL, PHD

Arguably, one of the best extended contemporary discussions of human dignity and its implications for biomedicine was commissioned under President George W. Bush and convened by his President's Council on Bioethics. The council's two reports, *Being Human* (2003) and *Human Dignity and Bioethics* (2008), are the results of more than a few public meetings, thousands of pages of expert testimony, and the work of two physician-scholar-chairmen, Leon Kass, MD, and Edmund Pellegrino, MD. The work of the council provoked bioethicist Ruth Macklin to brand human dignity a 'useless concept.' Cognitive scientist Steven Pinker even assailed the notion of dignity as 'stupidity.'

Nevertheless, both the term and the idea for which it stands continue to possess significant currency not only in the popular imagination but especially in medicine and law. In fact, Roberto Andorno, Senior Research Fellow and Lecturer at the Institute of Biomedical Ethics of the University of Zurich, maintains that the notion of human dignity is so ubiquitous in intergovernmental documents in biomedicine that 'It is therefore not exaggerated to characterize it as the "overarching principle" of international biolaw' ('Human dignity and human rights as a common ground for a global bioethics', *Journal of Medicine and Philosophy* 34 (2009): 223-240).

How does one account for this discrepancy? Can human dignity be at once both profound and indecipherable? Can it be both ubiquitous and useless? What happens if we expunge human dignity to the dustbin of incoherence, as Macklin and Pinker would have it? The implications of these questions for biomedicine, human rights, and public policy are difficult to overestimate.

Will our posthuman progeny one day see human dignity as a quaint historical artifact of our speciesist predilections? Perhaps. But removing human *dignity* from the table only seems to move the question of human *rights* to the foreground. Whence come human rights if not from human dignity? The United Nations' Universal Declaration of Human Rights of 1948 affirms that 'recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world . . .'. If human rights are merely a result of a social contract, humanity as we know it will survive only so long as the contract remains unaltered. In light of the history that gave new birth to this tradition—namely, the Nazi eugenics movement and the violations of human dignity that resulted from it—forefeiting the idea of inherent human dignity would seem potentially disastrous.

Alternatively, if human dignity turns out to be just a placeholder for rational autonomy, then another precarious state of affairs may follow. What of those at the margins? Patients in a persistent vegetative state, those with end-stage Alzheimer's, unborn children, and others, would lack dignity and, therefore, human rights. But this seems counterintuitive. Why should one's *ability to exercise* free and rational choice be the ground of human dignity? As Patrick Lee and Robert George have recently argued, 'the criterion for full moral worth is having a nature that entails the capacity (whether existing in root form or developed to the point at which it is immediately exercisable) for

conceptual thought and free choice—not *the development* of that basic natural capacity to some degree or another.’ Most of us would be able to say without any cognitive dissonance that the rape of a severely retarded person is a violation of his or her dignity as a human being quite apart from his or her ability to exercise rational, autonomous choice. How can this be so unless membership in the human species, not the exercise of rational and volitional abilities, is the ground of our notion of human dignity?

Human dignity is so robustly enshrined in international biolaw and policy, it seems unlikely that its appeal will fade away any time soon. Instead, we should take the current controversy as an opportunity to reinvigorate its meaning.

We must understand human dignity, therefore, as a first principle. That seems to be one of the significant ways we use the term in both ordinary language and in international policy. This, of course, does not resolve every difficulty. We may certainly ask questions of human dignity. What sort of thing is it? Why should we believe in it? What would follow if we do? What would follow if we do not? But beginning with human dignity as a properly basic notion rooted in our species membership and as the ground of human rights goes a long way toward an operational definition that helps us make meaningful decisions about how we treat one another and what obligations we owe to whom. Whether one is an atheist, Muslim, Christian, or Buddhist, there seems to be a very important overlapping consensus that what we share as a species should be the basis for solidarity, justice, humanitarianism, and moral medicine. **E&M**

GREY MATTERS

## TURNING A BLIND EYE: AN ETHICAL ASSESSMENT

WILLIAM P. CHESHIRE, JR., MD

*If you say, "But we knew nothing about this," does not he who weighs the heart perceive it?*

--Proverbs 24:12a

The phrase "to turn a blind eye" means to deliberately refuse to acknowledge something that one knows to be true. Etymologists credit its origin to Vice Admiral Horatio Lord Nelson, who, at the naval battle of Copenhagen in 1801, willfully disobeyed a signal to withdraw because he was confident of success. Having a more accurate view of the battle, Nelson acknowledged the signal but ordered it not to be repeated to his fleet. Turning to his flag captain, he was reported to have said, "You know, Foley, I have only one eye – and I have a right to be blind sometimes." Putting the telescope to his blind eye, he remarked, "I really do not see the signal."<sup>1</sup> Nelson's triumph at Copenhagen was a key victory for the British Royal Navy in the Napoleonic Wars.

Decisive action sometimes requires disregarding conflicting signals. In hazy situations such signals may indicate incorrect, incomplete, or misinterpreted facts. In other situations the signals are correct, but weightier matters may be at stake. Some signals assist while others impede progress. To neglect all signals is reckless, but to take notice of them all is to be encumbered in minutiae, if not stalled in doubt. Wise leadership involves discernment of which signals one ought to heed and how and when to respond in order to decide on the right action. That discernment entails the ethical task of assigning priority to various signals and rightly ordering the principles that guide responsive action.

When ethical principles are improperly ordered, turning a blind eye to inconvenient truths can lead to serious error. Some signals we ignore at great peril. A paramount signal in medicine is the Hippocratic maxim *primum non nocere* (first, do no harm).<sup>2</sup> The Hippocratic mandate to place the needs of patients above competing interests has guided the practice of Western medicine for centuries. Physicians who follow the Hippocratic Oath abide by the standard that, "whatever houses I may visit, I will come for the benefit of the sick..."<sup>3</sup> The Oath, writes Allen Verhey, "treats medicine as a form of human activity with goods internal to it and standards of excellence implicit in it, not simply as an assortment of skills which can be made to serve extrinsic goods with merely technological excellence."<sup>4</sup>

Much of the history of medical ethics concerns efforts to avoid turning a blind eye to human suffering while intentionally turning a blind eye to external influences that compete or interfere with the care of patients. The practice of medicine in general adheres to the highest ethical standards, but exceptions do occur. Sadly, highly educated and scientifically trained professionals are not immune to the tendency to turn a blind

eye in the wrong direction. Especially grotesque is the example of Nazi physicians who violated the Hippocratic Oath they had sworn.<sup>5</sup> One need not look just to the brutality of the concentration camps to recognize that a dense moral fog had descended on medicine under the Third Reich in mid-twentieth century Germany. The break with Hippocratism began insidiously. The 1920 book, *Release and Destruction of Lives not Worth Living*, by Alfred Hoche and Karl Binding signaled a sea of change in German culture and introduced the idea that there is human “life unworthy of life” (*Lebensunwertes Leben*). The break widened with doctrines of racial hygiene and utilitarian justifications for ending the lives of those perceived as having no right to live. About that break, Nigel Cameron writes, “The signal point of departure from the humane tradition of Western medicine lies in the euthanasia programme with which pre-war Germany busied itself, exterminating its own citizens and beginning with mentally defective children.”<sup>6</sup>

In 1939, Adolph Hitler issued an order requiring physicians to report any child in their care up to the age of three with certain physical deformities or mental defects. A selection committee reviewed the questionnaires submitted by physicians and, without examining the children in person or consulting families or guardians, from a distance determined which children would be transported to extermination facilities, some of which were within prominent hospitals. The methods of killing included slow poisoning by pills with the intent of mimicking death due to natural causes, lethal injections, and gassing with cyanide or chemical warfare agents. More than 5000 children were killed in this first phase of the German euthanasia program.<sup>7</sup>

Shortly thereafter, Hitler extended the program to adults and issued an order authorizing certain physicians “to grant a mercy death to patients judged incurably sick” in order to rid society of its weak, handicapped, costly, and “inferior” members.<sup>7</sup> Code-named Aktion T-4, the German adult euthanasia program perfected the method of killing by gas chambers disguised as showers and set the stage for the systematic murder of Jews, homosexuals, communists, Gypsies, Slavs, and political prisoners in the death camps. Young, inexperienced physicians were promoted to manage the efficient facilities.<sup>7</sup> From 1939 to 1941, more than 70,000 patients from more than a hundred German hospitals were killed.<sup>7</sup> The Aktion T-4 business director Hans Hefelmann later testified that “no doctor was ever ordered to participate in the euthanasia program; they came of their own volition.”<sup>7</sup>

Such large-scale operations are not easily kept quiet. Suspicions grew, and rumors spread, but many turned a blind eye.

Richard L. Rubenstein writes, “Once German physicians realized that they had an almost limitless supply of human beings at their disposal for experiments, some very respectable professors at medical schools and research institutes seized the unique opportunity.”<sup>8</sup> One such professor was Julius Hallervorden, a neurologist who trained in Königsberg and Berlin. Hallervorden was a prolific author of scientific publications and rose to the position of Chair of Neuropathology at the Kaiser Wilhelm Institute in Berlin-Buch.<sup>9</sup> The degenerative brain disorder Hallervorden-Spatz disease still bears his name.<sup>10</sup> Hallervorden was also the pathologist at the Brandenburg-Goerden State Hospital, which was one of the six centers of the killing process. Although Hallervorden did not directly participate in the killing of patients, he took advantage of the opportunity for scientific research available to him due to his proximity to the euthanasia program. During the summer of 1942, he wrote that he “was able to dissect 500 brains from feeble-



minded individuals.”<sup>10</sup> In an interview with American neuropsychiatrist Leo Alexander, Hallervorden recounted his involvement with Aktion T-4 as follows:

“Look here now, boys, if you are going to kill all these people, at least take the brains out so that the material could be utilized.” They asked me: “How many can you examine?” and so I told them an unlimited number – “the more the better.” I gave them fixatives, jars and boxes and instructions for removing and fixing the brains and then they came bringing them like the delivery van from the furniture company. There was wonderful material among these brains, beautiful mental defectives, malformations and early infantile disease. I accepted these brains of course. Where they came from and how they came to me, was really none of my business.<sup>11</sup>

Nelson and Hallervorden both turned a blind eye, but the comparison stops there. Even in that turning, there are morally significant differences between their actions. Nelson took upon himself the responsibility for what he believed to be the right action and became a national hero. Hallervorden attempted to wash his hands of others’ wrongdoing while seeking to gain from its byproduct. Hallervorden’s error exposes the ethical flaw in starkly utilitarian reasoning that disregards the moral principle of respecting human dignity. Hallervorden’s greatest blindness was not to the killing around him from which he felt insulated as long as he looked the other way but to his own complicity with evil.

The ethical evaluation of moral complicity is complex. Robert Orr has outlined a number of considerations that help to weigh questions of complicity.<sup>12</sup> The first is timing, and, related to it, incentivization. For Hallervorden, since his ongoing arrangement with the executioners may have facilitated future immoral acts, this would incur greater moral culpability than association with an act that had already been completed. Rather than turning from a wrong once realized, Hallervorden continued to accept brains from the executioners. A second question is proximity. The executions were carried out at the very hospital where Hallervorden had a senior faculty appointment. A third question is the degree of certitude. A student training under Hallervorden might have been unaware of the source of pathological material and thus noncomplicit in its acquisition. Hallervorden’s statements, however, leave no doubt that he knew that innocent people had been killed. A fourth question in determining moral complicity is knowledge of association. For example, a medical student using the *Pernkopf Anatomy Atlas* might be unaware that the detailed illustrations in that text were drawn from the dissected bodies of murdered Holocaust victims.<sup>13</sup> However, when there is clear awareness of the source of medical material or scientific knowledge gained, as Hallervorden in this case admits, then the degree of blame seems more clear. The fifth and perhaps most important question relevant to the presence or absence of guilt concerns intent. Since intent is subjective, it must be inferred. Hallervorden’s primary intent cannot be known with certainty but seems to have been morally commendable and directed toward a different goal (medical scientific knowledge) than that for which the immoral act was performed. If, however, the executioners tried to ease their consciences by accepting the neurologist’s promise that the brains would not go to waste but would be used to advance science, then the neurologist would have implicitly encouraged the immoral act, thus incurring some degree of moral complicity.

Hallervorden apparently rationalized that the commendable end of advancing scientific knowledge gave him the right to be blind sometimes to the means by which



that end was attained, especially if he did not participate directly. The sharpest ethical scalpel, however, cannot completely separate means from ends, as if only one mattered. Robert George writes, “The conviction that a little evil may rightly be done for the sake of a greater good, or for the sake of preventing a greater evil, puts human beings on the path to losing their grip on good and evil altogether.”<sup>14</sup>

Turning a blind eye to signals to pull back from doing good may be appropriate. No method of moral reasoning succeeds, however, in justifying turning a blind eye to the violation of basic human rights. Nor should physicians turn a blind eye to the instructive lessons of history. In all situations, one should strive for clear ethical vision.

This essay concludes by returning to the open seas to illustrate how decisions and acts affect other people in unexpected ways. Four years after Lord Nelson turned his blind eye in Copenhagen, he led the British Royal Navy in its most decisive victory against the French and Spanish Navy at the battle of Trafalgar. Shortly before that battle, one morning off the coast of Cadiz, one of Lord Nelson’s scouts was keeping watch in an outlying frigate when he saw dimly through the lifting fog a galley of Barbary corsairs fleeing at the sight of the well-armed British frigate and leaving behind an American vessel they had captured. The British officer fired a few choice shots at the Barbary galley, but in a moment it had disappeared and was seen no more. The British then boarded the American vessel, which was a brigantine with a cargo of lumber that had sailed from Edenton, North Carolina and was bound for Marseilles. The British freed the American captives bound up below deck who, at the hands of the pirates, had been destined to be killed or sold into slavery in North Africa. Among them was a young, as yet unmarried man responsible for the sale of the cargo. His name was John Cheshire, the third great-grandfather of this writer.<sup>15</sup>

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*The infertility industry has a dirty little secret.*



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CLINICAL ETHICS DILEMMAS

## CAPITULATION TO A PATIENT'S DEMANDS

ROBERT E. CRANSTON, MD, MA (ETHICS), FAAN, CPE

**Editor's Note:** *This column presents a problematic case that poses a medical-ethical dilemma for patients, families, and healthcare professionals. As it is based on a real case, some details have been changed in the effort to maintain patient confidentiality. The intent of this presentation is to offer ethical analysis and medical recommendations that are consistent with biblical principles. In this case, we explore the weakness of professional healthcare when the patient is demanding, the medical team has weak communication, and there is subsequent capitulation.*

### Column editor:

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### Question

Should a patient and family be allowed to demand continued medical or surgical care when the physicians believe that the patient will not benefit from further attempts at curative therapy?

### Case Presentation

WB is a fifty-six-year-old woman with a known history of gastric carcinoma, first proven by biopsy during esophagogastroduodenoscopy (EGD) in October, 2009. The patient had a history of another medical event many years ago in another hospital (details not revealed) where she believes she was deceived by medical staff and underwent a procedure that was unnecessary. During her care following the EGD, WB was scheduled to be seen by an oncologist (Dr. R). There had been numerous documented discussions by the physicians regarding her cancer, and she appeared to acknowledge her illness. Nonetheless, she remained reluctant to proceed with evaluation, treatment, or other interventions; she missed appointments and did not return phone calls.

In February 2010, when she sought care from a new gastroenterologist, WB requested a second confirmatory biopsy. In March 2010, a second biopsy was performed, and it confirmed the diagnosis of gastric malignancy. Several days later, emergent surgery was performed for acute gastric bleeding. At that time, in addition to partial gastric resection, a stoma was created for decompression. The surgeon noted that she had a "[l]ong discussion with many family members regarding incomplete resection..." Unfortunately, at the time of the surgery, WB suffered a stroke and was sent to a rehabilitation center for recovery.

Dr. R remained involved in discussions with the patient, and a follow-up appointment was scheduled for WB to be seen after discharge. However, in April, 2010, the patient was readmitted to the hospital for a bowel obstruction. A CT scan of abdomen and pelvis showed widespread liver metastases, and obstruction was felt to be due to the metastases.

Later in April, the hospitalist (Dr. A) had several discussions with WB, emphasizing the fact that several doctors did not believe that there was any definitive intervention that would be helpful for her. PEG placement for comfort and decompression, pain control, and palliative care were considered to be her only reasonable options. The patient and family demanded further treatment and also insisted that all involved consultants meet with them later that week to confirm for them that the patient had cancer. (The patient had not used the word cancer in discussing her problem with her family, and they had not accompanied her to any previous appointments.) The family also requested transfer to a facility two hours away that advertised heavily through the media. This facility was reported to be an unaccredited hospital, and her current hospital did not condone transfer.

Dr. A suggested that if the patient and family requested, she would contact a tertiary facility three hours away to see if anyone there would be willing to accept WB in transfer. It was uncertain if they would, given the extensive nature of the disease process and unlikelihood of any benefit from surgical or medical intervention. WB and her family chose to decline this offer. The patient remained Full Code status despite the disease progression.

Dr. A contacted the Ethics Committee, as no staff member believed that any further medical or surgical intervention would be helpful for the patient, and all were convinced that further intervention could result in increased harm with complex complications. Dr. A. asked that the Ethics Committee review the case and offer suggestions regarding management.

### **Recommendations**

The Ethics Committee reviewed the medical case and interviewed the physicians caring for WB. The chair of the Ethics Committee did not feel that direct intervention by the Ethics Committee was indicated, as members of the medical team intended to meet with the family for a conference the next day. He offered that if the treating physicians believed that more direct intervention by the Ethics Committee was needed after the family conference, he would be glad to participate in ongoing discussion. Additionally, to clarify issues in light of the patient's extreme denial during the previous six months and again in the last few weeks, the Ethics Committee suggested a formal Psychiatry Consultation to establish if WB should be granted decision-making authority regarding her care. Further, the Ethics Committee suggested that if the patient and family desired, the treating team should reconsider the possible transfer of WB to a tertiary facility.

The following day, prior to the full family conference, Dr. R reversed course. He met with the family alone, and negotiated a plan to institute one round of chemotherapy; he also told the family this might easily precipitate her demise. He dictated in the record that since the patient and family demanded further treatment, he would bow to their wishes.

### **Discussion of Ethical Principles**

*Autonomy:* Patients and surrogates have long-established right to refuse treatment that they deem unwanted, even if providers believe such treatment could be beneficial. In this case, even when the patient refused interventions, physicians did their best to persuade

her to seek a cure, but they had no authority to compel action. Providers have the right to not perform interventions that they deem to be more likely dangerous than beneficial. (Historically this has been particularly held true for surgical interventions.) Medical professionals, however, do not have the right to compel medical treatment in a decisional adult against his or her will.

**Beneficence:** No benefit was initially deemed possible by surgeons or the oncologist. The oncologist subsequently altered his position on this, though he equivocated as to the extent of benefit.

**Non-maleficence:** Significant risk of injury to patient could result from intervention.

**Justice:** Since little possible benefit and significant risk of injury pertain to this question, justice—making sure that the patient is given fair access to needed supplies or therapies—does not directly apply. On the contrary, one could argue that an appeal to justice would compel cessation of further intervention so that expensive resources would not be used on a patient who might not benefit from treatment, and these resources could be used for other patients who might benefit from treatment. (In reality, there is no quid pro quo: medicines not used on her would have no obvious intended recipient.)

**Compassion:** Patient would continue to be treated compassionately despite physicians' decision to withhold further medical or surgical intervention. The emphasis would be placed on pain and symptom management.

**Veracity:** Patient had been informed repeatedly in certain terms, well-documented in the record, by multiple physicians of her diagnosis and the prognosis associated with her cancer.

**Coordination of care:** This case demonstrates the difficulties that can arise when one member of a complex medical team alters his direction of care without informing the other team members of his decisions and actions. The morning after he agreed to initiate therapy the other physicians continued their plans to meet with the family. It was only when they checked the electronic medical record later in the day that they discovered the conference was no longer needed and would not be welcomed by the family.

**Competency:** No one specifically tested for decisional capacity or competence. It was generally assumed that the patient remained decisional. It was only when the Ethics Committee reviewed the record that this question was formally posed.

**Futility:** As a concept, futility is complex. Arguments can be entertained as to whether intended interventions will help in the short term, or will help provide significant long-term improvement or cure. In WB's case, no therapy was deemed likely to do either during the first phase of the management. Dr. R reversed course, however, and stated that though the chance of long term improvement was nil, the chance of short term improvement was not negligible, thus arguing for some form of short-term intervention.

## Follow-Up

Dr. R instituted chemotherapy and WB did "quite well" for about seven days. Subsequently, she became hypotensive and went into septic shock. She was transferred to the ICU, but her condition deteriorated. Two days later, after discussions with the ICU staff and family members, the family asked that WB be moved from the Intensive Care Unit, and care level was changed to palliative care status. She expired ten hours later.



## Editor's Comment

We must not underestimate the intense pressure that accompanies decision-making at the end of life –for the physicians, for the healthcare agent, and for the family. Understandable medical details and identifiable patient preferences are the primary sets of information that are necessary for medical decision-making. The family or the physician, once having made a decision, may become more anxious if it seems that their personal decision may contribute to the patient's demise. This may give way to personal or group disquiet which can be made manifest in several different ways. For example, the family may become even more insistent and demanding, or the physician may acquiesce and agree to provide a treatment that he originally opposed.

So, how can we explain the oncologist's apparent change of attitude or reasoning and the surprising decision to offer a round of chemotherapy at such a late stage in the patient's medical course? The physician certainly had a claim to the right of conscience; perhaps he had remembered a singular case report from the past. Or perhaps, as our present case reports, there was pure capitulation to the family request. Patience, wisdom, and communication skills are of utmost importance in attempting to identify certain end-of-life choices. There are often several options that may be considered ethically permissible, and the most correct option may remain stubbornly elusive until very late in the medical course.

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# THE PRACTICE OF TELEMEDICINE: MEDICO-LEGAL AND ETHICAL ISSUES

FATIMAH LATEEF, MBBS, FRCS

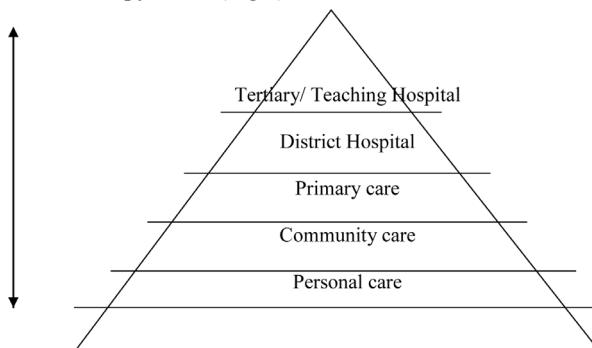
## Abstract

*Generally, the medicolegal position of doctors in telemedicine (TM) consults is similar to telephone, fax, email, or communications by letters. All these amount to the provision of advice from a distance but where the usual standards of care and skills must apply. Patients permission, ethics and confidentiality issues still predominate, whilst right to privacy and autonomy must be maintained. TM places obligations on both distant and local providers. With time, the patient (also the consumer here) must become more educated about the nature, purpose, and use of equipment as well as both what TM can offer and its limitations. Any potential breaks in confidentiality must be addressed to enhance the level of patient satisfaction and maintain excellent standards in healthcare.*

## Introduction

With all the challenges facing the healthcare industry today, the burgeoning old and new mix of diseases, increasing public and patient expectations, as well as the evolution of technology, it appears healthcare personnel cannot run away from practising some degree of telemedicine. The gradual birth of telemedicine can be traced to advances in electronic modes of communications, radio, television, and personal computer usage.<sup>1,2</sup>

Telemedicine literally means the practice of “medicine at a distance”, beyond geographical boundaries, i.e. the delivery of healthcare and the exchange of health information across distance. It encompasses diagnosis, treatment, prevention, continuing education, research, and evaluation. TM allows rapid access to shared and remote medical expertise by means of telecommunications and information technology, no matter where the patient or relevant information is located.<sup>1,3,4</sup> It can enhance communications up and down the healthcare pyramid (Fig 1).<sup>1</sup>



TM should be differentiated from *telecare*, which is defined as the provision of nursing and continuing support to patients at a distance, and *telehealth*, which is public

health services delivered at a distance to people who are not necessarily unwell. All three have the common basis of requiring telecommunications networks.

### **Practice of Telemedicine**

Today, there are many modalities of TM already in use and in different applications:<sup>3,5</sup>

1. *Pre-recorded*: this information is used in teleradiology, telecardiology, teledermatology, and telepathology
2. *Real-time*: this can be in the form of images (eg. telepathology, teleradiology, and emergency medicine) or videos (eg. telepsychiatry, teledermatology, tele-ENT, emergency medicine, tele-oncology and teleneurology). It is also applied in prehospital medical care in which paramedics communicate with doctors and medical control for advice and conveyance of information
3. *Tele-education*: this can be at different levels such as undergraduate, post-graduate, instruction for residents and trainees as well as part of continuing medical education for doctors and healthcare professionals

TM can be classified according to:

1. The type of interaction, i.e. between patient and doctor, between doctors or different specialists, or
2. The type of information being transferred, i.e. data, text, still images ( radiological images like X-Rays and scans or clinical photos) or moving images (video). These data and information can be pre-recorded and then transmitted or transmitted directly in real time.

The essential components of the TM system which will help to ensure it works and is sustainable, include:

- a. Adequate and suitable personnel who are trained, familiar, and have ownership of the system and programmes,
- b. The relevant technology, which will have to take into account the type of information to be transmitted, the speed of transfer, the quality as well as size of information to be transmitted, and
- c. One or several champions for the programme. These are trained persons committed to oversee the system and encourage others as well as keep them motivated. They can help with compliance and other teething issues, especially in the early phases of implementation.

Another consideration is whether to include audio capabilities, documents and text, still images, or moving images (video). As information is captured, the type and mode of display must also be decided. Issues such as resolution, clarity, and quality become important.<sup>6</sup>

### **The Medico-Legal and Ethical Issues**

The standard of clinical practice must apply regardless of whether the technology is used or not. Therefore, the intervention of the technology does not reduce the obligation to meet standards, and failure of the technology does not mitigate the failure to meet the standard. This must motivate us to ensure the equipment is reliable, the technical

specifications are adequate, and backup hardware and software are available. Whilst the benefits of telemedicine are known, many are still reluctant to engage in the practice due to unresolved legal and ethical concerns. The tenets of professional conduct and physician-patient relationship must be upheld when using electronic communications or telemedicine. These should include record-keeping, provision for physical examination and confidentiality. As TM is a very promising field that will increasingly become incorporated into medical practice, it is important to clarify doubts pertaining to the ethics of its practice. Institutions and organisations where this is practised must provide an ethical-legal framework within their current laws, statutes, and medical standards that will guide professionals. This is also an important step for upholding public and patient trust.<sup>7-9</sup>

Physicians practising telemedicine must be authorised to practise medicine in the country or state where they are located and must be competent in the field of reference. This is one of the initial and most fundamental considerations. When practising telemedicine directly with the patient, the doctor must be authorised to practise medicine in the state where the patient is normally a resident, or the service should be internationally approved. Similarly, the decision on practice insurance coverage will have to follow licensure.

According to the Joint Commission Accreditation, Medical Staff Standards on TM<sup>9</sup>, practitioners who diagnose or treat patients via telemedicine link are subject to the credentialing and privileging processes of the organization that receives the TM service (MS 5.16).

Use of TM must be based on mutual respect, the independence of judgment of the doctor, the autonomy of the patient, and professional confidentiality. In emergencies, judgment may have to be based on less complete information but in these cases, any danger to the health of the patient will be the determinant factor in the provision of advice or treatment. The doctor asking for another doctor's advice remains responsible for the treatment, any decision, and recommendations given to the patient. When there is direct doctor-patient relationship in TM, the doctor is responsible for the case in question. The doctor performing medical intervention via TM equipment is responsible for these interventions.

A doctor practising TM is responsible for the appropriate quality of his or her service. It must be of sufficiently high standard, and it must be adequately operational. All doctors must keep adequate records of patients and cases consulted. Patient identification, quality and quantity of data, findings, recommendations, and management must be documented. Storing and transmission methods must also ensure that confidentiality and security are guaranteed.

The introduction of emergency TM raises unique legal and ethical situations. However, the fundamental nature of the clinical consultation remains unchanged and must conform to the principle of safety and excellence in healthcare.<sup>2</sup> In emergency care, judgment may be based on incomplete information, but this is similar to other emergent situations in which patients may be non-communicative or may have an altered mental state. Emergency TM has been shown to have the ability to change patient management and outcomes indicator<sup>10</sup>. Thus, important considerations include real-time broadcast

quality, low-latency audio-visual communications, time-sensitive issues and consults between hospitals, and the hospital and pre-hospital environment.<sup>10-14</sup>

Emergency departments offering TM services must ensure these are given due consideration in their clinical workload as TM consults may take longer than standard ones. Accurate activity records must be maintained, especially to justify need for increased manpower as necessary. At the end of the day, those using this service must be aware of the advantages as well as the limitations.<sup>15-17</sup>

The potential new clinical risks opened up by the world of telemedicine include the following:<sup>14</sup>

1. Teleconsultants acting beyond ability
2. Ensuring the quality of the materials transmitted e.g. photos, videos, slides, radiographs, data
3. Improper or negligent delegation of tasks and responsibilities
4. Poor or inadequate training and skills
5. Unclear delineation of responsibilities
6. Subnormal standard equipment
7. Communications problems
8. "Telecomplacency"

Other issues to be considered are the possibility of fraud and abuse and copyright, trademarks, and intellectual property rights.

It is thus important for physicians practicing telemedicine to ensure that:

- a. They give all the necessary information to the patient and family,
- b. They answer all the patient's concerns and questions, and
- c. They give the patient the opportunity to refuse or limit their consent where applicable.

In some countries there may be other Bills, laws or Acts which will lend support, such as those applicable in the UK below:

Data Protection Act 1998 <sup>18</sup>

Computer Misuse Act 1990 <sup>19</sup>

Access to Health Records Act 1990 <sup>20</sup>

Access to Medical Records Act 1988 <sup>21</sup>

Institutions may set up standards related to credentialing and privileging of TM. In general, practitioners can provide either 'interpretive service' or 'consultations.' The former is the official reading of images, tracings, or specimens through TM link e.g. radiologist, pathologist. This is done in real time or transmitted by storing and then forward technology. Consultation services offer expert opinions and/or advise the treating physicians.

Perhaps the best suggestion for the institutions using or planning to set up TM services would be to set up or tie up with an ethics training centre. The centre can have programmes and training which help with clarification, understanding, and management of social, legal, and ethical problems which may arise. It can also be used to help to train

researchers possessing knowledge and skills in the domains of ethics, law, and sociology, relating to the use of information and communications technologies and networks in healthcare. With modernization and increasing technological sophistication, research funded by Information Technology companies has to be selected with caution as some may have a vested interest.<sup>22</sup>

Many will ask the question: if we are indeed using telemedicine, what are the appropriate clinical and technical standards we should adopt? No one will disagree that standards must be addressed by rigorous risk assessment backed by evidence as much as possible. Standards in most branches of medical practice are set by the professional organizations that govern the relevant specialities, such as the Royal Colleges in the UK. Until today, no formal professional organization has been convened for teleconsultants. Coordination between specialists and professional organizations is essential if compatible technical and clinical standards are to be adopted and understood by all. Only then can there be some harmonization of these standards.

### **Security and Confidentiality**

The principle of confidentiality that has been at the heart of medical ethics since the time of Hippocrates applies to TM just as it does to the conventional way of practice. Patients have a right to expect that one will not disclose any personal information, in the course of one's professional duties unless they grant permission. Electronic patient records and health records transmitted over national and international networks offer unprecedented opportunities for healthcare but pose complex challenges to confidentiality. Unauthorised users could attempt access to a computer system connected to a network illegally and even intercept transmission at times. Most systems are now password-guarded, and institutions must clearly demarcate the boundaries between the person who has access and the one who does not. There may also be special protection for 'sensitive personal data', and access to such information is only possible when certain safeguards are imposed.

When we use computer networks for communications in healthcare, we need to be able to digitally 'sign' documents in a way that guarantees the sender that documents can only be read by the intended recipient (confidentiality). It also needs to inform the recipient who the document is from (identity) and reassure them that the document has not been altered in any way (integrity). This is now being done through the use of encryption methods. Digital signatures can indeed be useful in many instances, but their utility also greatly depends upon the legal acceptability of electronic documents.

### **Responsibility in Telemedicine**

The responsibility in TM should be viewed as involving three fundamental relationships:

- a. The relationship between clinician and patient
- b. The relationship between clinicians (e.g. specialists, general practitioners, and nursing staff), and
- c. The relationship between the provider of the TM system and the user (clinician and patient).

In each of these relationships there is a duty owed by one party to another. The situation may be complicated by the involvement of multiple clinicians and the construction

of the TM system itself from a number of components such as the call centre, the telecommunications network, and the various types of hardware and decision support software (including databases and algorithms) that makes the system work. There are also a number of separate organizations involved in the manufacturing, installation, maintenance, and operations of the system. Thus in the events where harm to a patient arises during teleconsultation, a number of these organisations or individuals will be defendants to a legal action for negligence if it is unclear what went wrong and where the responsibility lies.

### **Jurisdictional Issues**

Conducting telemedical consultations across national borders raises the interesting, complex, and practical question: which country's law applies to the cross-border communications? Oftentimes it must be the country which has the most real and substantial connection to the case. Other factors would include the availability of witnesses, conveniences, expenses and residence of the parties involved. If the defendant is ordinarily a resident of a European country, jurisdiction is governed by the Civil Jurisdiction and Judgements Acts of 1982. This act provides for proceedings to be issued in a defendant's country of residence (the 'primary jurisdiction') or the place where the harmful event occurred (the 'alternative jurisdiction').<sup>23</sup>

State-based licensure systems for clinicians are structured around certain national standards. These standards have evolved in a profession in which physicians trained in one country travel and practice in another where they have been accepted. Often this has to come with obtaining an endorsement to practice in the new country through taking additional examinations or qualifications tests and often overcoming some bureaucratic hurdles of the receiving country. Meeting these requirements can indeed be a daunting and substantial task for individual teleconsultants to undertake and repeat in every country in which they wish to practice this.<sup>23,24</sup>

### **Conclusion**

Telemedicine is another technological advance that physicians and patients will embrace in our never-ending pursuit of the restoration and maintenance of optimal health. The field is rapidly changing, but tenets of professional conduct must be upheld and applied to the practice. Barriers to the expansion of telehealth industry can be overcome with a positive outcome as long as they are approached with the right attitude, mindset, and understanding of the issues concerned. While in many respects the legal and ethical aspects of the patient-doctor relationship remain unaltered, new and innovative ways of conducting this relationship from a distance do require us to change not only the process of healthcare but also the way in which we regulate it. If we need to seriously consider addressing the healthcare disparity issues and inequality of distribution, then health informatics and telematics technologies must be fully exploited to our and our patients' benefits. To overcome barriers of this exploitation, global cooperation between governments, professional bodies, and healthcare systems need to be commenced sooner rather than later.

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## IS AGEING BAD FOR US?

MICHAEL HAUSKELLER, MA, PHD

### Abstract

*It is often argued that advancing the development of life extension technologies and engaging in what is referred to as the 'crusade against ageing' is of the utmost importance because ageing is clearly bad for us and death an obvious evil. The purpose of this paper is to question this assumption and to demonstrate that, on the whole, ageing and death are not bad for us, so that there is no particular moral urgency to the extension of maximum human life span.*

*Key words:* evil of death, ageing, life extension, immortality

### The Greatest Evil

Advocates of radical life extension are often puzzled about the fact that relatively few people are willing to wholeheartedly embrace and support the “crusade against aging” (de Grey 2007, x), which they themselves regard as *self-evidently* of the utmost importance and as something we simply cannot afford to not engage in. From their point of view, it is plainly irrational to have any reservations about the project, and the only explanation they can see for people having such reservations despite its obvious irrationality is that they are caught in some kind of “pro-aging trance” that has its roots in a psychological need to regard what is unavoidable as, to some extent at least, good and desirable (ibid., 10-11).<sup>1</sup> Yet, it is argued, now that we are on the brink of understanding why we age and of using this knowledge to arrest or even reverse the process, this trance has lost its use, and we should wake up, see ageing and the resulting death as the evils that they are, and fight them with all our strength and all available means. Ageing, writes de Grey, “is just like smoking: It’s really bad for you. It shortens your life..., it makes the last several years of your life rather grim, and it also makes those years pretty hard for your loved ones” (ibid., 10). Although ageing has some unpleasant concomitants (those grim last years), for de Grey it is clearly the fact that ageing eventually leads to death that makes it such a “curse” (ibid., 14). For this reason, and this reason alone, ageing must be understood as a “humanitarian crisis”, taking a “toll of tens of thousands of dead every day.” De Grey regards this situation as intolerable and is determined to put “an end to the entire horror show” (ibid., 36). This view of death is shared by many other convinced life extensionists. Max More, one of the founders of the transhumanist movement, already demanded in 1990 that “science, technology and reason...be harnessed...to abolish the greatest evil: death” (More 1990). More recently, Nick Bostrom even published a colourful ‘fable’ in a respectable journal in which he represents death as a thoroughly evil, giant dragon that tyrannises the planet: “The dragon stood taller than the largest cathedral, and it was covered with thick black scales. Its red eyes glowed with hate, and from its terrible jaws flowed an incessant stream of evil smelling yellowish green slime” (Bostrom 2005, 273). Just as in real life, the people in Bostrom’s fable are at first reluctant to accept the moral necessity of killing the dragon until a small boy – and, as we all know, small boys always tell the truth— points out what should have been obvious to everyone all along: “The dragon is bad!” (ibid., 275). The object of the fable is obviously

to convince us that the boy is right and that therefore searching for a cure of ageing is “an urgent, screaming moral imperative” (ibid., 277).

What I am going to do in this short paper is take a closer look at the assumption, which life extensionists tend to regard and present as a self-evident truth, that ageing (and what it leads to, namely death) is “really bad for us.” Is it really? Before we can answer this question, we obviously need to know what it is we are asking. That, however, is not at all clear. Neither is it clear what ‘bad’ means and in what sense ageing and dying might be considered bad nor who the ‘us’ is for whom it is supposed to be bad. We also need to differentiate between ageing and dying because, although as yet ageing inevitably results in death (as its principal cause), in theory we could age and not die, just as we can now avoid the process (or, more precisely, processes) of ageing altogether and die young (or die old, but from other causes than ageing, say a car accident). So let us first look at death and ask whether *dying* (that is, the loss of life, or death) is really bad for us. This question can be understood in at least two different ways. First, we can ask whether each person’s own death is bad for himself or herself. In other words, is *my* dying bad for *me*, and *your* dying bad for *you*? Second, we can ask whether each person’s death is bad for everyone else, in other words: is *my* dying bad for *you*, and *your* dying bad for *me*?

### Is My Dying Bad For Me?

Philosophers occasionally deny that death is an evil on the grounds that nobody is able to experience their own non-existence. If death is real and is indeed the non-existence that it is commonly imagined to be, at least among non-believers, then we don’t suffer at all from being dead. As Epicurus was the first to argue, our fear of death (and the implicit conviction that death is an evil) rests on a conceptual confusion: when we imagine ourselves as being dead we tend to imagine ourselves as at the same time being aware of our condition, that is, as somehow being both dead and alive. Yet, in fact, we won’t experience anything at all. Properly speaking, we won’t even *be* dead because there won’t be anyone left to be anything at all. “Death, therefore, the most awful of evils, is nothing to us, seeing that, when we are, death is not come, and, when death is come, we are not” (Diogenes Laertius 1958, 651).

Those who are not convinced by Epicurus’s argument think that he rather misses the point because it is precisely the expected absence of all experience that makes death such a terrible thing. Thus, the poet Philip Larkin, in his poem *Aubade* (1977) complains about “specious stuff that says no rational being / Can fear a thing it cannot feel, not seeing / that this is what we fear - no sight, no sound, / No touch or taste or smell, nothing to think with, / Nothing to love or link with.” That sounds frightful indeed, but it only shows how right Epicurus was to suspect a fallacy. Larkin invites us to imagine how terrible it would be to be completely deprived of our senses and thus of the means to relate to the world, and to be unloved, unloving, immersed in utter loneliness. But we won’t be alone and disconnected from the world. We won’t *be* at all. Sure enough, what we fear most in death is probably nothingness itself, but we mistakenly fear it as something that will happen to us.<sup>2</sup> And it is the same nothingness that lies behind us and the same nothingness that would have been if we had never been conceived in the first place. And we wouldn’t have been if things had been only slightly different. Would that have been bad for us? I don’t think it makes sense to say that it would.

Admittedly, it seems that people can be harmed even when they are not aware of it. I can, for instance, be deceived without knowing it, and we may want to insist that my being deceived is bad for me, even if I never learn of the deceit and never suffer any negative consequences from it (though it's rather difficult to explain why that should be so). But my point is not so much that I won't experience my death and hence it cannot be harmful to me, but rather that there will no longer be an I that can be harmed.<sup>3</sup>

However, although this is a beautiful argument that, as I find, does a lot to dampen our fear of death, it seems to have the disadvantage of proving too much. If there is no harm whatsoever in death, why then do we regard taking someone's life as a serious offense and having one's life taken one of the worst harms that can befall an individual? If death is not bad for us, then it seems that killing someone can only be wrong to the extent that it involves suffering for the victim or third parties. There should be nothing wrong then with taking someone's life if they are not aware of it and if nobody minds their being gone. Yet most people would not accept this. Neither would they agree that in cases where there *is* suffering involved, it is *this* aspect that makes the act of killing bad, and not the fact that somebody is dead as a result of it. But again, why should we regard death itself an evil for the one who has died, or is about to die? The fact that we do does not necessarily show that we also have a good reason for it. The answer that immediately springs to mind is that people do not normally *want* to die. In fact, to most people at most times that seems to be their strongest, most fundamental desire, in the sense that when their lives are in obvious and imminent danger there is little that they would not sacrifice to avoid death. The desire to stay alive is deeply ingrained in our minds and perhaps even more so in our bodies, which will fight death even when our minds have already given up all hope. Sometimes, of course, we will sacrifice our own lives if that seems necessary to protect something that is even dearer to us: perhaps the life or wellbeing of a loved one, our own personal integrity, or a project we identify with. However, that doesn't show that we no longer regard our death as bad for us, but only that we regard something else as even worse than that.

On the other hand, we do not have to regard death as an evil in order to understand why we should feel strongly about killing and erect robust legal and moral barriers against it. Take the case of personal property. Being robbed of what belongs to us is certainly something that we deeply resent, and we do so even if we might in fact be happier without it. In other words, having what we own taken away is not necessarily always bad for us. But the fact that I might be better off without my TV or my car does not invalidate my right to them and does not make it less of an injustice to have them taken away from me without my consent. John Stuart Mill defined a right as "something which society ought to defend me in the possession of", for the sake of "general utility." He argued, very convincingly I think, that the reason why we feel so strongly about these rights is that this utility is a special one, namely the "extraordinarily important and impressive kind of utility" that is attached to the protection of *security*, which is something "no human being can possibly do without" and "the most vital of all interests" (Mill 1998, 98), in the sense that it is absolutely essential to human well-being (*ibid.*, 103). In other words, we need to have some assurance that we will be allowed to hold on to what we have worked for (right to property), and we need to be fairly certain that we are not killed when we meet other people (right to life), that is, we need to have reason to believe that it is rather unlikely that they will harm us. If that were not so we wouldn't be able to live in community with other people. Being what we are, social beings who

need and seek one another's company, our well-being depends on it. Hence the killing of a member of the community needs to be sanctioned. None of this would be necessary, of course, if we did not value our lives. But from the fact that we do, it does not follow that having our life taken away from us is in any way bad for us. We can value a thing, demand that it be protected, and feel insecure and hence unhappy when it is not, without being the least worse off when it is taken away from us. Nothing is good or bad for me when I'm dead, but as long as I'm alive, I have good reason to want to stay alive and to applaud institutions, such as moral inhibitions, that help me achieve this. Thus we can't infer from my preference of life over death and my desire to put death off as long as possible that my dying is bad for me.<sup>4</sup>

### **The Inevitability of Death**

However, one may object that perhaps it is not so much my death itself that is bad for me, but rather it is the fact that I have no choice: I *must* die, whether I want to or not. The inevitability of death as a result of ageing is what makes it bad for us. We want to make our own choices, and, whether or not my dying is bad for me, the mere fact that it is being *forced upon me* is already sufficient reason to resent it and declare the whole process of my ageing (as the gradual deterioration of my body leading to its final breakdown and disintegration) bad for me. Yet this alternative interpretation is hardly convincing. If it isn't death itself that is bad for me but rather the fact that it comes unbidden—the sheer involuntariness of it—then we should expect other things that we cannot avoid doing or prevent from happening to us to be considered at least equally bad. That is not the case, though. There are many things that come unbidden without this fact worrying us too much. We do not only have to die, but we also have to eat or breathe, and we would normally not say that eating or breathing, or having the impulses that make us eat and breathe, is “really bad for us.” At worst we will think of it as a minor inconvenience. The reason for that is quite obvious, namely that we don't normally regard eating or breathing themselves as bad, and hence neither do we regard the need for it as bad. So if death is not bad for me, then the inevitability of death doesn't seem to be much of an evil either.

### **Is Your Dying Bad For Me?**

Now let us assume that, contrary to what I just argued, my dying really was bad for me. Would that be sufficient to justify the claim that dying is really bad for *us*? Not necessarily. Even if we had a good reason to believe that our own dying is bad for each one of us—that is, my dying is bad for me, and your dying is bad for you—we could still deny that, all things considered, my dying is bad for you and your dying bad for me. If it is far from obvious that we suffer any harm by dying, it is even less obvious that other people's deaths harm us. On the contrary, in a very real sense we benefit from the fact that other people die. Of course, there are people whose death is harmful to us, because we depend on them in some way, or care for them. But in general we need other people to die so that we can find ourselves a place in this world, just as they need us to die to make room for them. If people didn't have to die it is extremely unlikely that we would have been born in the first place, and, in the unlikely event that we were born, that we would have found a partner or a decent job. While it may not be strictly necessary that in a world populated by potentially immortal humans the birth rate would dramatically decrease, it is for several reasons a probable outcome. There would be much less room

for new people, and no gaps in the social fabric which they could fill. There would also be much less need for them. Nobody would have to take over, nobody would have to pay for our pensions, and no other being would have to satisfy our longing for continued presence in this world. If it is likely that, once we have discovered how to stop ageing and thus extend our lives indefinitely, having children will become the exception rather than the rule, then it is also likely that if scientists had made this discovery a century ago, we would not exist. A Kantian might consider this already a sufficient reason for judging the attempt to abolish ageing with its resulting death to be unethical. If we test the maxim that guides the attempt by applying Kant's Categorical Imperative (cf. Kant 1786, B 53-58), we will find that this maxim can never become a universal law, nor can we ever desire for it to become one. If the maxim of our course of action is that if we can abolish death and thus become virtually immortal, we will do so, and if we then try to turn this maxim into a universal law so that *everybody* (including, as complete universalisation demands, those who lived before us) followed it, we find that this is not possible since it would remove the grounds of our own existence. If everyone chose to be immortal, then we couldn't. In fact, we couldn't exist at all (that is, most of us couldn't, though some might). Hence, seeking to end ageing and the resulting death is, from a Kantian perspective, morally wrong.

The same result can be derived by applying the Golden Rule, according to which we ought to do to others what we would like them to do to us. As Richard Hare has argued, the internal logic of morality compels us to prescribe every action as universally binding that we approve of when we are affected by it. In other words, the Golden Rule is a, if not *the*, fundamental principle of morality. According to Hare, the rule entails, as its "logical extension", that we ought to do to others what we appreciate they *did* to us. Since we do appreciate being alive and that our existence has not been prevented, we must also abstain from preventing the existence of others (Hare 1975, 153). Hence, if putting an end to human ageing prevents the existence of other people (namely all those that would have been born otherwise), then it is clearly morally wrong.

Yet even if we don't accept this kind of ethical reasoning, the fact remains that if the people who went before us had not aged and died it is unlikely that we would exist. If we consider our own existence a good, then whatever was a necessary precondition of it must also be regarded as a good, or at least can not be plausibly regarded as bad for us. Hence, to the extent that my existence requires the death of others, their dying (or having died) is not at all bad for us.<sup>5</sup> And if ageing is the process by which nature ensures that people die if other circumstances fail to kill them, neither is ageing.

### Ageing Itself

But what if we separate the issues and look at the process of ageing itself, ignoring for the moment its outcome, i.e. death? Would we then still be able to deny that "ageing is really bad for us"? Obviously we are here talking about biological ageing, and not chronological ageing. Biological ageing can be defined as "the inexorable increase in molecular disorder" (Hayflick 2002, 419), which results in a gradual loss of function and physiological capacity. It doesn't seem that there is anything good in that. It is hard to doubt that getting old is generally not fun and often comes with plenty of discomfort, pain, and constriction. In ageing, we experience the gradual disintegration of our bodies and, often enough, our minds. Taken by itself this really is bad for us, that is, your ageing

is bad for you and mine for me. And even though *your* ageing is not in any obvious sense bad for *me*, it is, other than your dying, not particularly good for me either. I might benefit from your growing too old to continue doing your job when I am keen to do it myself. Yet there is also the downside that I might have to look after you or pay for your subsistence. Since there is no clear advantage to any of us, it's probably fair to say that, on the whole, ageing itself (disconnected from death) is bad for us.

However, in reality, ageing does not occur without subsequent death. It is a process that leads to death, and we cannot ignore this when we answer the question whether ageing is bad for us. When ageing leads to death, ageing functions as a kind of attunement to our mortality—a slow, gradual dissolution of the body that exemplifies our, to use Heidegger's term, "being-toward-death"—and familiarizes us with the idea that one day we will no longer be.<sup>6</sup> The transition between life and death seems less incisive when death is preceded by ageing. To be torn from life in the midst of youth is commonly regarded as a tragic event<sup>7</sup>, not only because there was so much life still to be lived, but also because neither the one who dies nor the ones who survive them have had time to get accustomed to the idea of their passing. Ageing makes dying easier, both in the sense that it helps us to cope with the inevitability of it, and in the sense that it gives death ample opportunity to strike. Without ageing, death would occur far less frequently, resulting in the problems outlined above. Ageing, as a prelude to death, is a precondition of our existence. So to the extent that ageing leads to death, it is, on the whole, *not* bad for us—neither my ageing for me and yours for you, nor ageing as a general feature of human life (i.e., that we *all* age and die) for the community of humans. Ironically, ageing would only be bad for us if it did *not* result in death. So if we managed to abolish or indefinitely postpone death without arresting the ageing process, then ageing would indeed become bad for us. But as long as that is not the case, ageing is not really bad at all.

## Conclusion

I have argued that despite the apparent plausibility of the claim that "ageing is really bad for us" there is little reason to believe this. Death does not seem to be an evil from the perspective of the individual (i.e., it won't be bad for *me* to be dead), nor from the perspective of the community (i.e., it isn't bad for me that other people die). The same holds, though for slightly different reasons, with respect to ageing. Ageing coupled with death is, all things considered, not bad for us—neither for the individual nor for the community. Ageing is only bad when it does not lead to death. Thus, far from being "the greatest evil", it appears that death is no evil at all, and neither is ageing. And if that is the case, then finding a cure for ageing is not an "urgent, screaming imperative" after all.

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## Endnotes

1. Nick Bostrom and Toby Ord (2006) suggested an alternative psychological explanation, the "status quo bias", which is the irrational preference that things stay as they are despite the fact that we can't give a good reason why the present state of affairs should be regarded as optimal. According to Bostrom and Ord, this bias is the main reason why some people oppose radical human enhancement (including radical life extension).
2. This claim has been ably defended by Burley (2006).
3. It has been argued that it is not the dead who are being harmed through death, but the living. Geoffrey Scarre (1997) makes the point that it is the shortness of human life that is bad, not death itself: "shorter-lived people really are worse off than longer-lived people *while they are still alive*." (273) But Scarre is mistaken when he claims that "short lives (...) have actual, living subjects" (279), because a life cannot be short before it ends. It is death that makes it short, so that only once I'm dead can I be said to have had a short life. Hence the shortness of life cannot be an evil for the living.
4. That is why arguments that focus on the value that life and continuing to live has for the living do nothing to invalidate the Epicurean conclusion that death is no evil for us. Kai Draper (1999) for instance argues that we have good reason to be sad and disappointed to see our lives end when we could reasonably have expected to live longer and reap the benefits that would have come with it. Yet the disappointment is merely an expression of what we knew all along—namely, that normally life is a good for us, and we don't want to die.
5. Although it may be a *contingent* fact that there is limited space for people to live in, it is a fact nonetheless. So I have *in fact* benefited from the death of others, just as others will *in fact* benefit from my death. And even if that were to change, so that the existence of others would no longer depend on my death, and my existence no longer on the death of others, that would still not make the death of others bad for us. It would simply be not good (i.e., positively beneficial).
6. This point is also emphasised by Kass (2004), 310-11.
7. The premature death of the young can be seen as tragic, not because death is an evil for them, but because in a young person life is still conspicuously present as the great good that it no doubt is. And when the young die we deplore the loss of this good. Thomas Nagel (1970) has argued that it is that loss, rather than the state of being dead, that makes death an evil. But his argument is not convincing because a thing can be good without its absence being bad. When I, for instance, enjoy a trip to the seaside and appreciate it as a good, it cannot be inferred that it would have been bad for me if I had decided to stay at home and catch up with my reading instead. From the fact that a particular condition (like that of being alive) is good for us, nothing follows regarding the goodness or badness of alternative conditions (such as being dead). Moreover, it is not clear why the loss of something good should be *in itself* (that is, in the absence of any distress that this loss may cause) worse than not having it in the first place. In other words, why should

*losing one's life be worse than not having been born at all? See on this point Brueckner and Fischer 1993, 226-7.*

# FORCED STERILIZATION OF NATIVE AMERICANS: LATER TWENTIETH CENTURY PHYSICIAN COOPERATION WITH NATIONAL EUGENIC POLICIES?

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Many consider their plight an “archetypal” genocide. Others posit, however, that every essential characteristic of genocide has already been realized throughout their tragic history. A short summary of activities qualifying for genocide, each directed against disparate Native American tribes, may lend historical clarity. Centuries ago, the British suggested that they should be exterminated.<sup>1</sup> Their soldiers proceeded to decimate them with smallpox—a virus to which native populations had no immunity. Additional efforts, literally over centuries, to eradicate their race would follow. There would be a “Trail of Tears,” lethal attacks on Nez Perce men, women, and children to acquire their ancestral homeland, and the infamous massacre at Wounded Knee—to name only a few. The protracted policy directed against the United States of America’s indigenous peoples represented misguided governments, widespread avarice, and enforcement by an at times ruthless, undisciplined military. When naïve efforts with smallpox and crude annihilations with bullets were eclipsed by scientifically sterilized technique, two twentieth century neologisms—genocide and eugenics—would be added to contemporary reflection. When the United Nations approved Resolution 96, five activities would serve as the definition for Genocide under International Law. They were: killing members of a specific group; causing serious bodily or mental harm to other members of that same group; deliberately inflicting conditions aimed directly at those persons’ destruction; imposing measures to prevent births of the group’s progeny; and, last, forcibly transferring children for rearing from the individuals in question to ethnically-dissimilar families.<sup>2</sup> In this regard, the second Twentieth Century phenomenon mentioned—eugenics—has imposed measures to prevent births within many groups undergoing similar persecutions. A book by Edwin Black, *War Against the Weak: Eugenics and America’s Campaign to Create a Master Race*, exhaustively studied the evolution of America’s eugenics policy, which, in various guises, was exported to Germany as a template for the Third Reich’s Final Solution. These immoral activities, verified by many since, should have ended after Nuremberg’s deliberations. A recent, albeit weakly publicized, continuation of eugenic policy in the context of genocide has been well-documented. It has again been specifically directed towards Native Americans. The arena in question has been inhabited by the old evils of forced abortions and sterilizations. That two-pronged approach to knowingly limiting births in a targeted population had been emblematic of eugenic policy in the early to mid-Twentieth Century. Unfortunately, eugenic “birth control” had been resuscitated, or simply continued, as recently as the 1970s with voluntary physician complicity. That will be the issue before us.

## Investigation into Allegations of Forced Abortions and Sterilizations in the 1970s

When she was twenty years old, a Native American woman underwent a total hysterectomy by an Indian Health Service (I.H.S.) physician for unconvincing indications.<sup>3</sup> Her experience came to light in the 1970s when she visited Dr. Connie Pinkerton-Uri herself a physician of Native American heritage. About the same time, two other young Native American women in Montana underwent appendectomies and also received “incidental” tubal ligations. Were these merely aberrations or the first publicized examples of a disturbing pattern? The three individuals represented, unfortunately, the “tip of an iceberg.” Documentation of physician complicity in the forced sterilization of Native American women will be pursued hereafter as a serious bioethical issue that has been virtually ignored in the U.S.A., where each and every part of it took place. Mere description of the events, however, cannot stand alone. Prescriptive discourse can only proceed if those events in question are placed in the specific context of prior eugenic policy in America. A critical question must then be posed. Was physician complicity in the forced abortions and sterilizations of Native Americans purely a result of eugenic designs, or was it fueled by other precipitants?

On November 6, 1976, the Government Accounting Office (G.A.O.) released the results of its investigation (HRD-77-3) into allegations of forced abortions and sterilizations specifically targeting Native American women. Similar events at four of twelve I.H.S. areas (Albuquerque, New Mexico, Aberdeen, South Dakota, Oklahoma City, Oklahoma and Phoenix, Arizona) were included in the tabulations. Records verified that the I.H.S. performed 3,406 sterilizations between 1973 and 1976.<sup>4</sup> “Tip of the iceberg” would be an appropriate metaphor. Per capita, the figure was equivalent to sterilizing 452,000 non-Native American women within the same time frame.<sup>5</sup> One location in Albuquerque “contracted out” sterilizations to local, but non-I.H.S. physicians; therefore, their region did not add any procedures to the Fed’s final count, contributing to the underestimate. Independent research demonstrated that as many as 25-50% of the Native American women of that era were sterilized between 1970 and 1976.<sup>6</sup> Independent verifications thus were critical. The G.A.O. did not interview a single woman subjected to sterilization. That task would be left to others. The G.A.O. also admitted that “contract” physicians were not required to comply with federal regulations (including informed consent) in the context of the surgical procedures. Further study of consent forms utilized revealed that three substantively different ones proliferated. Verbal and written consent information, in some instances, neither apprised women that they could refuse nor informed them that the procedure was irreversible. It also appeared that “consent,” in many instances, was obtained only with coercion.

What may be the most disturbing aspect of the investigations also surfaced: *it had been physicians and healthcare professionals in the I.H.S. and contracted by the I.H.S. who coerced these women and performed the procedures.* It was they who abandoned professional responsibilities to protect the vulnerable. Substantive judicial investigations did not follow. In most instances, reparations would not be forthcoming. That the timing of events transpired a generation after similar atrocities during World War II—these precedents already adjudicated, proscribed, and punished—made the events all the more disturbing.

Further perspective on the magnitude of the travesty emanated from selected independent statistics. On a single Navaho Reservation, from 1972-1978, there was a 130% increase in the number of abortions (a ratio of abortions per 1000 deliveries increasing from 34 to 77).<sup>7</sup> The same study also demonstrated that in the interval between 1972 and 1978, sterilization procedures increased from 15.1% to 30.7% of the total female surgeries performed.

When a more thorough investigation of the consent process followed, resultant data only added to professional embarrassment. Healthcare professionals' coercive tactics to obtain consent included threats of withdrawing future healthcare provisions or even custody of Native American children already born.<sup>8</sup> The scandal of what had in all particulars become a replay of earlier twentieth century eugenic policies led to a Congressional hearing. Senator James Abourezk, Democrat, South Dakota, who was the individual who had been the moral instigator for the GAO investigation, chaired the hearing. Little else in terms of publicity, justice, or public outcry would eventuate. The results of the investigation have not been evaluated, only if even retrospectively, solely from a bioethical perspective. The inherent behaviors that led to forced abortions and sterilizations are obviously disconcerting in many ways, but particularly as a result of two characteristics. First, although shocking, they were completely consonant with federal and state policies from the early to mid-twentieth century regarding the treatment of vulnerable populations marginalized under descriptors such as "feeble-minded, criminal," as well as a host of other equally demeaning epitaphs. Did history merely recycle or continue to enforce the prejudices of preceding generations? Or, alternatively, was another sinister dynamic in place to manipulate a new generation of physicians? Second, how could the activities transpire in America after the corpus of the Holocaust, Nuremberg, and Geneva was made public? Furthermore, as a contemporary contingent, could the presently dormant activities resurface today if eugenics is repackaged by the Spirit of the Age as genetic engineering? Answers to these and other seminal queries require historical context as a foundation to further study. Efforts must begin with an overview of eugenic policy and practice in the America of the early to mid-twentieth century.

### **Background: Physician Complicity with Twentieth Century Eugenic Policy**

The early to mid-twentieth century not only witnessed the cruel enforcement of eugenic philosophy throughout America, but also was followed by genocide writ large on an international stage. It goes almost without saying that the world-at-large concurrently experienced a progressive and dramatic deterioration in a Hippocratic ethos. The decline of Hippocratic ideals preceded the disappearance of the Oath from medical school graduation ceremonies by decades. Participation by physicians would become critical to the success of both eugenics and genocide. The next generation of physicians to follow these notorious pioneers would continue the misguided activities—targeting Native Americans. Although Native Americans were not the only marginalized group of this era to suffer at the hands of governmental policies implemented by physician technique, their experiences would catch up to some of the others (African Americans and Latinos, especially).

Despite the continued “swearing” of the Hippocratic Oath in both the U.S.A. and Germany, eugenic sterilizations and euthanasia, targeting the weakest, were explicitly practiced in both countries.<sup>9</sup> As prime examples of breeches against the mandate to “Do no Harm,” these were not the only proscribed, but nonetheless lethal, physician misadventures surfacing elsewhere, for the first time, within that same time frame. Bacteriological warfare began under direct physician aegis. It had been initiated on a small scale during WWI by Turkish physicians (not soldiers) and later expanded by Japanese physicians as early as 1927.<sup>10,11</sup> These same Japanese physicians had sworn a Shinto-Buddhist Oath that, exactly like the Hippocratic Oath, explicitly proscribed patient harm at the hand of physicians.<sup>12</sup>

The earliest examples of eugenically-directed harm to individuals in America, albeit not generalizable to a majority of physicians, have included a physician in Kansas, F. Hoyt Pilcher, who surgically sterilized fifty-eight “feeble-minded” children as early as the 1890s.<sup>13</sup> Another, Harry Clay Sharp, graduated medical school in 1893 and explicitly practiced medical castrations on individuals who masturbated.<sup>14</sup> Albert John Ochsner advocated the compulsory sterilization of criminals before the turn of the twentieth century and his philosophy was enthusiastically published in the *Journal of the American Medical Association*.<sup>15</sup> The late nineteenth century would be a harbinger of worse things to come.

W. Duncan McKim, in 1899, was one of the first American Physicians to suggest professional complicity in the execution of undesirables, and he provided a pragmatic way to accomplish his end. He observed, consistent with an eugenic “frame”, “heredity is the fundamental cause of human wretchedness...the surest, and most humane means for preventing reproduction among those we deem unworthy of the high privilege of reproduction is a gentle painless death...In *carbonic acid gas* we have an agent...”<sup>16</sup>

The eugenic activities herein superficially chronicled from the early to mid-twentieth century—forced sterilizations, euthanasia of sick newborns, the proposed “gassing” of a wide variety of “undesirables”—openly inhabited mainstream America. The nefarious behaviors were supported at the highest seats of government and disseminated by the intelligentsia and wealthy (Woodrow Wilson, Teddy Roosevelt, Oliver Wendell Holmes, both the Rockefeller and Carnegie Foundations). The activities were so imbedded into the cultural psyche that they may have persisted.<sup>17</sup> They were an indelible stain of blood on America and its medical practitioners. They are chronicled in this manuscript only in a selective and abbreviated fashion in order to illustrate a critical point. The sterilization practices of the physicians targeting Native American women in the 1970s were very similar to the “typical” legalized behavior of physicians in the eugenics movement only a single generation removed. They were similar in philosophy as well as in technique. Unlike the physicians described above, the physicians of the 1970s were protected from publicity and were thus rendered “anonymous.” Only a single legal recourse to identify a culpable practitioner would be pursued.<sup>18</sup> Three Northern Cheyenne women filed suit against the hospital at which they were sterilized. Defendants’ attorneys convinced the women to settle for a cash settlement prior to a Supreme Court hearing. The women complied, and names of physicians who participated in theirs and others’ sterilizations and abortions would be forever lost.

Another historical question that should be confronted follows naturally: did eugenically-driven policies and practice in America disappear after WWII? Or since

“old habits die hard,” was it more likely that the events propagated against Native American women represented a continuation of said policies, oblivious to both Nuremberg and United Nations directives? There has been substantial evidence brought to bear to support the proposition that eugenic practice survived the decades consequent to WWII in the U.S.A. and was “alive and well” in a protected environment during the 1970s. In Edwin Black’s book, he observed through many examples that the scientific transition from eugenics to “genetics” merely repackaged the same, sinister techniques under an old but durable philosophical umbrella.<sup>19</sup> Another peer review source named both the individuals and foundations that continued to engineer minority populations’ futures through eugenic birth control techniques—each similar to the preceding generation.<sup>20</sup> In fact, in 1952, of the ten members of John D. Rockefeller’s Population Council, six had been openly active in the enforcement of U.S. eugenic policies during the preceding era.<sup>21</sup>

Since it seems that eugenic technique in the U.S.A. continued to prosper after WWII, there is still something else left to consider in this context: were these anonymous physicians who sterilized and performed abortions on Native American women solely motivated by the same animus as their recent and contemporary colleagues? Were they knowingly participating in a policy of eugenic birth control through abortions and sterilizations? Or, alternatively, might there still be additional rationale for their unethical professional behavior?

### **What was it that motivated certain physicians to sterilize and abort Native American Women during the 1970s?**

From the outset, it may be prudent to separate the physicians under study into two groups. There are those who were members of the I.H.S. and those who were in private practice and were contracted solely for technique (in this instance sterilizations and abortions in Albuquerque, N.M.). The salaried physicians of the I.H.S. possessed certain characteristics that may help explain their ethical behavior. First, they were not well paid. New recruits were salaried at \$17,000 to \$20,000 per year.<sup>22</sup> Their average workload could be exhausting and approximated 60 hours per week.<sup>23</sup> Applications for vacant I.H.S. positions dwindled from a peak of 700 in 1971 down to 100 in 1974. These are mundane statistics, possibly, but in total they are suggestive that I.H.S. physicians of the early 1970s were not looking to increase their workload. There would have been no incentive to do so. Additional surgical procedures would not increase income. But what else were they like culturally and what may have motivated them since it does not appear to be money? One 1972 study demonstrated that 6% of their contemporary physician colleagues would have recommended sterilization as an option for birth control to “white” women, but as many as 14% would have recommended sterilization if the woman was from a minority group or on welfare.<sup>24</sup> In the specific scenario of a welfare mother with three or more children, 97% preferred the sterilization option. One year later, another study suggested that physicians of that era believed that they were performing society a service when they limited the growth of poor populations by whatever means available.<sup>25</sup>

A quote from that time, by the President of the Association for Voluntary (sic) Sterilization, Dr. Curtis Wood, illuminates the issue further:



After 30 years of delivering babies, I've found that if the doctor does a proper job of offering sterilization to these women on welfare, a high percentage of them would accept it. I have found after 3 to 4 minutes of talking with them they will accept it.<sup>26</sup>

In fact, in the same article as Dr. Woods' quotation, the primary author, Barbara Caress, summarized prevailing cultural attitudes thus,

Sterilization abuse is both systematic and wide-spread...it stems from a combination of factors... teaching and research...*fee for service systems*...it is the most widespread example of *medicine as an instrument of social control*... Since 1970, the figures show an almost 3-fold increase in the incidence of female sterilization, from 192,000 in 1970 to 548,000 in 1974...Many young Gynecologists in training have united their professional needs for training and *their political ideas*...Another reason for an increase in operations is *greed*... Between 1967 and 1973, federal support for family planning services increased more than 1300%...the line between voluntary and involuntary sterilization becomes thinner all the time.

The cultural evidence supports, at least for I.H.S. physicians exempt from greed, a push towards sterilizations and abortions within Native American communities consistent with the predominant medico-cultural zeitgeist—responsive to eugenic aims. That particular tendency again betrayed a critical fact alluded to before: eugenic philosophy and practice persisted in the U.S.A. despite the Nuremberg Trials. It was still a problem for medical ethics, but it was barely ever spoken of. The author attended medical school at the same time and was never apprised of the issue in any educational venue. Laws after Abourezk's investigations stopped the forced sterilizations on reservations as well as activities aimed at removing children from their birth families (see also *Relf v. Weinberger* and the Indian Child Welfare act of 1978 for additional information). Repeat surveys are not available, however, to attest to whether physicians would have surrendered their eugenic dogmas if legal punishment did not follow. One may conjecture that the answer would resonate loudly—probably not. Since there has been a paucity of evidence to draw firm conclusions regarding equivalent eugenic bias of the private practice physicians, who themselves were not salaried government employees, but rather, were paid for additional procedures, were there other plausible dynamics adding to their motivation?

These private physicians would become the first generation reimbursed dollar for dollar by the U.S. taxpayers and solely for technique. These physicians had been "contracted" only to perform surgeries on Native American women that could not be provided by the resources of the I.H.S. They inhabited an environment that rewarded eugenic-minded procedures whether or not the physicians in question deemed them appropriate or ethical. In fact, for them, the ethical dilemma could be totally avoided. They would be reimbursed for every sterilization and abortion, neither audited nor "capitated" in any manner. They were free from ethical restraints—including stricter informed consent practices. Could the characterization of their practice style, that is, a contract model, have contributed in any way to what eventuated?

William May has conceptualized potential descriptive models for medical practice. In essence, such practices may philosophically emanate from the perspectives of a Code,

a Covenant, a Contract, or as Philanthropy.<sup>27</sup> It may be reasonable to proceed and place the private practices in question, that is, those contracted for abortions and sterilizations, in one or more of these categories. Would categorization determine what impact, if any, the practice “frame” might have on physician behavior? This line of reasoning may be buttressed by excluding conceptual models that are thoroughly inconsistent with the behaviors under scrutiny.

First, the activities studied to this juncture were definitely not philanthropic. Government monies reimbursed the physicians *quid pro quo*. Second, covenantal practice assumes respect for patient dignity no matter the patient’s ethnicity, and in this narrative that means neither harming nor coercing, as well as actively advocating for the vulnerable. Therefore, Covenantal behavior was lacking. Code for our purposes will refer to Hippocratism, solely for reasons that it represented medicine’s longest-lived and most internationally apprehended Code. Since harm is implicit in the activities of coerced sterilization or abortion, traditional “codified” professional behavior was also lacking. Others may argue that the physicians acted by the tenets of other “codes,” but May would classify those particular codes as variants of Hemingway’s “code-hero” model. That model merely represented a passing, fictional fad best represented in *A Farewell to Arms*. That leaves what has appeared “prima facie” to fit best, a contract model with reimbursement in full for an unlimited number of sterilizations and abortions.

The ethical dangers lurking behind a contract model for medical practice may be probed through the behaviors leading to the bioethical dilemma under study. Technique is all that was rendered by the contracted physicians, and expenditure of that technique equalled exactly what was reimbursed. The contract model can completely divorce the surgical activities from any and all ethical deliberation. Contract medicine rewards technique. It has no room in its ontology for right or wrong. Although his deliberations regarding a Technological Society preceded much of what would become contemporary medicine as technique, Ellul has something to say about contracted physicians trapped in the ethical vacuum of technique. In his own words, “Technique becomes autonomous; it has fashioned an omnivorous world which obeys its own laws and which has renounced all tradition. Technique no longer rests on tradition, but rather on previous technical procedures; and its evolution is too rapid, too upsetting, to integrate the older traditions.”<sup>28</sup> If “poetic license” is allowed, tradition in this instance may be interpreted as Hippocratism or at least some acceptable ethical structure conjoined to medical technique. Ellul described technique further for our age, “In fact, technique is nothing more than means and the ensemble of means. This of course does not lessen the importance of the problem. Our civilization is first and foremost a civilization of means; in the reality of modern life, the means, it would seem, are more important than the ends.”<sup>29</sup> Contracts have the inherent potential to reward physicians for technique as means devoid of an ethic to elevate technique towards the ends of medicine. Physicians can be rewarded for “means” to the exclusion of the laudable, traditional “ends.”

Whether money for technique superseded or merely contributed to the loud, persistent sirens of eugenic philosophy in the decade of the 1970s cannot be addressed with any greater certainty. However, if reimbursement without consideration of right and wrong was a catalyst, the present generation had better take heed. That criticism follows.

## Conclusions

Although the travesty of forced sterilization and abortions targeting Native Americans occurred a generation ago and has ended, a revisit in 2010 is appropriate for a number of reasons. At this juncture, the irrefutable facts should be summarized. There has been ample evidence, gleaned from both governmental as well as private investigations, that Native American women underwent an excess of forced sterilizations and abortions at the hands of the I.H.S. and privately contracted physicians during the decade of the 1970s. Furthermore, the data retrieved were also consistent with coerced and otherwise flawed informed consent procedures. The foundational breach in ethics animating the procedures occurred in America. The United States of America already possessed a twentieth century historical record that had actively fostered eugenic sterilizations. Multiple state and federal laws protected each perpetrator throughout the overlapping eras. The activities heretofore summarized have continued even after they ended on Indian reservations. A prime example was the state of California, whose record for forced sterilization prevailed from 1909 through 1979, subsidized through federal funding.<sup>30</sup> Approximately 20,000 operations similar to those studied herein were performed in that state (mostly on the institutionalized, African-Americans, and Latinos), some of these occurring nearly thirty years after the Nuremberg Trials.

It also seems reasonable to presume that it was the power of eugenic philosophy—rather than other motives such as money—that drove those physicians employed by the I.H.S. Their generation's responses to confidential questionnaires betrayed a commitment to eugenics that seemed barely effected by events consequent to WWII. The private practice physicians' behavior under government contract may be more difficult to completely explicate. Despite a similar influence of eugenic philosophy for them as members of the same medical culture and generation as I.H.S. employees, obvious from the time they were educated and practiced, their example as a first generation of contracted U.S. physicians may bode poorly for a continued reliance on rich monetary awards dedicated solely to technique.

Might imitation of a similar contract model, that is, one protected by law, be viable today? With increased attention paid to declining physician reimbursement concurrent with debate on healthcare reform, there may be enough evidence to sustain the proposition that "quid pro quo" payment for technique could result in increased physician consumption of resources. The Dartmouth Atlas has demonstrated that Medicare beneficiaries in "higher spending" regions undergo a greater volume of procedures than comparably matched individuals in "lower spending" regions.<sup>31, 32</sup> The procedures involved correlate with less quality and greater mortality. Much like the movie "Field of Dreams," if the Government (i.e. Medicare/Medicaid) pays for it, they (i.e. certain physicians) will come and perform specific procedures for the requisite reimbursement.<sup>33</sup> The ethical issues inherent in whether the procedures in question are in the best interests of the patient are being broached in Congress now, but only in an effort to save money—not right wrongs. If indeed quality, morbidity, and mortality are paramount, as human dignity demands that they are, then reimbursements for some or all of these procedural disparities are unethical.

In fairness, one must also comment that the negativity in this manuscript towards some physicians caring for Native Americans during a particular historical era should not be construed as a blanket condemnation of all or even a majority of physicians

who serve the Native American community. In fact, the subjects for ethical scrutiny in this report probably represented a minority of physicians. Recent publications have demonstrated the high scientific and professional integrity evidenced by physicians in this area.<sup>34</sup>

Finally, the addition of physicians to the armamentarium of both eugenics and genocide, especially during this and the last century, is an ominous observation. Physicians in the I.H.S. during the time in question were young, often “fresh” out of training. Since their generation, additional medical graduates have moved even further from the tenets of “Do No Harm” along with many other critical yet disregarded traditions of Hippocratism. Furthermore, the ever-increasing shift away from any semblance of a covenantal model for medical practice—replacing that paradigm with a pure contract model—is in itself foreboding. Payment for any medical technique removed from the brackets of ethical consideration may tempt physicians in an era of decreasing reimbursement. In fact, recent economic realities suggest that today’s plethora of temptations will probably exceed those of the 1970s. Erosion of Hippocratism seems to inhabit every aspect of these tragedies and many others like them.

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# TELEOLOGY, EMBRYONIC PERSONHOOD, AND STEM CELL RESEARCH

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## The Necessity and Irreducibility of Teleology

From Aristotle to Darwin, philosophers and biologists have recognized that there is a principle of teleology inherent in biological entities. Aristotle, in his *Parts of Animals*, claims,

The causes concerned in natural generation are, as we see, more than one. There is the cause of for the sake of which, and the cause whence the beginning of motion comes. Now we must decide which of these two causes comes first, which second. Plainly, however, that cause is the first which we call that for the sake of which. From this is the account of the thing, and the account forms the starting –point, alike in the works of art and in the works of nature (Aristotle, “On the Parts of Animals,” 639b10).

Following Aristotle on this point, Darwin held that biological teleology is quite evident in the natural world, and teleology is part and parcel of Darwinian natural selection and transmutation of species. Asa Gray, a friend of Darwin’s, wrote that “We recognize the great service rendered by Darwin to natural science by restoring teleology to it, so that instead of having morphology against teleology, we shall have henceforth morphology married to teleology” (Gilson, p. 89). Of this passage Darwin replied, “What you say about teleology pleases me especially, and I do not think anyone else has ever noticed the point. I have always said that you were the man to hit the nail on the head” (Gilson, p. 84).

Following Aristotle, I understand the notion of biological teleology to be a logically prior and ontologically contemporaneous principle of change which is contained within beings containing heterogeneous parts such that this principle accounts for the order and developmental plan of an organism, “with the result that species exist whose characteristics are constant, as if the future of these beings had been predetermined in the seed from which they were born” (Gilson, p. 7). I will henceforth call this view *finalism*, which is in part an “attempt to give a reason for the very existence of [the] organization” of living things (Gilson, p. 3).

What I am calling *finalism* is distinct from *vitalism*. *Vitalism* is roughly the idea that there is a biological or physical “ghostly” force that literally operates on living cells, such that “the activities of living organism cannot be explained solely by the interaction of their component atoms and molecules, by known chemical and physical forces” (Barry, p. 158). In the introduction to *Molecular Embryology*, J. Michael Barry cites the early experimental embryologist Hans Dreisch (1867-1941) as a vitalist who maintained that living things possess a “vital force unlike any force familiar to scientists – a purposeful directive force like that suggested by Aristotle” (Barry, p. 2).

The way to distinguish between *finalism* and *vitalism* is to consider this last quotation from Barry together with a comment from Gilson, who recognizes that although Aristotle talks about ‘life’ (*zoe* or *vita*), “he never intends by this word a distinct

principle, a force, an energy to which science or philosophy ought to have recourse, as to a cause, in order to make reasonable what we call the facts of biology” (Gilson, p. 108). If *finalism* and *vitalism* can thus be distinguished, is it possible then that *finalism* can be understood not as a physical vital force that works mechanically alongside the interaction of bio-molecules, but rather as a philosophical/ontological explanatory principle that helps to explain the philosophical questions about biological subject matter that have to do with what “Aristotle calls simply ‘the end’ (*telos*), the ‘in view of which’ (*to ou eneka*), the ‘why’ (*dia ti*)” (Gilson, p. 2).

Teleology as an ontological reality is not reducible to physicalistic or mechanistic processes. Any mechanistic reduction simply pushes teleology to a lower level (molecular, atomic, subatomic, sub-subatomic, etc...). Pushing teleology down is not elimination. There is a logical limit to what any attempted mechanistic explanatory reduction of teleology can accomplish, since, necessarily, biological mechanisms require at least three things: (1) certain existing entities (whether at the level of whole organism or at ‘lower’ molecular, atomic, subatomic, sub-subatomic, etc...), (2) an environment in which they exist, (3) “specific potential behaviors” of those entities.<sup>1</sup> This is especially important if necessarily “to be” is “to be an entity with determinate properties.” (What would it mean for something to have being or exist without any properties at all?!)

If teleological reductionism fails, another way to reject teleology would be to attempt to explain our common sense observations of natural teleology by appealing to chance: teleology is only apparently real, but is really nothing but the chance causal connections between complex physical processes. However, to appeal to chance is a “refusal to give an explanation rather than an explanation” (Gilson, p. 107). Additionally, appealing to chance does not seem to be a particularly useful proposal in aiding scientific inquiry into biological processes.<sup>2</sup> I propose that if Aristotle is right that human beings who “by nature desire to know” (Aristotle, 980a25), and know more than mere appeals to ‘chance,’ then teleology and finalism are necessary ineliminable components for biology and philosophy of biology.

## Human Teleology and Human Personhood

If teleology can’t be eliminated from our ontology, then how should we understand it? One way of understanding teleology in biology comes from Aristotle, who claims that teleology should be understood as analogous to human actions.<sup>3</sup> Recent philosophers have called this Aristotelian analogy into question. For example, Ernest Nagel claims that the use of the notion of goal-directedness does not appropriately apply to organisms as it does to intentional human acts. He questions the way in which an “inner state” of an organism resembles a “complex mental state involving an intention, a desire, and a belief” (Nagel, p. 203). The Aristotelian rejoinder to this type of objection is that the resemblance here can be accounted for by considering that the parent animal pre-exists, with its determinant end having been realized, and that the generation of the offspring proceeds according to a definite ontological plan contained within the organism itself. The resemblance of natural teleology to intentional human acts is the antecedent nature of the end which humans have ‘in mind’ and biological organisms have ‘in nature’; both are internal to the thing in question.



Given the internal-law-like pattern which the reality of teleology brings to organisms, we can also understand teleology to be a normative notion: there are correct and incorrect realizations of the internal teleological “blueprints” possessed by organisms. Even contemporary embryological biologists like Barry, who rightly reject vitalist explanatory concepts, use teleological concepts in describing embryological development. For example, in chapter two of Barry’s text entitled “How an Embryo Acquires the *Correct* Shape as its Cells Divide” (emphasis added), Barry discusses how cell adhesions function as the “principal agents of *morphoregulation* [sic], the arranging of cells into the *correct* [emphasis added] body structure” (Barry, p. 37). The notion of “correct” is fully normative. There is a way that the shape of cells should be, but this is simply to include a teleological ontology into our understanding of embryological cellular development. The underlying morphoregulation is not guided by a mysterious vital physical force (Barry does a thorough job of summarizing the bio-chemistry behind morphoregulation), but the explanatory concept of teleology is not eliminated from the ontology of the biochemistry of embryology. It is presupposed by it.

Since teleology is real and is part and parcel of biological development there are implications for the concept of personhood as applied to early stage embryos. If the concept of teleology makes reference to the final *end* of the thing in question, as that towards which the teleological process is moving, then the question becomes a logical one: which is logically prior? Is it the complete end or the instrumental end which allows the complete end to come about? If it is the instrumental end, then when studying embryological development one cannot adjudicate between successful or unsuccessful developmental stages. For example, the initial cleavage divisions creating blastomeres can be identified not only as having occurred but as having occurred successfully, but no such identification could be made if it were not antecedently known what exactly a successful cleavage division was. In cases of cryopreservation of early stage embryos, during the first five days after conception, the only way that one can tell whether the freezing process was successful is to look at typical cases of normal gestational processes which have successfully reached the goal of normally developed five day old (or younger) embryos. The general logical point is that knowledge of biological processes and their achievement or successful completion is always had with reference to the end result in question. Therefore, teleological processes are logically prior epistemologically.

Suppose that it is possible to have a strong version of naturalistic reductionism regarding the common criteria for personhood. For example, consider two common criteria that many philosophers who argue about personhood take to be central for being a person: possession of rationality and self consciousness.<sup>4</sup> Suppose that these two criteria can be functionally reduced to biological processes, even in the strong materialistic sense that they are identical to brain states. If this were possible, then we only know what is required biologically for these criteria to be manifest from a study of the specific biology of cases where these traits are manifest. This also shows the epistemically logical priority of teleology. How do we know whether an organism will manifest these common criteria? We know from examining paradigmatic cases where they do occur, and we can trace back in time the necessary antecedent biological processes that are required for these criteria to be manifest.

This now raises the question of the logical priority of the existential or ontological teleology of any paradigmatic criterion for personhood. The actualization of any

physicalistic criteria for personhood is either teleologically ontologically prior to the manifestation of those criteria or it is not. If it is not teleologically ontologically prior, then the criteria can never be reached, or one must arbitrarily select reasons for thinking that those criteria are present. Even worse, one can simply (again arbitrarily) construct the criteria for personhood. It does not seem reasonable to believe that teleological processes are ontologically absent from the biological processes by means of which any criteria of personhood are physically manifest. They can be identified easily, especially if these criteria are ultimately reducible to (or co-manifest with) physical properties. If, however, they are not ontologically absent, and if the idea of personhood is to remain a real ontological category (as opposed to an arbitrarily constructed one), then it seems reasonable to grant that the criteria for personhood—whatever they may be—are ontologically logically prior to their actual manifestation.

If this is right, then we can make, with Aristotle, a distinction between two logical modes of actually having a property (in this case the properties are possessing rationality and self consciousness), both of which are logically entailed by the reality of natural teleology in human biological development. The distinction can be generalized from a consideration of a few claims by Aristotle. Consider the following:

It is possible that a thing may be capable of being and not *be*, and capable of not being and yet *be*; it may be capable of walking [or in our case rationality and self consciousness] and not yet walk . . . A thing is capable of doing something if there is nothing impossible in its having the actuality of that of which it is said to have the capacity (Aristotle, *Metaphysics* 1047a 20-30).

From this passage we can distinguish between two ways in which a biological organism can actually have a property (whether mental properties, e.g. self-consciousness or physical properties, e.g. having a nervous system). The first way that an organism can actually have a property is in the mode of actuality; the second is the mode of potentiality. For example, the property of being self-conscious of my typing this sentence is now had by me in a mode of actuality, while the property of my being self-conscious of my typing the next sentence is had by me in a mode of potentiality. It will be true of me, just as long as nothing interferes with the requisite conditions for this property to be actualized.<sup>5</sup> The second way that an organism can actually have a property is in the mode of potentiality. It is important to distinguish between at least two types of potentiality. There is the potentiality of one thing to cease being what it is and become another kind of thing (i.e. substantial change), and there is the potentiality of a thing to actualize something that is present within it such that it remains what it is (e.g. accidental change). Teleological processes involve only the latter for a biological organism. For a biological organism to undergo the former, it would cease to exemplify the kind of teleology that is typical of it and begin to exemplify a new teleological order. Thus, gametes, which are ontologically internally related to the organisms which have them, cease to be what they are (i.e. substantially change) in becoming a new organism which exemplifies a new (although similar in kind) determinate set of teleological processes that involve accidental changes for the organism. In this mode, it is actually true of me that I am the kind of being who has consciousness, even when I am not presently conscious.

The ontological distinction of modes of having a property is ontologically dependent on the existence of teleology in nature, which I have argued is an irreducible ontological reality. Necessarily a being which has a property in the mode of actuality had that

property ontologically prior to it in the mode of potentiality. The two are inseparable. The existence of natural biological teleology in human organisms implies the reality of the distinction. Thus, necessarily any property that is specified as the determinate mark of personhood will be had in the mode of potentiality logically prior to the mode of actuality by the human organism capable of having that property in the mode of actuality. This is guaranteed by uninterrupted natural biological teleology. Thus, any property specified as a criterion for personhood is actually had by the human organism at all stages of its teleological development. This would indicate a strong reason to think that personhood is continually had by all organisms capable of teleological development that ends (without interruption) in the exhibition of any criterion of personhood.

In a rather arcane fashion, whole persons are sometimes referred to as souls. For example, a recent headline read “Fisherman’s Wharf Chapel Remembers Souls Lost At Sea.”<sup>6</sup> Those lost at sea weren’t ethereal ghosts; they were persons. So, “persons” and “souls” mean roughly the same thing. So the reality of teleology implies soul, i.e. a whole person. We thus might borrow a phrase from Eleanor Stump and say something like teleology indicates a soul as a “configured configurer” (Stump 1995, p. 519). The soul is configured naturally as a real teleological entity and configures the development and expression of all of the essential properties had by the whole human person.

From the existence of the reality of a person, it is an objective truth that persons are worthy of moral treatment. If this is so, then it follows that since teleology is real in human organisms, the reality of human persons worthy of moral treatment is necessarily implied. Thus, teleology implies ethics, or ethical treatment even before the brain or mind manifests itself teleologically. Teleology, personhood, and meriting ethical treatment are ontologically coextensive properties of all human beings, regardless of their level of development.

## **Human Teleology and the Ethics of Embryo Destruction**

Are human persons at the embryonic stages of teleological development worthy of the same moral treatment as human organisms at later stages of teleological development in cases of stem cell research done in which embryos are destroyed? There are at least two possible reasons why human beings at temporally earlier stages of teleological development might be worthy of less moral treatment than those at later stages, both of which are unsatisfactory.

1) There could be a real conflict between the survivability of an earlier stage human person and a later stage human person. This seems to be a limit case of Judith Thomsons’ views on an argument for abortion based on bodily rights (Thomson 1971). This type of case is one in which one human person, a pregnant woman, at a later stage of teleological development can exercise her will to survive over and above the teleological intentions of her offspring. This type of case seems reasonable to many on both sides of the abortion debate, if it is a case in which the death of the mother is nearly guaranteed in the attempt to bring her child to term. The cause of death of the mother in this case is the continued teleological development of the child. If the teleological development of the earlier stage human person continues, it will stop the teleological development of the later stage human person.<sup>7</sup> Unfortunately, this case does not bear on the issue of stem

cell research, since no one's life is threatened by the mere existence of the teleological biological development of early stage frozen embryos.

2) Proponents of stem cell research (or other embryonic research resulting in the death of an embryo) could argue that there is a putatively greater good that comes about from the destruction of a human person at an earlier stage of teleological development. What might such a good be? Any discussion of this will simply be a matter of the qualitative and quantitative goods that are specified. This will have to be weighed against the putative goods of the attainment of the teleological ends of personhood. Stem cell research which is done through the destruction of frozen embryos is exactly this type of greater goods consideration. However, I believe that, given the reality of teleology and human personhood, any attempt to do so is absurd.

One can paint extreme cases in terms of thought experiments where one might save four billion teleologically advanced persons from excruciatingly painful suffering and death through one or two teleologically less advanced human persons who actually feel no pain. The idea is that it is a greater good to save billions of people by destroying a few people (whether early stage embryos *in vitro*, adults in permanent vegetative states, etc...). This situation, no matter the numbers involved, is reducible to the conflict between two teleological beings at different stages of personhood. Those suffering from conditions which inhibit the normal functioning of their teleological systems are aided by processes which inhibit the normal functioning of the teleological systems of other less teleologically developed human beings. In other words, the very criteria often cited for personhood is used to make impossible the criteria of personhood in some human beings in order to make possible the criteria in other human beings. This seems to nullify the goods involved, unless one simply quantifies the goodness of the number of rational beings as the sole good involved in moral conflicts between human persons.

The absurdity of this consideration of bringing about goods with respect to the intentional destruction of teleological entities can be seen by considering that if the teleological end of human biological organisms is the actualization and use of self consciousness and rationality, and if it is this very actualization and use of self consciousness and rationality (which is taken to be a good) which intentionally stops the actualization and use of self consciousness and rationality (which is taken to be a good), then it follows that the use of the good, in this case, is self-undermining. The use of a good which makes impossible the use of that very same good cannot be a good.

This is reminiscent of Plato's claims in the *Republic* that a man skilled in horsemanship cannot make someone unskilled in horsemanship by the exercise of horsemanship.<sup>8</sup> Thus, the exercise of reason cannot make someone unskilled in reason by the exercise of reason. If there is an activity that makes someone unreasonable, then that activity itself is unreasonable. This, of course, presupposes that there are real teleological ends of these activities, whether artificial, in the case of horsemanship, or natural, in the case of human reason. I have argued that there are real teleological ends in human biological organisms, and thus it is unreasonable to use reason to undermine the proper rational ends of human biological organisms. Thus, it is unreasonable to believe that the intentional destruction of innocent human persons at any stage of teleological development is morally justified.

Stem cell research involving the harvesting of stem cells which results in the destruction of a frozen embryo promises much for the curing of debilitating diseases and conditions in order to alleviate the suffering of many. If teleological realities in human beings imply a way that human beings ought to be, and if one of the ways that human beings ought to be is to be self-conscious and rational, then we ought to seek ways in which we can bring about the maximization of these real teleological ends. However, specific techniques which in turn undermine the teleological realities of other human organisms seem to stultify the process.<sup>9</sup> It turns out to be like the man who believes that since buying a new hybrid car will reduce his gasoline consumption by half, then buying two such cars will allow him to drive around with no gas at all.<sup>10</sup> The idea of teleological beings at advanced stages eliminating the teleological outcome of other teleological beings in order to advance teleological development in themselves seems to undermine the very *telos* of being human and therefore ought to be avoided if achieving human ends are good in themselves.

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## Endnotes

1. I owe this insight to Dallas Willard's discussion of teleology (Willard 1993).
2. For a similar treatment of appeals to teleology versus chance in questions of philosophy of religion see Keith Yandell's *Philosophy of Religion* (London: Routledge, 1999) pp. 192-198.
3. See Aristotle's *Parts of Animals* 640a10-30, also discussed in Gilson, p. 6ff.
4. See Warren 1973. Although the dialogue on personhood discussed in Warren's famous article is in the context of the abortion debate, the issues seem to be the same with respect to the ontological status of early stage embryos *in vitro*. This is assuming of course that early stage human organisms have their identity independent of their location, whether *in utero* or *in vitro*.
5. Other philosophers have recognized this Aristotelian distinction as well. See

Schwarz 1990, chapter seven. Schwarz classifies the distinction as one between present immediate capacities and basic inherent capacities.

6. NBC11.com headline, March 30, 2007 (<http://www.nbc11.com/news/11459376/detail.html>).
7. I am presupposing that the attainment of teleological ends in human persons (i.e. any criterion/criteria for personhood) is a good thing. This assumption is that such criterion as consciousness and rationality are good things to have and that the teleological means to having them are good, too.
8. Plato *Republic*, 335d.
9. Other techniques for alleviating human suffering and allowing human beings to reach their ends might pose viable alternatives to embryonic stem cell research. Such techniques might include adult stem cell research, embryonic stem cell research that does not stop embryonic teleology, or somatic cell gene therapies.
10. See C.S. Lewis' story of the Irishman's wood stove in *The Abolition of Man*, chapter 3.

# GENES, JOBS, AND JUSTICE: OCCUPATIONAL MEDICINE PHYSICIANS AND THE ETHICAL, LEGAL, AND SOCIAL ISSUES OF GENETIC TESTING IN THE WORKPLACE

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## Abstract

*The application of new genetic technologies in the workplace not only holds the promise of improving worker health and safety but also raises significant ethical, legal, and social issues which could have serious adverse effects on workers, including effects on their employability and insurability. In the workplace, one appropriate target for study and intervention concerning the use of genetic technologies and information is the occupational health care professional, particularly the occupational medicine physician. Occupational medicine physicians frequently are directly involved in the development and implementation of employer policies regarding medical testing in the employment setting as well as in the control, interpretation and application of the resulting information. Therefore, a study was undertaken to determine the extent of involvement of occupational medicine physicians in the U.S. in genetic testing in the workplace and their level of knowledge and concern about the ethical, legal, and social issues of such testing. A questionnaire survey of members of the American College of Occupational and Environmental Medicine (ACOEM) was performed with distribution by email and in-person at the organization's annual national meeting. Among respondents, 7.7% reported being currently engaged in genetic testing in the workplace, primarily to protect workers from workplace hazards. Overall, 40% of respondents felt that workplace genetic testing should be used in decisions about job placement, but 17% felt that workplace genetic testing was never appropriate. Most respondents (57%) did not feel competent dealing with genetic testing issues, and the vast majority (75%) reported feeling ethically conflicted about workplace genetic testing. For guidance in the resolution of ethical conflicts, respondents reported relying primarily on professional codes of ethics and guidelines, but their level of familiarity with ACOEM's position on genetic testing in the workplace was generally low. These results suggest that occupational medicine physicians do not feel prepared to deal with the ethical, legal, and social issues of genetic testing in the workplace and that professional organizations should consider increasing their educational efforts in these areas.*

## Introduction and Review

Concern over the use (and mis-use) of genetic information in the employment setting has a long history (Brandt-Rauf and Brandt-Rauf, 2004). Genetic testing to “eliminate potters’ bronchitis by regulating entrants into the potters’ industry who are congenitally disposed to it” was suggested as a workplace health strategy by the British geneticist



J.B.S. Haldane as early as 1938 (Haldane, 1938). However, it was not until the advent of relatively simple blood tests to detect protein or enzyme genetic variants in the 1950s and '60s that the idea was first applied in practice. As a result of acute hemolysis noted in soldiers serving in Korea who had taken the antimalarial drug primaquine and were also glucose-6-phosphate dehydrogenase (G6PD) deficient, it was suggested that workers who were exposed to various oxidant stresses from their workplace exposures to aromatic nitro and amino compounds, metal hydrides, and dyes and were similarly G6PD deficient could also develop hemolytic anemia if not identified and removed from working with these chemicals (Stokinger and Mountain, 1963). By 1973, blood tests for other genetic conditions were identified and considered for workplace testing, including alpha-1-antitrypsin deficiency, sickle cell trait, and carbon disulfide or isocyanate sensitivity (Cooper, 1973). In the 1970s, the Air Force tested African-Americans for sickle cell trait and excluded those who tested positive from Academy admission and flight training due to suspected risks at high altitudes, and DuPont used preemployment testing of African-Americans for sickle cell trait to restrict their work with nitro and amino compounds (Reinhardt, 1978; Omenn, 1982). Since then, additional examples of workplace genetic tests have been added to the list, including N-acetylation ability, paraoxonase activity, nicotine-adenine dinucleotide dehydrogenase deficiency, and various cytochrome P450 and HLA variants (Gochfeld, 1998).

Over the years, several attempts have been made to determine the scope of genetic testing in the workplace. The first systematic survey was conducted by the Congressional Office of Technology Assessment (OTA) in 1982 among the chief executive officers of the nation's top 500 companies and 50 largest private utilities (OTA, 1982). Among 366 respondent companies, 5% reported using workplace genetic testing in the previous twelve years. A follow-up survey of the chief health and personnel officers of 1500 large U.S. companies, 50 largest utilities and 33 largest unions conducted by OTA in 1989 found similarly that among 260 respondent companies, 5% reported using workplace genetic testing, and an additional 3% reported having used workplace genetic testing in the previous nineteen years (OTA, 1989). The most recent survey was conducted by the American Management Association in 1999 among its member companies (Schill, 2000). Among 1,054 respondent companies, 16.7% reported using workplace genetic testing to determine susceptibility to job exposures, and 10.3% reported using the results in making employment decisions including hiring, job assignment or reassignment, or dismissal.

While genetic testing is already being conducted in the workplace, it has been anticipated with the completion of the Human Genome Project that its use would significantly increase. Genetic tests have the potential to identify groups of workers at higher risk from workplace exposures and thus may be useful for prevention and early intervention. Some corporations already use general health screening to minimize the economic cost of employee health care, and it can be expected that this might include genetic testing as well. However, the application of genetic technologies and the use of the resulting information in the workplace also generate ethical, legal, and social issues which have potentially serious adverse effects on workers, including effects on their employability and insurability. As early as 1982, then Representative Al Gore, who was Chair of the House Subcommittee on Investigations and Oversight of the Committee on Science and Technology, noted that workplace genetic testing has "potential to serve as a marvelous tool to protect the health of workers or a terrible vehicle for invidious

discrimination” (Severo, 1982). Subsequent reports provided support for the notion that the concern over discrimination was warranted. A 1992 survey of genetics professionals collected 41 cases of genetic discrimination in the previous two years, including discrimination in employment (Billings et al., 1992). In 1996, a survey by the Council for Responsible Genetics identified over 200 cases of genetic discrimination (Geller et al., 1996), and another survey of volunteers from genetic support groups reported that among 332 respondents 13% had been terminated from or denied a job based on genetic information (Lapham et al., 1996). Recent examples, including the action by the Equal Employment Opportunity Commission against the Burlington Northern railroad for inappropriate genetic testing for carpal tunnel susceptibility, underscore some of the specific problems (Schulte and Lomax, 2003). In this case, besides failing to meet the minimal scientific basis for a genetic testing program, the program also neglected informed consent, failed to provide genetic counseling, and threatened employees with dismissal for failure to comply. Besides the impact on an individual’s employability and insurability, all of these examples raise significant ethical issues relating to privacy and confidentiality, personal autonomy, stigmatization, and quality of life.

Although significant ethical, legal, and social issues of genetic testing in the workplace have been identified repeatedly, legislative and regulatory responses have generally been deemed inadequate (Rothenberg et al., 1997). Until 2008 with the passage of the federal Genetic Information Nondiscrimination Act (GINA), legal remedies could only be described as variable, scattered and unclear (Erwin, 2008; Abiola, 2008; Rothstein, 2008; Tan, 2009). Legal remedies had been bolstered by ethical recommendations by various organizations with a major focus on the ethical responsibilities of the occupational health professional in this process, particularly the occupational medicine physician. For example, the American College of Occupational and Environmental Medicine (ACOEM), the largest professional organization of occupational medicine physicians in the United States, issued its first position statement on genetic screening in the workplace in 1994 to provide physicians practicing in the employment setting guidance on the potential uses and misuses of genetic tests. This statement “recognizes that the greatest potential for misuse of genetic testing in the workplace involves discrimination in employability and insurability” and that applications of such tests should be guided by the ethical principles of “voluntary, informed consent, and confidentiality with due respect for autonomy, equity and privacy considerations of those tested” (ACOEM, 1994). The focus on occupational medicine physicians is highly appropriate. It is the occupational medicine physician who has traditionally been called upon to make medical decisions that directly affect the employment (and, in some cases, the insurance) status of workers. The occupational medicine physician is usually responsible for the development of employer policies on the implementation, application, and uses of medical tests in the workplace and is directly involved in the design, gathering, interpretation, and control of all medical information in that setting. It is not only likely that occupational medicine physicians are involved in decisions about genetic testing in the employment setting but also that they are concerned about the use of such tests and need to be better informed about the issues they raise. For example, in a previous survey of occupational medicine physicians examining ethical problems in their practices, respondents raised concerns about genetic testing in the workplace (Brandt-Rauf et al., 1989). Although occupational medicine physicians’ level of understanding of the ethical, legal, and social issues of genetic

testing in the workplace has not been directly assessed, their knowledge in related areas appears less than optimal. For example, a survey of occupational medicine physicians in Minnesota, which concerned their understanding of the requirement for job-relatedness in pre-placement tests for prospective employees and for the release of their medical records, found a general lack of familiarity with the relevant legal and ethical principles (Rothstein et al., 1998). In addition, in general, the level of understanding of physicians of the use and interpretation of genetic tests and related ethical, legal and social issues has been found lacking in several studies (Hayflick et al., 1998; Acton et al., 2000; Greendale and Pyeritz, 2001; Metcalf et al., 2002; Kirkland, 2002). In these areas, there is no evidence that occupational medicine physicians differ.

Thus, the current study was undertaken to test the hypothesis that occupational medicine physicians are becoming involved in genetic testing in the workplace with insufficient background to adequately address the ethical, legal, and social issues raised by such testing. This was accomplished by surveying members of ACOEM to determine the extent of their genetic testing practices in the workplace and their level of knowledge and concern about the ethical, legal, and social issues of this testing.

## Methods

A questionnaire was developed through a multi-step process. The authors prepared an initial draft based on previous surveys of ethical issues faced by occupational medicine physicians and surveys on genetic testing in the workplace (Brandt-Rauf et al., 1989; OTA, 1983, 1990). The questionnaire was modified based on the results of focus groups of workers and occupational medicine physicians. Final refinements were made based on the comments of an expert review panel that included a member of the ACOEM Committee on Ethical Practice, a physician geneticist, a bioethicist, a genetic counselor, a worker health and safety advocate, and a community environmental advocate.

The final questionnaire included 61 items that covered several different constructs: experience with genetic testing (current practices, purposes, uses, outcomes); knowledge of genetic testing (scientific considerations in choosing, using, and interpreting tests, ethical standards and laws relevant to testing), attitudes and beliefs about genetic testing (the ethical, legal and social concerns raised by testing), demographics (age, gender, race/ethnicity, medical training and certification, employer, type and amount of occupational medicine practice); and other (e.g., methods and preferences for learning about genetic testing).

The questionnaire was emailed to a 20% random sample (n=817) of the 4,085 active members of ACOEM with currently-functioning email addresses listed in the membership directory in two separate mailings, two months apart. As noted, ACOEM is the largest professional organization of occupational medicine physicians in the United States; it is estimated that up to half of all practicing physicians engaged in the full-time practice of occupational medicine in the country are members. To increase the coverage and response rate, the questionnaire was also distributed to a convenience sample of 100 ACOEM members who attended the annual national meeting and had not already responded to the email survey approximately two months following the second emailing, so a total of 917 members received the questionnaire, either by email or personal distribution.

Returned questionnaires were de-identified to maintain confidentiality, and the responses were entered into a database for analysis. Respondents were first compared to the total ACOEM membership in terms of available demographic information (age, gender, race/ethnicity, type of occupational medicine practice, amount of occupational medicine practice, board certification) to test the generalizability of the responses. Summary data for each individual item were then compiled. Finally, correlations between item responses were examined using Chi-square and Fisher's exact tests (e.g.: demographic variables with involvement in genetic testing or with knowledge of genetic testing or attitudes and beliefs about genetic testing, involvement in genetic testing with knowledge of genetic testing or with attitudes and beliefs about genetic testing).

## Results

Despite the multiple distributions, the response rate was relatively low; of the 917 questionnaires distributed, 209 completed questionnaires were returned (22.8%). However, respondents were found to be generally representative of the ACOEM membership as a whole based on the available comparison data (see Table 1). There were no statistically significant differences ( $p>0.05$ ) between respondents and all members in terms of age, gender, race/ethnicity, or type or amount of their occupational medicine practice, but respondents were more likely ( $p<0.05$ ) to be board certified and to be board certified in occupational medicine.

Of the 209 respondents, 16 (7.7%) reported being currently engaged in genetic testing in their workplace. In addition, one respondent (0.5%) reported being involved in testing previously, but not at the time of the survey. Those doing testing reported their involvement to be primarily interpreting test results (83%) or recommending company policy (17%). Reasons reported for doing testing included: to protect workers from workplace hazards (69%), to protect employers from legal liability (44%), and/or for research purposes (31%). Primary factors dictating the choice of the tests included the relationship of the test to workplace exposures (92%) and the possibility of taking ameliorative action (72%). Administration of tests was generally based on job category (85%) and performed after hiring but before job placement (62%). Pre-test and post-test counseling was not generally available for those tested (8% and 15% offered pre- and post-test counseling, respectively). The actions taken in the workplace as a result of testing were reported to include changing the employees' jobs (56%), adding engineering or administrative controls (38%), adding worker personal protective equipment (19%), and/or implementation of a research program (19%). The majority reported that results were not ordinarily disseminated to employees (69%) or to employers (56%).

Compared to respondents not currently engaged in genetic testing in their workplace, those respondents who were engaged were statistically significantly different ( $p<0.05$ ) in a few key aspects (see Table 2). For example, as might be expected, they were more likely to be employed by industry and to be practicing in a managerial position, and they reported feeling more competent interpreting the results of genetic tests. They were also more likely to be board certified in occupational medicine, and they were more likely to be factually knowledgeable about the relevant ethical and legal questions pertaining to testing. In terms of their attitudes toward genetic testing in the workplace, they were less likely to believe that the person being tested should always be told of the testing or always be given the results of the tests.

For the respondents not currently engaged in genetic testing in their workplace, the most common reasons given for the lack of testing included: that genetic testing was not medically appropriate for their workplace (56%), that genetic tests do not yet provide useful information (9%), that genetic testing is discriminatory or illegal (5%), and/or that their training did not prepare them to deal with genetic testing (4%).

For questions answered by all respondents, several responses merit comment. For example, 40% felt that workplace genetic testing should be used in decisions about job placement, but 17% felt that workplace genetic testing should never be conducted. Although reasonably knowledgeable about the scientific and legal issues related to genetic testing (the percentage of correct answers to these factual questions ranged from 63-94%), most respondents did not feel competent to deal with genetic testing issues. For example, only 4% felt competent interpreting the results of genetic tests, only 0.5% felt competent counseling those tested, only 7% felt competent referring those tested for further intervention, and only 4% felt competent recommending company policies on testing; overall, 57% did not feel competent doing any of these tasks related to genetic testing. In addition 75% reported feeling ethically conflicted about workplace genetic testing with the most significant issue presenting ethical conflict in this case being making employment recommendations based on genetic testing (67%). For guidance in the resolution of ethical conflicts, respondents reported relying on position papers (56%), other health care professionals (63%), but primarily, professionals codes of ethics and guidelines (75%). However, as many as 33% of respondents were even unaware that ACOEM has a Position Statement on Genetic Screening in the Workplace, and the level of familiarity with the details of the position statement was quite low (only 18% of those aware of the statement were accurate about key points of the position). The lack of knowledge regarding policy for genetic testing is not generalizable to other related policy statements: 91% of respondents were aware that ACOEM had a Position Statement on Confidentiality of Medical Information in the Workplace, and, of those, 70% were accurate about the key points in the statement.

## Discussion

This survey indicates that immediately prior to the passage of the Genetic Information Nondiscrimination Act, approximately 8% of the members of ACOEM were engaged in genetic testing in their workplaces. Although not directly comparable, this number can be viewed as being within the same range as the results of different types of surveys on this issue in the past. For example, as noted above, the 1982 OTA survey found that 5% of respondents reported using genetic testing in their workplaces in the previous twelve years (OTA, 1983). Likewise, the 1989 follow-up survey by OTA found that a similar 5% of respondents reported employing genetic testing in their workplaces at that time (OTA, 1990). Also, the 1999 American Management Association survey found 16.7% reporting using genetic testing (Schill, 2000).

From this survey as well as prior surveys, it is impossible to know how many individual workers have been affected by this testing or whether the effects were generally positive or negative in terms of workers' health and well-being. It is somewhat encouraging to note that the single most important reason given for testing by the current survey respondents was to protect workers from workplace hazards. On the other hand, the manner in which the testing was being carried out to achieve this protection may

be viewed as less encouraging since pre- and post- testing counseling was negligible and the results were generally not disseminated to those tested. In addition, although in 56% of cases the results were also not disseminated to the employer, the implication is that in 44% of cases they were disseminated to the employer, which would constitute a significant violation of the ACOEM code of ethical conduct in occupational medicine.

It is impossible to predict from this survey how the passage of GINA will alter these practices in the future. As noted above, one of the primary reasons for the passage of GINA was to address perceived abuses of genetic testing in the workplace that adversely affected workers' employability and insurability. However, if one effect of the new law were to discourage testing programs, workers would be deprived of access to information that might have been useful to them in making informed decisions about workplace health risks, surely an unintended consequence of a law designed to protect individual rights. To the extent that any testing continues within the constraints of the new law, it is clear from this survey that occupational medicine physicians in general do not feel competent in dealing with it. This is true both for the clinical aspects of genetic testing, such as interpreting test results, counseling and referring, the managerial aspects of testing such as recommending policies, and for the ethical/legal aspects such as making employment recommendations. Future educational efforts for occupational medicine physicians by ACOEM or other professional organizations should consider these findings when developing programs to inform workplace health professionals on this subject within the context of the new legal requirements.

This survey also provides some interesting insights into the nature of ethical conflicts in occupational medicine and how occupational medicine physicians deal with complex and difficult ethical, legal, and social issues that arise in their practices. The primary source of the ethical difficulty with genetic testing in the workplace was identified by respondents as its use in making employment recommendations. The role of the occupational medicine physician in making recommendations to the employer about the fitness of a particular employee for a job is one of the fundamental tensions in occupational medicine, the case of genetic testing representing just one example. This is due to the fact that making such recommendations is one of the primary tasks of the occupational medicine physician, and it brings into play the divided roles, loyalties, and responsibilities – to the patient/employee, company/employer, the medical profession/oneself—that exist for the physician in the workplace. An extensive theoretical literature (Walsh, 1986; Brandt-Rauf, 1989; Lurie, 1994; London, 2005) has been devoted to the existence of such conflicts but much less to the manner in which practitioners resolve them. In this survey, for the particular problem of genetic testing in the workplace, it is interesting to note that the primary source of guidance for respondents was reported to be professional codes of ethics and guidelines. These findings are similar to prior results of surveying occupational medicine physicians about ethical conflicts in their practice in general (Brandt-Rauf et al., 1989). In that study, respondents reported that ethical conflicts usually involved conflicting responsibilities to themselves, the patient, and management, and that in resolving these conflicts they most frequently relied on professional codes of ethics. These consistent results strongly suggest that in occupational medicine, codes of ethics and ethical guidelines play a critical role in helping practitioners deal with complex and difficult issues. This finding suggests that professional organizations should regularly review their codes of ethics and guidelines to make sure that they fully and accurately reflect the standards of practice expected of members of the profession.

Fortunately, ACOEM has been sensitive to this issue as it has reviewed its Code of Ethical Conduct several times (most recently in 2009) and issues frequent policy statements and guidelines on relevant topics. However, ensuring that professionals are knowledgeable about the existence and contents of codes and guidelines remains a challenge. As noted, only 33% of our survey respondents were aware that a guideline on genetic testing existed, and only 18% of those were accurate about the content. This underlines the need for professional organizations to continue and to expand informational efforts dealing with workplace genetic testing as well as those dealing with other difficult ethical, legal, and social issues in occupational medicine.

**Table 1.** Comparison of Demographic and Practice Characteristics of Survey Respondents with All ACOEM Members

Characteristic		ACOEM Members (n=4725)	Survey Respondents (n=205)	Significance
Age:	≤45	30%	25%	
	46-63	65%	67%	p=0.07
	>65	5%	8%	
Gender:	Male	80%	80%	p=1.00
	Female	20%	20%	
Ethnicity:	White	89%	86%	
	Asian-American	5%	5%	
	African-American	2%	3%	p=0.10
	Hispanic	1%	3%	
	Other	3%	.%	
OM Practice:	Private	36%	38%	
	Hospital	18%	185%	
	Corporate	24%	23%	p=0.78
	Govt/Academic	15%	16%	
	Other	7%	5%	
OM Time:	Full-Time	66%	72%	p=0.06
	Part-Time	34%	28%	
Certification:				
All:	Any	75%	94%	p<0.00001
	None	25%	6%	
OM:	OM	28%	45%	p<0.00001
	Other/None	72%	55%	



**Table 2.** Comparison of Selected Characteristics, Knowledge, and Attitudes of Respondents Engaged in Genetic Testing with Respondents Not Engaged in Genetic Testing

Characteristic/Knowledge/Attitude		Testers (n=16)	Non-Testers (n=189)	Significance
Primary Employer:	Industry	75%	17%	p<0.00001
	Other	25%	83%	
Primary Responsibility:	Managerial	56%	27%	p=0.02
	Other	44%	73%	
Certification:	OM	81%	28%	p=0.00003
	Other/None	19%	72%	
Competency:	Interpreting Tests	69%	6%	p<0.00001
	Other/None	31%	94%	
Knowledge:				
Medical Record Owner:	Correct	94%	42%	p=0.00007
	Incorrect	6%	58%	
ADA Requirements:	Correct	88%	56%	p=0.01
	Incorrect	12%	44%	
Attitudes:				
Always Revealing Testing:	Yes	6%	88%	p<0.00001
	No	94%	12%	
Always Give Results:	Yes	19%	86%	p<0.00001
	No	81%	14%	

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## BOOK REVIEWS

### **The Evolution Controversy: A Survey of Competing Theories**

Thomas B. Fowler and Daniel Kuebler. Grand Rapids, MI: Baker Academic, 2007.

ISBN 0-8010-3174-5; 384 PAGES, PAPER, \$28.00

The relationship between faith and science has been the subject of debate since Galileo challenged the assumption that the Earth was the centre of the universe. It was at that time in history that the Church's interpretation of the universe as depicted in Scripture was challenged. The challenges that science presents to religious faith and its interpretation of the world around us continue to this day, and there is probably no greater challenge than that presented to the biblical account of creation by the theories of evolution. Since the publication of Charles Darwin's *The Origin of Species*, the battle lines have been drawn between the scientific establishment and the Church.

Logic would suggest that before taking one side or another in any debate, one should try to fully understand each perspective objectively in order to effectively engage opposing views. With this in mind, Fowler and Kuebler have written *The Evolution Controversy*. They suggest in the preface that '[t]he book is not written for people who have already made up their minds about the facts and have no desire to review the debate in an unbiased fashion.' (17) Rather, it is written with the intent that the reader is open-minded to the varying positions in this debate with the understanding that no perspective is without weaknesses.

The book is laid out in three parts. The first part discusses the background to the debate by looking at the history of evolutionary thought, reviewing evidence for the theories, and concluding with the major points of dispute. The second part follows by examining the major schools of thought: the Neo-Darwinian school, the Creationist school, the Intelligent Design school, and the Meta-Darwinian school. The book concludes by considering the importance of the debate as it relates to the establishment of public policy and the funding of education and scientific research.

The authors have taken on a gargantuan task in endeavoring to distill the evolution controversy down to a treatise that is digestible both to the layperson as well as the academic and doing so in a manner careful not to take sides (as with many other books that argue from one perspective). One of the book's strengths is that it uses tables and illustrations to help the reader understand the varying positions and their strengths and weaknesses, then challenges the claims made by each perspective.

I would recommend this book to anyone who wants to better understand the debates that center on evolution, both religious and otherwise; it contains a wealth of information on the major perspectives and their respective arguments in one volume. It also serves as a good starting point for further study on the subject.

**Reviewed by Jeffrey G. Betcher, MD, FRCPC, MA (Ethics)**, who practices anesthesiology and critical care medicine at the Regina Qu'Appelle Health Region in Regina, Saskatchewan, CANADA.

## Reviving Evangelical Ethics: The Promises and Pitfalls of Classic Models of Morality

Wyndy Corbin Reuschling. Grand Rapids, MI: Brazos Press, 2008.

ISBN 978-1-58743-189-0; 188 PAGES, PAPER, \$22.99

Given the way evangelicalism is viewed by many today—as concerned primarily with right doctrine or personal piety, or perhaps as a conservative voting block—it may seem strange to talk about “evangelical ethics.” But these perceptions (and the half-truths they are rooted in) simply speak to the need for evangelical ethics to be “revived.” As Ashland Theological Seminary professor of ethics and theology, Wyndy Corbin Reuschling, notes in her introduction to *Reviving Evangelical Ethics*, there was a time when evangelicals “were known for their participation in the abolitionist movement, for promoting equal rights for women, for addressing the causes of poverty, and for peacemaking” (20-21). Is it possible that such evangelical ethics might be revived? Corbin Reuschling believes so, but she finds it first necessary to identify the pitfalls that have gotten evangelicalism off track. For her, these pitfalls can be found in evangelicalism’s unwitting appropriation of three classic ethical models: Kant’s deontology, Mill’s utilitarianism, and Aristotle’s virtue ethics.

Corbin Reuschling thus begins by describing each of these three classic models in some detail, identifying briefly their appeal to evangelical sensibilities. In her next three chapters, she describes how evangelicals have appropriated each of these models. She describes in chapter two how deontology can be located in a rather naïve “trust and obey” approach, where Scripture is read primarily as a rule book to be followed. For Corbin Reuschling, the Bible gives us more than commands to follow; it invites us to view ourselves as participants in the narrative of God’s redeeming work, in which our obedience forms us into the kind of community God desires us to be in and for the world. In chapter three Corbin Reuschling describes how utilitarianism is the guiding principle behind many of evangelicalism’s evangelism strategies, where the driving force is to get the most people saved by whatever means necessary. In contrast to this thin description of evangelism, she argues that evangelicals must present a thick description in which the story of the Kingdom and the church’s role in God’s work is central to the message we convey. She identifies the average evangelical’s inability to think morally about questions of war and nationalism as symptomatic of evangelicalism’s general lack of moral imagination. Then, in her fourth chapter, Corbin Reuschling identifies the way evangelical pietism and spiritual growth practices reflect certain aspects of virtue theory. She worries about the implicit individualism of such an approach and proposes instead a social understanding of Christian virtues.

In chapter five Corbin Reuschling ties her insights together to offer a constructive approach to reviving evangelical ethics, which she breaks down into “three dimensions of morality . . . vital for a more vigorous appreciation of the ethical life in an evangelical context. These are the development of conscience, the role of Christian community, and the actual practicing of moral reflection and ethical deliberation as a means for becoming an ethically competent thinker and practitioner” (145). Finally, in her conclusion she briefly describes how three common evangelical practices—preaching, small groups, and service—can become means for evangelical moral formation.

*Reviving Evangelical Ethics* is an important book in that it reveals the blind spots in evangelical ethical reasoning and calls evangelicals to a richer participation in the moral life. There are points in the book, however, where it seems that Corbin Reuschling caricatures evangelicalism a bit by painting a dark picture in broad brushstrokes and not offering many counter-examples in which evangelicals are beginning to get it right. (One might have expected to see such names mentioned as Ron Sider or Greg Boyd, for example.) There are also points where Corbin Reuschling relies too heavily on previous scholarship, explicating others’ works on Christian ethics for multiple pages at a time. Nevertheless, *Reviving Evangelical Ethics* offers a distinct call of its own—a call that needs to be heeded by all Christians, evangelical or otherwise.

**Reviewed by David C. Cramer, MDiv, MA (Philosophy or Religion),** who is Adjunct Faculty for the Division of Religion and Philosophy at Bethel College, Mishawaka, Indiana, USA.

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