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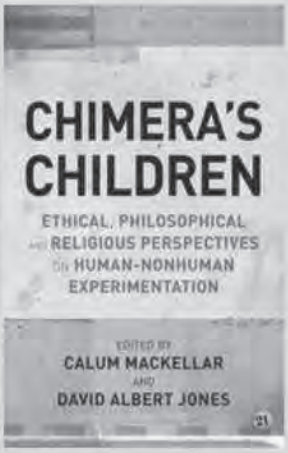

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The idea of human-nonhuman combinations has been a recurrent theme throughout the history of humanity. From the myths of the Minotaur and the centaurs in ancient Greece to the dogheads of the Middle Ages right through to the monsters of modern science fiction, these beings have always been a source of fascination. In recent years, however, biomedical advances have demonstrated the potential to make these entities a reality through the creation of inter-species combinations. As a result, pressing and perplexing ethical questions arise.

Introducing the reader to the historical context of human-nonhuman experimentation and potential future developments, this volume offers clarification, analysis and a thorough overview of the ethical challenges relating to human-nonhuman chimeras, true hybrids, cybrids and other combinations.

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GUEST EDITORIAL FROM THE FOUNDING EDITOR

BRAVE NEW WORLD/PEOPLE/TECHNOLOGY/QUESTIONS . . .

NIGEL CAMERON

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The emerging technology agenda has barely begun to take shape. While developments in the biosciences over the past 30 years have led to hope (much of it premature) and anxiety (justified or not), 'we ain't seen nothing yet,' as the saying goes. The struggles over genetically modified foods and the use of the human embryo for purposes of experimentation and therapy have not gone away. Older anxieties over "gene therapy" have, to some degree, been set aside because the idea has, in general, proved to be either dangerous or unworkable. Meanwhile, very rapid developments are taking place in nanoscale engineering and, similarly, in synthetic biology. The advance of "big data" is essentially digitizing bioscience. The nanoscale has begun to blur the line between biology and engineering. In the back of it all, artificial intelligence and its embodied cousin, robotics, are finally finding their feet.

It is important, though difficult, to understand two things about the rapidly changing technological landscape. Firstly, technology is essentially a department of anthropology—that is, of the understanding we have of what it means to be human. Whether we see such technologies as good or bad (or whether we are indifferent), technological questions are human questions. Secondly, technology has long ceased to be on the outside, an add-on, an option. It has begun to integrate with every detail of our lives. Put these two propositions together and you can begin to see what few have seen: that there is nothing at all as significant or threatening or problematic or potentially wonderful as "emerging technologies." This phrase is interesting, and in increasingly common use, since to focus on biotechnology or nanotechnology or any other particular technology is becoming less and less relevant. Specific tech areas are melding and being reshaped by each other; whole disciplines like 'materials science,' 'bio-engineering,' and 'nano' have converged and created a fresh field of inquiry in which practitioners wear different hats but do the same thing in the lab. The somewhat notorious National Science Foundation conference report from a decade ago, "Nano-Bio-Info-Cogno: Converging Technologies for Improving Human Performance," made just this point. A recent MIT report, launched at the American Association for the Advancement of Science, made the same assertion nearly 10 years later. Though the academic world is very slow to adapt, these technologies are becoming both integrated and, in some measure, indistinguishable. New ones will follow. "Emerging technologies" is the name of the game.

Behind the presentation of issues such as GMO foods and embryonic stem-cell research lies the ubiquitous Moore's Law, the principle that computer chips get smaller, cheaper, and faster all the time. This law drives every technology, and we do not need to buy into Ray Kurzweil's "singularity" theory, which says that in a couple of decades machines will be smarter than we are and will begin to run things, to recognize that "artificial intelligence" is improving dramatically. California recently passed a law that enables cars that don't have drivers—or rather, whose drivers are computer programs (AIs)—on the roads. Google Cars have driven 300,000 miles without a single accident. My view is that within 6 or 7 years, at the most, self-driving cars will be the norm and that, within 10 years, human-driven cars will either be illegal or simply uninsurable. In such a case, everyone who presently earns a living by driving—millions of men and women in the United States alone—will be jobless. Similar disruption will occur in the next decade, in my opinion, in both higher education and retail banking—the current structures will collapse in the face of machines and new economics, just as surely as print magazines and books are in retreat today (In fact, the day that I write this *Newsweek* announced it will cease print publication. What could be clearer as an example of the power of disruptive innovation in publishing?).

Yet, the problem is not whether we prefer Kindle books or get annoyed by people using their cell phones in restaurants (or worked up by how many use them in their cars). Such things represent only the beginning of the beginning. And time, as it were, is speeding up. Look back and see how fast Google and Facebook caught on, basically inventing (or at least perfecting) two completely fresh ideas (and business models): search and social. If we believe Moore's Law, what took 10 years in the past will now take a much shorter time. Such shifts have just begun.

What do all these things mean for human dignity, the freedom and responsibility of the individual, the sanctity of life—for what Christians (and Jews) have indicated by that phrase "the image of God"?

I have no simple solution. I just know that these questions are only beginning to be raised, that there will be new and harder questions every year, and that the church is at least as unprepared for their implications as the rest of society.

What to do? Well, you tell me. **E&M**

GREY MATTERS

THE MIDDLE WORD IN BIOETHICS

WILLIAM P. CHESHIRE, JR., MD

"Man is neither angel nor brute, and the unfortunate thing is that he who would act the angel acts the brute." - Blaise Pascal[1]

Abstract

The language of bioethics occupies a middle ground of meaning. Within this median of dispute and uncertainty, and central to nearly all questions facing medicine and society, is the meaning of dignity. The language of human dignity in particular has been criticized as vague and, therefore, useless as an operational criterion by which to formulate pragmatic agendas. In response, proposals to eliminate the long-cherished moral principle of respecting human dignity bear a greater burden of proof than do appeals to sustain it. In defense of a provisional understanding of dignity, definitions that elude precision may be appropriate for a people who live in the middle. Temporally, bioethics concerns people who live in the midst of an unfolding history. Philosophically, the significance of moral principles and the accumulated consequences of decisions are not yet fully known. An as yet incomplete understanding of human dignity represents an opportunity for discovery, not simply in abstraction, but in community.

In 2011 the *Oxford English Dictionary* declared its Word of the Year to be "squeezed middle." The term refers to "the section of society regarded as particularly affected by inflation, wage freezes and cuts in public spending during a time of economic difficulty, consisting principally of those on low or middle incomes."[2] Although "squeezed middle" lacks the precision of a scientific term, it captures a political mood and names a deepening economic anxiety. In an interview, lexicographer Susie Dent defended its vagueness, asserting that "Therein lies its power."[3]

Turning to the lexicon of bioethics, perhaps no word is more distrusted by some for its vagueness and cherished by others for its importance than "dignity."[4] Squeezed in the middle as well as at the beginning and the end of the lifespan, "human dignity," in particular, is a piece of language that draws ongoing controversy. "Dignity" can be variously interpreted, and as such occupies a provocative central position in contemporary bioethical discourse. However, this central position is not a middle ground between opposing viewpoints. Nor is the centrality of dignity equivalent to neutrality. More accurately, conflicting appraisals of dignity clash and collide over the sometimes-erratic pursuit of moral clarity.

Noting this lack of consensus, Francis Fukuyama takes an agnostic stance, writing that, "Human dignity is one of those concepts … that almost no one can either define or explain."[5] The lack of a universally accepted definition of human dignity does not, however, exclude the possibility that truth can be found in problem which dignity presents. The weightiest dilemmas seldom yield their answers easily.

Some bioethicists seek a shortcut to an understanding of dignity by simply proposing that the term be banished. Steven Pinker dismisses the concept of human dignity altogether and casts suspicion on anyone who appeals to it, alleging that such a term "springs from a movement to impose a radical political agenda, fed by fervent religious impulses, onto American biomedicine," and adding that 'dignity' ought to mean "just another application of the principle of autonomy."[6] Similarly, Ruth Macklin argues for disposing of the concept of dignity altogether, writing that it is "a useless concept in medical ethics and can be eliminated without any loss of content."[7]

However, other bioethicists appreciate in the words "human dignity" a larger meaning. C. Ben Mitchell and colleagues maintain that the meaning of dignity is not reducible to respect for persons or their autonomy. "Rather," Mitchell and colleagues affirm, "it is the basis for why such respect is warranted."[8] Drawing attention to its further aspects, Gilbert Meilaender emphasizes the human qualities of embodiment, purpose and self-sacrifice, adding that the effort to reduce dignity to autonomy "assumes that freedom is the sole truth about human beings and this reduces the complexity of our humanity."[9]

Some of the most profound articulations of human dignity have come from religiously informed perspectives. Richard John Neuhaus writes that the concept of human dignity has been sustained by "a form of understanding that is carefully reasoned, frankly moral and, for most people who affirm it, is in fact, if not by theoretical necessity, inseparable from a comprehensive account that is unapologetically acknowledged as religious."[10]

Respect for human dignity is not, however, a principle that belongs exclusively to religious thinkers. Secular and pluralistic organizations have also embraced the language of human dignity. The drafters of the United Nations Universal Declaration of Human Rights, who represented diverse cultural, intellectual and ideological perspectives worldwide, stated in unity 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."[11] In the United States, the President's Council on Bioethics affirmed the primacy of dignity while distinguishing it from autonomy. Chair of the Council Edmund Pellegrino decisively asserted:

> Humans possess autonomy because of their intrinsic dignity; they are not dignified because they are autonomous. Holocaust victims did not lose their dignity or the rights that it entailed because they were despoiled of their autonomy. Nor do infants, the comatose, or the brain-damaged lack dignity because they are not fully autonomous.[12]

Explanations of human dignity have elaborated its meaning both positively and negatively. Positive assertions recognize something unique about humankind that is distinct in degree and kind from all other animals. This includes, but is not limited to, the cognitive capacities for abstract language, moral awareness, engagement in scientific investigation, and a longing for ultimate meaning. Within the Judaic and Christian traditions, recognition of human dignity derives also from the biblical teaching that all human beings are created in the image of the Creator.[13,14] Mitchell and colleagues expound that, "if there is a God who establishes a special relationship with human beings that confers special worth on them, all people may be said to have a dignity that is distinctively human."[8] Moreover, the concept of human dignity has also, according to

Neuhaus, been "defined negatively against the background of evils to which the [United Nations] declaration says, in effect, 'Never again!'"[10]

Meilaender contributes a helpful further distinction. With Solomonic wisdom, he divides what he calls "human dignity," which "has to do with the powers and the limits characteristic of our species," from "personal dignity," which has to do with the equal worth of individual persons, "grounded not in any particular characteristics but in the belief that every person is equidistant from Eternity" and "whose dignity calls for our respect whatever his or her powers and limits may be."[15]

The diverse perspectives on dignity, from Pinker, who would banish the word, to Pellegrino, who defends it as being crucial to ethics, span the spectrum of viewpoints on a wide range of issues in bioethics. Wisdom in articulating conceptualizations of human dignity in the public square requires an attitude of humility that respects the deeply held views of other healthcare professionals and bioethicists who may disagree.

In balancing the need for a common language with the fact that people hold diverse, and sometimes irreconcilable, perspectives, inclusivity is preferable to exclusion. Those who are uncertain of the validity of human dignity must consider whether its exclusion or inclusion in decisions affecting individuals and society would be the best path to human flourishing. Like the scientist who hastily dismisses inconvenient facts and arrives at a faulty theory, the bioethicist who disbelieves in human dignity may point medicine down a perilous road.

There are many possible reasons why well-intentioned people would disagree on fundamental questions such as the meaning of dignity. People differ in their life experiences, which is why seeking to understand, or at least respect, the views of others who have encountered circumstances in life that are different from one's own is so important. People differ in their likings and dislikings, desires and loyalties, as well as in their commitments to teachings received through reading, lectures, the media, or handed down through tradition.

People differ also in the neurobiology of their thinking. A number of familiar examples illustrate the point. Some people are gifted in the arts more than the exact sciences. An artist who is able to paint breathtaking landscapes may struggle to understand advanced mathematics. One thinks mainly in words, while another imagines pictorially. Someone with amazing athletic talent might win at Wimbledon, yet struggle unsuccessfully to pen a novel. Still another may have the skills to manage a business and encourage teamwork but might not be suited for a career in music. These talents and skills correspond to both innate and learned brain processes.

Taken to a further level, people differ in their capacities for appreciating color, comprehending size and proportion, remembering detail, experiencing anxiety, and discerning the mental states of others. Some are bewildered by facial expressions displaying emotion. Others lack adequate language to express their own emotions.

Functional magnetic resonance imaging (fMRI) is elucidating some of the specific brain structures involved in the capacities for moral reasoning. Preliminary fMRI studies have suggested that damage to the ventromedial prefrontal cortex, which is a brain region involved in social emotions, results in a bias toward making utilitarian judgments over judgments based on moral duty.[16] Other researchers have investigated the neural correlates of decisions based on sacred values, finding that fMRIs performed during experimental paradigms that call upon moral norms show increased activity in the left temporoparietal junction and ventrolateral prefrontal cortex, which are brain regions associated with semantic rule retrieval.[17] Studies such as these add pieces to the puzzle of moral reasoning, the neuropsychological models of which are still incomplete.

What is clear from current science is that people differ in their approaches to moral reasoning. If human nature is such that people differ in their capacities for empathy and awareness of moral norms,[18] then it follows that people might also, no matter their level of general intelligence, differ in their capacity to comprehend the meaning of human dignity. To the strictly utilitarian mind, dignity may seem an imprecise concept, not very useful to the calculus that knows only the weighing of pleasure against pain and benefit against cost. To the deontologic mind, by contrast, dignity stands out as plainly as the sun on a clear day and signifies a reality about human life that ought to be held inviolable.

There is no simple middle perspective between the voices of Pinker and Pellegrino, no mediocre depiction of human dignity, cast in an intermediate shade of grey, that would satisfy the demands of both. Human dignity, although central to bioethics, is unlike Aristotle's golden mean, which is defined as the virtuous middle between two unacceptable extremes, one of excess and the other of deficiency. Human dignity is not something halfway between, say, righteousness and depravity in the way that courage may be defined as an attitude midway between recklessness and cowardice. If dignity merely a golden mean between vulgarity and saintliness, then one would have to accept as reasonable the notion of a socially desirable mild stench. Such logic would also find fault with anyone thought to have too much personal integrity.

Dignity, the middle word in bioethics, lies somewhere in between the first and the final words. It is not the first word because it derives ontologically from a source that is unknowable, at least directly, through what the senses can detect in the world. Dignity is not the last word in bioethics because it invites questions rather than stopping conversation. It has origins and purposes that exceed the capacity of bioethical language.

Viewed in the context of the present, human dignity appears vague, as if seen through a glass darkly.[19] However, when it is considered alongside recorded history the outline of human dignity appears more distinct, where it has triumphed and when it is has been violated. Contemplated with the endpoints of history in mind, human dignity transcends the present. Accepted through faith, human dignity awaits a final pronouncement that will redeem its failures and make indisputable sense of the terrible tribulations of history. In order to understand human dignity, it is necessary to learn from the past and anticipate the future. It is interesting to note that the cognitive capacities for memory and foresight share some of the same brain circuits.[20]

Dignity is also the middle word in bioethics because it is relational. Dignity is not solitary, but rather something a shared element. People in the middle of life sometimes must make decisions on behalf of those at life's beginning or end, recognizing that one has been or will be as they are.

Dignity, finally, acts as the middle word in bioethics because a complete understanding of its significance is provisional. History, society, individual lives, scientific theories, and ethical frameworks are all works in progress, and human dignity is in the middle of it all. It is the moral emblem of a universal human condition that, although fraught with foibles and failures, reaches beyond itself. Human dignity, in this respect, is not a static equilibrium but a dynamic entity, ever in transition, learning and discovering.

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CLINICAL ETHICS DILEMMA

HOW SHOULD THE MEDICAL TEAM RESPOND TO A PATIENT'S REQUESTS?

JAMIE CAUDILL, MD, GREGORY W. RUTECKI, MD

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 situation, some details have been changed in the effort to maintain confidentiality. In this case, the medical team struggles with the family and patient request that all services be provided in the face of a lethal condition.*

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Question

Is it the role of the medical team to dissuade a patient from demanding non-curative medical treatments in an eminently lethal condition?

Case Presentation

A 37-year-old man with Autoimmune Deficiency Syndrome (AIDS) was admitted to the hospital for an altered mental status. Extensive workup revealed a disseminated *M. avium* intracellulare complex infection (primarily a lung infection that spread to other parts of the body). Appropriate treatment was initiated. The patient was not taking antiretroviral medications and his CD4 count was remarkably low, indicating a very severe AIDS infection. The hospital course was extraordinarily stormy, as the patient became septic from a resistant bacterium and suffered a heart attack after being in heart failure. Subsequently, as a result of the multiple comorbid conditions, he developed irreversible renal failure that required dialysis three times a week. Because of his antibiotic coverage he developed pseudomembranous colitis (a severe intestinal complication) and was intubated and made temporarily ventilator-dependent. Ultimately, a tracheostomy was placed. He experienced terrible wasting (deteriorating physical appearance and weight loss) though, on multiple occasions, he declined nutritional support and refused to eat. During the worsening hospital course he began to refuse medications (including antidepressants), subsequently refusing additional diagnostic and therapeutic procedures. The physicians suspected that he desired palliative care and fewer procedures. When asked about his end-of-life wishes, he said that he desired a "full code." Physicians reviewed his dismal prognosis with him and, despite the information they provided, in the event of medical deterioration he requested a battery of drugs, IV fluids, defibrillation, and mechanical ventilation. However, he refused chest compressions. The resident physicians requested an ethics consultation to assist in end-of-life planning and medical treatments.

The ethics consultants spoke to the patient and his family: consisting of a fiancée (who was aware that he had AIDS) and his mother. Apparently misunderstanding his dismal prognosis, they agreed with the patient's wishes. The ethics consultants met with the patient and family on an ongoing basis in order to educate them about both the reasonableness and prognosis related to "code" interventions in his terminal situation. Thus far, the patient has not changed his wishes.

Discussion

The ethical issues and content were framed for the resident, and part of the process was a review of recent editorials from *The New England Journal of Medicine* identifying the importance of end-of-life decision-making in both patient-centered and societal contexts.[1, 2]

The authors of one article lamented the inability of medical education to train young physicians to lead a compassionate end-of-life discussion. A recent survey demonstrated that only about 30% of medical residents feel comfortable leading such a discussion. In fact, many residents have not even had the opportunity to witness an experienced physician direct an end-of-life medical discussion. To that end, the authors suggest a change in approach, towards one that only offers a patient medical interventions that are reasonable based on their prognosis. Some even suggest that more open-ended questions should be replaced with stronger suggestions to limit invasive resuscitative procedures that have little likelihood of success. This is why they (the authors) suggest that unfettered autonomy is unfair to patients [ed.: and inappropriate for the medical system].

In another article, the authors recount the societal costs of unnecessary interventions in the light of the realization that 30% of the medical budget is waste [ed.: care that likely will not benefit or correct the medical condition, and which will likely add to the pain and suffering of the patient or family]. In the specific patient being discussed, ventilator intervention followed by intensive care will not significantly impact longevity

Denouement

The Ethics Committee met with everyone involved in this patient's care—the patient himself, his family and fiancée, in addition to the primary care team and consultants—iteratively on multiple occasions. The committee suggested both re-evaluation and institution of clearly defined milestones (medical treatment goals) over short time frames. The patient and family agreed to continue aggressive therapy, pending a trial of Antiretroviral Therapy (ART) to determine whether the AIDS infection could be successfully treated. The CD4 count did not improve with appropriate therapy. Everyone was apprised that the primary disease was incurable. The patient and his family agreed to forego any resuscitative attempts; however, he desired to continue renal dialysis. Approximately a week later, the patient became confused, struck nurses, and tried to pull out his dialysis needles. His family was asked if they thought his behavior reflected his desire to withdraw dialysis and die. They affirmed, saying that they sincerely thought the patient's recent behavior was indicative of this medical preference. Dialysis was discontinued, and the patient died quietly about 72 hours later in the presence of his family and fiancée.

Medical Attending Comment

The patient and family should be counseled about end-of-life medical therapeutic options, being told the risks, benefits, burdens and appropriateness of these modalities. It is the responsibility of the medical staff to present medical treatments as options of a properly discussed medical plan, and not as options granted through vicarious autonomy. Therapeutic goals and medical parameters for treatment options should be identified and placed early in a patient's clinical course.

The patient, the family, and the medical team should be apprised of the patient's care, medical prognosis, and end-of-life decision-making through iterative revisits, thus allowing them the benefit of a better understand of the medical prognostic indicators.

Editor's Comments

End-of-life recommendations are often not only difficult to recommend, but difficult to receive. The patient and family desire to be heard and understood, while the medical staff desires to be trusted and believed. These worldview goals often come into conflict with each other, and resolution is often problematic. Frequent discussion is often helpful, and setting time-based trials with identified expectations can often help to progress the decision-making. Integrity and truth-telling is paramount, and the medical team must abide by the fiduciary responsibility.

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A CASE AGAINST GERM-LINE GENE THERAPY

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Is germ-line gene therapy acceptable in order to avoid the maternal transmission of mitochondrial disease? Yes, says the UK think tank, the Nuffield Council on Bioethics. The Council's endorsement of the technology is declared in its recently published report, *Novel Techniques for the Prevention of Mitochondrial DNA Disorder: An Ethical Review*, which was launched at a meeting in the Houses of Parliament on 12 June 2012. It should also be noted that the Human Fertilization and Embryology Society (HFEA) launched a public consultation in September of 2012 asking the public what it thinks about germ-line gene therapies that allow mothers with a mitochondrial disease to give birth to children free of the disease.

Of course, there is nothing intrinsically wrong with parents, or society, wanting healthy children. However, the traditional aim of medicine in the Hippocratic and Christian traditions is one of healing or, if such is not possible, the alleviation of symptoms. Such traditions are both patient-centered and pro-life. The traditional Hippocratic Oath does not permit killing and so, along with Christian ethics, does not allow abortion. Indeed, a Christian and Hippocratic view of medicine cannot allow the killing of human life at any stage, nor can it be selective in its welcome of the patient. Rather, A Christian and Hippocratic view must be respectful of the patient, regardless of age, gender, social status, or ethnic origin. This, as I see it, is what constitutes good medicine. According to this Hippocratic and Christian mold of medicine there are limits to what should or should not be done.

For those who embrace this tradition of medicine, such affirmations beg the question: to what length should parents and the medical profession go in order to promote the births of healthy children? When faced with new technologies such as germ-line gene therapy we must ask ourselves whether or not such technologies are compatible with our understanding of medicine as a healing profession.

At present, the medical profession is helping parents and society to 'weed out' unborn children with certain conditions. According to our understanding, such action is beyond the remit of medicine as a healing profession. Nevertheless, the practice of prenatal testing to avoid the births of children with certain conditions has become institutionalized. There exists in both America and the UK what might be described as a soft and liberal practice of negative eugenics. In other words, though parents are not forced to avail themselves of prenatal diagnosis, and even less is any pregnant women in the Western world mandated to undergo a termination of pregnancy to avoid the birth of a child diagnosed with an adverse condition, they are, arguably, subjected to a soft pressure to avoid the births of children with conditions such as Down's syndrome. Society and parents are not offering every child and unconditional welcome. In addition, many members of the medical profession are cooperating in this practice of selective welcome.

This observation should serve as a warning to anyone belonging to the Hippocratic school of medicine. What the Nuffield Council suggests is that women with a mitochondrial disease should be offered the choice of germ-line gene therapy in order to avoid transmission of the disease. This, I fear, could take us down the path to liberal positive eugenics; that is, choice and selection by way of taking measures to have children with the traits that we most want them to have.

Arguing that the UK has strict laws in place to regulate reproductive technologies and that British scientists are at the fore-front of the fields of embryonic stem-cell research and cloning techniques, the Nuffield Council feels that the UK is well placed to be the first country (or one of the first countries) to introduce germ-line gene therapy for humans. I say "for humans" because experiments with animals have already taken place, both in America and elsewhere.

No doubt many people would welcome the prospect of germ-line gene therapy. Mitochondrial disease is incurable and can be fatal. Caused by faulty genes in the mitochondria, the tiny organelles within human cells that produce the cell's energy, and transmitted from mother to child with the mitochondria in the maternal egg, the symptoms of mitochondrial disease include, among other things, loss of motor control, muscle weakness, pain and problems with digestion, difficulties in swallowing, impaired growth, heart problems, and blindness. According to the UK's Human Fertilization and Embryology Authority (HFEA), approximately 1 in 5000 babies are born with mitochondrial disease. Thus, in the UK alone 160 babies a year are born with such diseases.

The UK would need to alter its current regulations before such germ-line gene therapy could be legalized, for this form of therapy is presently forbidden in the UK in any capacity other than for research. However, a clause in the HFE ACT 2008 grants to the Secretary of Health the power to make an exception for germ-line gene therapy that would overcome maternal transmission of mitochondrial disease. This demonstrates just how eager UK scientists are to begin experimenting with germ-line gene therapy.

The Nuffield Council report suggests two types of germ-line gene therapy techniques that could be used to avoid maternal transmission of mitochondrial disease. Both are similar to the cloning technique used in embryonic stem-cell research when the cell nucleus from an adult cell, such as a skin cell, is transferred to an enucleated egg, thus creating an embryo that is virtually genetically identical to the person whose skin-cell nucleus was used. The only genetic difference between the embryo and the more mature individual is that the embryo carries mitochondrial genes from the donor egg, genes that are different from the mitochondrial genes of the more mature individual.

Now, we know that most of the DNA in a newly fertilized embryo is situated in the two pronuclei, one from the maternal egg and one from the paternal sperm, and that only a small fraction of the embryo's DNA comes from the mitochondria in the maternal egg. Thus, the aim of the suggested germ-line gene technologies is to create embryos free of faulty mitochondria, but with pronuclei DNA from women with mitochondrial disease. However, it is argued that such action would make this woman, the woman with the mitochondrial disease, the true mother of the embryo—and so of the child-to-be.

One of the envisaged techniques to avoid maternal transmission of mitochondrial disease would involve the transfer of the maternal and paternal pronuclei of an embryo with unhealthy mitochondria to one with healthy mitochondria—but only after the healthy embryo's maternal and paternal pronuclei had been removed. The result would be a "combi-embryo," an embryo with two genetic mothers and one genetic father that would be free of mitochondrial disease. The true genetic mother, so the Nuffield Council argues, would be the woman with the mitochondrial disease, for she provided the 'combi-embryo's' pronucleus DNA.

Of course, both the healthy embryo (created by IVF using a donated egg and, probably, sperm from the partner of the woman with the faulty mitochondria) and the embryo with defective mitochondria (created by IVF using an egg from the woman with the disease and sperm from her partner) would perish. That the two original embryos would be destroyed is not a matter of no concern to the Nuffield Council. It is, however, a matter of grave importance for anyone who considers that human life begins with the process of fertilization.

The alternative technique, called maternal spindle transfer, involves removing the cell nucleus of an unfertilized egg from a healthy woman and replacing it with the cell nucleus from the woman with faulty mitochondria. The technique gets its name from the fact that the cell nucleus of an unfertilized egg is found in the spindle-like structure at one side of the egg. The result of the maternal spindle transfer is a "combi-egg" with healthy mitochondrial genes. The egg can then be fertilized in vitro, thus allowing the woman with mitochondrial disease to have a baby free of the disease. No embryos are destroyed in this case but, again, the baby would have two genetic mothers, the true mother—so it is argued—being the one with mitochondrial disease.

However, both techniques raise questions about the status of the egg donor. The Nuffield Council advises that current UK law which regulates egg and sperm donation should be inapplicable in the case of germ-line gene therapy to avoid maternal transmission of mitochondrial disease. Presently, on reaching the age of 18, the child created by egg or sperm donation in an HFEA licensed clinic has a legal right to discover the identity of the donor. The Council's argument for its recommendation lies in the fact that the only things the child inherits from the egg donor are mitochondrial genes.

By way of comment, mitochondrial genes could be used to trace one's genetic and ethnic origins thousands of years back. These genes would link the child to its maternal origins on the side of the egg donor! Surely, such information suggests that the maternal input on the part of the donor is far from negligible.

There is also a major question of safety implicit in a discussion of this new germ-line gene therapy. It is far from certain that the mitochondrial genes from the egg donor are compatible with the DNA of the woman with mitochondrial disease. Moreover, the envisaged techniques to avoid maternal transfer of mitochondrial disease are, effectively, types of reproductive cloning; and we know that this is far from safe. Animal reproductive cloning often results in malformations and even death. Undeniably the first attempts at using either of the suggested techniques would be experimental. This raises the question of whether it would be morally justifiable to subject a child—and its parents—to the risks involved.

Germ-line gene therapy is illegal in the UK–as in most countries that legally regulate gene therapy—precisely because it is considered to be too risky. Unless the techniques have been thoroughly tested and perfected, the first-generation of individuals created with their help would clearly be in danger. Equally, such therapies would prove risky for any offspring of the first-generation individuals. Heritable mistakes could be passed on, especially because mishaps surfacing in the first generation might not manifest themselves until the individual is an adult, by which time the problem may have been passed on to the next generation.

More important still, once one kind of germ-line gene therapy is accepted, other kinds will almost certainly follow. The Nuffield Council seeks to refute the observation that granting permission to germ-line gene therapy to avoid mitochondrial transmission could be the start of a slippery slope. They claim that strict regulation could be put in place to avoid such an occurrence. But once germ-line gene-therapy has been given the green light, in principle, it difficult to see why these therapies would not be tried in order to overcome a variety of diseases.

However, the major concern with the prospect of a slippery slope is not related to the physical risks of germ-line gene technologies, but rather the social and anthropological consequences. The enormous progress in genetics that has occurred in this century and the last has promoted the belief that our genes determine nearly everything about us as individual humans. Yet, attributing all of our most human characteristics or conditions, both mental and physical, to genes underestimates the importance of other brands of cause and explanation for these traits. This is demonstrated by multifactorial human illnesses and physical traits, such as height, which might be partly related to diet. The importance of causes other than those of genetics is undoubtedly even truer in the case of intellectual skills and other personality traits and behavioural characteristics.

Danger lies in overestimating the extent to which we are genetically determined. Belief in genetic determinism could result in an overriding emphasis on ensuring that children have good genes. As a consequence, the traditional emphasis on good parenting and education could become less important. We must not overestimate nature at the expense of nurture. No technological fix can replace good parenting and good education.

That said, we must also beware of underestimating the importance of our genes. The tendency to "geneticize" might promote hubris and "Promethean" aspirations, with all of the social and moral dangers that such aspirations involve. Equally, the tendency to underestimate the importance of our genes has already led to the creation of new family types that prioritize the adults and lend little thought to the good of the child. Egg donation, for example, creates children with two genetic mothers. Fears have been expressed about the psychological effects that such a parental makeup has on children. Sperm donation has long been a part of our society, and there are at least anecdotal stories of the ill effects that such technology has on family relationships. What *is* certain, however, is that children are increasingly being treated as a commodity, created to satisfy adult desire, rather than being accepted as gifts from God and nature.

Both the tendency to overestimate the importance of genes and to underestimate them can lead to commodification of the child. Such commodification is morally and socially objectionable because it both depersonalizes another human and constitutes an unjust domination of man over man. Commoditization represents a denial of the child as one of us, an equal in human dignity. Thus, in addition to the medical risks involved, there are objections to germ-line gene therapy along the lines voiced by C. S. Lewis in *The Abolition of Man*. Warning that human nature is the last part of nature to be subject to human domination, Lewis notes that "the power of man to make himself what he pleases means… the power of some men to make other men what they please".[1] In other words, our new technologies might be developed in the hope that they will constitute progress in the service of humankind, but we should be aware that they may also tempt us to assume undue power over the next, and subsequent, generations.

The risk, then, is that germ-line gene therapy, like prenatal testing with a view to selective abortion, could become a tool for the service of liberal eugenics. It should also be noted that it might one day be possible to use somatic gene therapy for the treatment of those born with genetic diseases such as cystic fibrosis or thalassaemia. Healthy genes could be transferred to the patient with a view to alleviating symptoms or healing the patient. Such therapy would be uncontroversial once proven to be safe, for it would treat the affected individual only. This would be in line with conventional medicine. It would not constitute a failure to welcome the person or patient as he is. Such therapy would not fail to recognize the gift of life. There would be no question of "to be, or not to be," as in the case of prenatal diagnosis and selective abortion, and as there would be in the case germ-line gene therapy that ensures that a child is born either with or without particular characteristics.

My concern is for the treatment of children-to-be, for the relationship between generations. I fear that once we give the green light to germ-line gene therapy as a means of overcoming one particular kind of genetic imperfection, it will soon be used in the search to overcome many more and that, eventually, it could come to be used in the same spirit as prenatal diagnosis with a view to selective abortion. Just it is often suggested that bringing a Down's syndrome child into the world when it could have been avoided is irresponsible, in the future those who fail to avail themselves of germ-line gene therapy might be castigated for being irresponsible. Moreover, if parents feel that it is their duty to produce only a perfectly healthy child, they will not easily accept whatever is given to them, either by God or by nature. A less-healthy child, who fails to live up to expectations, would risk being shunned or even discarded *post partum*.

In short, if germ-line gene therapy were to become routine in the way that prenatal diagnosis presently is, it would lead to an ever-increasing failure to give the child an unconditional welcome. Germ-line gene therapy, when used to produce the perfectly healthy child, runs the risk of becoming a tool used to complement prenatal testing with a view to selective abortion. Liberal positive eugenics that involve a failure to welcome the child unconditionally would be no less a concern than liberal negative eugenics. Any form of eugenics involves discrimination based on the view that some individuals are either unwelcome or less welcome than others. Eugenics, in whatever form it takes, means usurping powers over the lives—and deaths—of others, while failing to recognize our creaturely limitations and the fact that true perfection is not of this world.

The traditional remit of medicine is that of healing and, if healing is impossible, the alleviation of painful or debilitating symptoms. Inherent in the traditional Hippocratic ethos of medicine is a fundamental respect for and acceptance of the individual, whatever his medical state. This respect applies to the unborn child as well as to the adult. Eugenic aspirations to genetically modify future generations in order to eliminate perceived diseases or weaknesses would, like all eugenic aspirations, both reflect and promote the view that some individuals are less human than others and that some lives are not worth living.

Not content to unconditionally accept the child-to-be as a gift, we are, it would seem, increasingly on a quest for the perfect child. This quest has often been aptly described as an attempt to play God. As such, eugenics represents an attempt at unreasonable domination over nature. Speaking in Christian terms, the quest for the perfect child represents hubris and, therefore, a sin against God. Of course, in a secular world this means little. If you do not believe in God, you will not recognize life as a gift from God. Nor can you recognize the image of God in your fellow human and neighbor. If you do not believe in the incarnation, you cannot see the dignity bestowed on humankind when God united Himself with us in Jesus, the Son of man and woman. And, unable to see in children as the image of God and a neighbor upon whom God has bestowed a special dignity because they are human, you might be tempted to treat them instrumentally, and to measure both their worth and their right to life in terms of social standards or even your own subjective criteria. These, then, are my fears with respect to germ-line gene technology were it to become routinely placed in the hands of a technocratic and secular world.

Before embarking on germ-line technology as a supplement to prenatal diagnosis with a view to selective abortion, we should consider the kind of society in which we would like to live. None of us is perfect and invincible. Some infirmity will, sooner or later, affect those of us who are lucky enough to grow old. Many of us would feel ill at ease in a society that fails to welcome the infirm and the disabled. Moreover, suffering might teach us better to co-suffering with others. It might help us to become more tolerant, more helpful, and more understanding of people who need us or who are looking to us for friendship, companionship, and sympathy. As Christians, we are called to love our neighbors.

In affirming these things, however, we are not saying that medicine should give up healing and stop fighting disease. Of course, disease is not a good in itself—nor is suffering. Nevertheless, disease and suffering can serve as means by which we can become better people and can give us an opportunity to, like the Good Samaritan, show neighborly love to others. By treating the infirm and injured as individuals to be cherished and cared for, we recognize them as a people like ourselves. In doing so, we can act and react as their neighbors.

Furthermore, we should accept that it is not in our power to eradicate all disease and human frailty. Frailty and death are part of our human and creaturely condition. To allow for imperfection is, therefore, to accept our mortal, creaturely nature. The use of technology may indeed be regarded as a response to the Genesis command to till and keep the land (cf. Gen. 2:15). Such is only the case, however, insofar as we use technology in ways that show a love of God and of neighbor. Conversely, the fear inspired by germ-line gene therapies is that, in societies permeated with a secular and consumerist ethos, scientists and politicians might be tempted to exceed the limits of reasonable domination over human nature and, thus, over future generations.

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Conscience and Competing Liberty Claims

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Abstract

Some treatment requests from gay patients seriously conflict with the religious or moral beliefs of their respective medical providers. Not all legal solutions to these disputes serve the common good. Therefore, this article proposes that state healthcare conscience protection statutes provide the most effective way to resolve these liberty conflicts and to serve the medical needs of all patients. Part one of this manuscript showcases four clinical scenarios that illustrate how a clash of liberty claims between homosexual patients and their respective clinicians could play out within today's healthcare setting. Part two describes the centrifugal legal forces that are shaping judicial opinion to favor sexual liberty interests over religious conscience concerns. Part three argues for a tri-phasic political solution. We encourage healthcare providers: (1) to present their state legislators with a conscience primer—reasons why, as legislative guardians of the common good, they need to care about conscience protection for healthcare professionals; (2) to prevail upon their legislators to sponsor and enact robust state healthcare conscience protections; and (3) to dialogue with the gay community and their advocates, making the case that, first, diversity of the marketplace is the most effective way to match the diverse needs of all patients and, second, a dialogical, rather than a coercive, method of accessing care is the best way to serve the good of all.

Introduction

This discussion investigates emerging conflicts in what could become a second cycle of healthcare conscientious objection. The first round, following *Roe v. Wade*, continues to involve religious healthcare providers in conscientious objection to abortion, contraception, and sterilization, and is directed toward the protection of the basic human goods of life and procreation. The second round follows both the legalization of sodomistic sex[1] and same-sex civil unions[2] and the introduction of sexual orientation nondiscrimination statutes that apply to public accommodations[3]. This new legal landscape will impel these same healthcare professionals to defend the basic goods of marriage and family as they conscientiously decline services that directly facilitate patients' same-sex relations or homosexual parenting.

Part One: Clinical Cases

In states with sexual orientation public accommodation laws, homosexual patients are given unfettered access to all public services, including healthcare. Against this legislative backdrop, the following clinical scenarios realistically illustrate how conflict between the sexual liberty claims of homosexual patients and the religious liberty concerns of their respective medical professionals could arise.

Case #1[4]:

A woman in a homosexual relationship seeks treatment from a gynecologist for endometriosis and polycystic ovaries. Once these pathologies are successfully resolved, the patient returns to the gynecologist and requests Clomid to stimulate her ovaries. The clinician insists that, although she has no moral reservations about improving the woman's health and wellbeing by treating her gyn-abnormalities, she does have a moral objection to providing Clomid. The physician explains that, since the only goal of giving Clomid would be to help the patient conceive a child, doing so would make her morally complicit in facilitating a pregnancy outside a heterosexual marriage and in depriving the child of the complimentary parenting of a mother and a father. Since providing the drug contradicts her religious convictions about the meaning of marriage and family, the physician advises the patient to seek the help of another gynecologist.

Case #2[5]:

A male patient seeks help from his internist for problems related to erectile dysfunction. Since the patient is no longer able to have satisfying sex with his male partner, he requests that the doctor write a prescription for medication that will address this problem. The physician explains that, although she is willing to treat the underlying health conditions that may be contributing to his erectile dysfunction, she cannot in good conscience write a prescription for a drug that would directly facilitate sex outside a heterosexual marriage. For this reason, she suggests the patient find another physician to help him meet his objective.

Case #3[6]:

A male client seeks psychological counseling for emotional issues pertaining to his sexual relationship with his male partner. The clinical psychologist explains to the client that she has no issue with helping him improve his psychological health, including resolution of emotional conflicts. She considers it a matter of professional and moral responsibility to provide sound counseling services irrespective of the client's sexual orientation. Nonetheless, the psychologist carefully delineates that to which she *would* object: providing counseling services with the direct goal of affirming the man's sexual relationship with his male partner. Since such affirmation fails to comport with her deeply held beliefs and moral values, the clinician informs the client she cannot effectively counsel him. When the client takes exception to her reservation, the counselor advises the man to seek the services of another clinical psychologist who may be better equipped to help him with these problems.

Case #4[7]:

A gravely ill patient arrives in the ICU suffering from liver failure. Knowing that death is near, he asks the attending physician to facilitate his marriage to his life-long same sex partner. The patient requests that the physician apply for a civil union license at the county clerk's office and then proxy-sign the license on the dying patient's behalf. The physician explains that, although she is willing to provide quality care in the ICU, she cannot conscientiously comply with the patient's extra-medical request, as her proxy signature would directly facilitate a same-sex union. The attending physician asks to be relieved of the case.

Although the four clinical scenarios involve different facts, they share some common characteristics. The patient in each scenario requests non-emergent assistance to achieve a result that is permitted by law. The professional is arguably competent to provide the services and presumably offers them willingly to other patients. However, she chooses not to offer treatment to the homosexual patient in order to avoid direct cooperation in actions that violate her conscientious beliefs regarding marriage and family. The professional accurately presents the medical options available to the patient, honestly and clearly discussing the basis for her refusal to provide the service.[8]

It is assumed that each clinician's counseling approach and decision not to provide treatment is consistent with the ethical obligations imposed by the applicable state licensing board, as well as any other board or organization to which the medical professional may belong.[9] But, will such refusal subject her to civil claims because she is allegedly discriminating against the patient based on his/her sexual orientation?

The answer to the civil liability question depends on where the treatment refusal takes place. If these cases were to occur in California, a decision of the California Supreme Court[10] allows us to reasonably predict that a patient-initiated lawsuit would likely favor the homosexual plaintiff against the conscientiously objecting healthcare professional. Although claims from homosexual patients in other jurisdictions with sexual orientation public accommodation laws (including Connecticut, Hawaii, Illinois, Iowa, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New Mexico, New York, Oregon, Rhode Island, Vermont, Washington, Wisconsin, and Washington, D.C.)[11] have not yet been similarly adjudicated, conscientious healthcare professionals have reason to be concerned.

Part Two: Why Healthcare Rights of Conscience (HCROC) Are an Endangered Species.

The Constitution Cannot Fully Protect HCROC.

Our nation has a long history of crafting legislative solutions for conflicts between laws of general application and the conscientious religious beliefs of minorities who are affected by them.[12] While utilitarian considerations played a role, our Constitutional tradition of religious liberty—and its foundational doctrine that there is a higher authority than that of the State—most fully explain our history of legislative protections for conscience.[13]

Nevertheless, a healthcare provider has limited constitutional protections. It is true that the First Amendment expressly constrains the government from enacting laws that infringe upon the free exercise of religion.[14] However, as the Supreme Court's decision in *Smith* indicates, state laws that impinge upon religious liberty may nevertheless be valid.

In *Employment Division v. Smith*,[15] the Supreme Court considered a conflict between state law and the religious freedom of Native Americans. The claimants ingested peyote for sacramental purposes at a religious ceremony of their Native American Church. Their employer dismissed them for illicit drug use. After being denied the unemployment compensation for which they applied, the claimants sued the state. In their decision, the Court noted that "the 'exercise of religion' often involves not only belief and profession but the performance of (or abstention from) physical acts."[16] If a state law bans acts or abstentions only for the religious belief they display—such as casting an idol or refusing to bow in worship—then such a law would violate the First Amendment.[17] Yet, First Amendment protections are less robust when the law prohibits conduct that the state is otherwise free to regulate—such as the use of an illegal drug. As the Court argued, "We have never held that an individual's religious beliefs excuse him from compliance with an otherwise valid law prohibiting conduct that the state is free to regulate."[18]

The Court opined that "the right of free exercise does not relieve an individual of the obligation to comply with a 'valid and neutral law of general applicability on the ground that the law proscribes (or prescribes) conduct that his religion prescribes (or proscribes).'"[19] Although the counsel for the plaintiffs argued that this law should be evaluated under a balancing test set forth in *Sherbert v. Verner*,[20] the Court rejected this more rigorous standard:[21]

> The government's ability to enforce generally applicable prohibitions of socially harmful conduct, like its ability to carry out other aspects of public policy, "cannot depend on measuring the effects of a governmental action on a religious objector's spiritual development." To make an individual's obligation to obey such a law contingent upon the law's coincidence with his religious beliefs, except where the State's interest is "compelling"—permitting him, by virtue of his beliefs, "to become a law unto himself," —contradicts both constitutional tradition and common sense.[22]

Referencing the fact that some states had already enacted religious conscience protections, the Court advised that state legislatures were the appropriate source for these protections.[23] Nevertheless, the Court was quick to point out that once you assign conscience protections to the care of legislators, you risk the possibility that the religious beliefs of minorities will be trumped by the resolve of the majority. This, the court declared, is the price we pay for democracy:

> It may fairly be said that leaving accommodation to the political process will place at a relative disadvantage those religious practices that are not widely engaged in; but that unavoidable consequence of democratic government must be preferred to a system in which each conscience is a law unto itself or in which judges weigh the social importance of all laws against the centrality of all religious beliefs.[24]

The decision in *Smith*, then, does not necessarily support the religious liberty of conscientiously objecting healthcare professionals against claims based on state sexual orientation public accommodations law. Without an exemption for moral or religious conscience, the legislative preference for sexual liberty interests of homosexual patients would likely trump the providers' religious claims of conscience.[25]

Congress Cannot Fully Protect HCROC.

In 1993, Congress reacted to the implications of *Smith* by enacting, in bipartisan fashion, the Religious Freedom Restoration Act (RFRA).[26] The Act begins with the following Congressional findings:

> (1) the framers of the Constitution, recognizing free exercise of religion as an unalienable right, secured its protection in the First Amendment to the Constitution;
>
> (2) laws "neutral" toward religion may burden religious exercise as surely as laws intended to interfere with religious exercise;
>
> (3) governments should not substantially burden religious exercise without compelling justification;
>
> (4) in *Employment Division v. Smith*, 494 U.S. 872 (1990) the Supreme Court virtually eliminated the requirement that the government justify burdens on religious exercise imposed by laws neutral toward religion; and
>
> (5) the compelling interest test as set forth in prior Federal court rulings is a workable test for striking sensible balances between religious liberty and competing prior governmental interests.[27]

Accordingly, the Act provides, in part, that:

> Government may substantially burden a person's exercise of religion only if it demonstrates that application of the burden to the person—
>
> (1) is in furtherance of a compelling governmental interest; and
>
> (2) is the least restrictive means of furthering that compelling governmental interest.[28]

This restriction on government authority applies "even if the burden results from a rule of general applicability."[29]

However, in *City of Boerne v. Flores*,[30] the Supreme Court declared that RFRA was an unconstitutional exercise of Congressional power.[31] RFRA remains applicable to the Federal Government, but it does not apply to the states.[32] Therefore, to expand protections for free exercise of religion, some states enacted their own version of RFRA.[33] Most, however, did not. This means that the courts of forty states will be applying the jurisprudence of *Smith* to determine constitutional protections for citizens (like the healthcare providers featured in our cases) who are affected by statutes that otherwise qualify as "neutral laws of general application."

Congress might enact additional legislation to address conscience protections for healthcare services that are funded by payments from the Federal government.[34] For example, Congress is currently considering conscience protections for healthcare workers, employers, and insurers in connection with proposed amendments to the Patient Protection and Affordable Care Act.[35] While such provisions may be helpful, they provide limited protections grounded only in federal law. Moreover, these safeguards do not necessarily preempt state public accommodation claims, such as those raised by the homosexual patients in the cases under consideration.

Sexual Liberty Protections Threaten HCROC.

As the demographics of religious belief have changed, the idea of protections for conscience has expanded to defend other deeply held personal beliefs and decisions that are not strictly religious in character. The Due Process Clause of the Fourteenth Amendment has become a significant constitutional vehicle for defining a "substantive sphere of liberty"[36] that extends to a broad range of other decisions including prevention of pregnancy, sexual relationships, and abortion.[37] As the Supreme Court has observed:

> These matters, involving the most intimate and personal choices a person may make in a lifetime, *choices central to personal dignity and autonomy*, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. *Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State*.[38]

Although the judicial approach in *Smith* allowed state laws to prevail over competing religious liberty interests, the emerging judicial approach for sexual liberty claims would strike down conflicting state laws with increasing frequency. The liberal ideal of personal autonomy and radical individualism animates these outcomes. Consistent with the tenets of secular humanism, the Supreme Court expanded sexual liberty or "privacy" interests by striking down state laws that restricted access to contraception[39] and abortion.[40] The Court also removed legal proscriptions against private homosexual conduct between consenting adults,[41] thereby expanding the range of choices for citizens in matters of sexual expression. Despite Justice Scalia's admonition in *Smith* that legislatures, not courts, should weigh the social value of laws against the value of other beliefs and religious practices,[42] the Supreme Court chose to become actively engaged in this balancing enterprise anyway.[43]

It should be noted that the Court is not alone in expanding sexual liberty. State legislatures have also been instrumental in removing barriers to sexual freedom. For example, before the Court effectively struck down the remaining state sodomy statutes in *Lawrence v. Texas*, a substantial majority of states had already removed criminal sanctions for such conduct.[44] State courts and legislatures have also enacted statutes that legalize various forms of relationships between same-sex couples, extending the "approval" of the state toward such liaisons.[45]

State Sexual Orientation Public Accommodation Laws Threaten HCROC.

A recent California case ruled in favor of a lesbian patient who claimed sexual orientation discrimination because two physicians refused to provide intrauterine insemination to facilitate her pregnancy. In *North Coast Women's Care Medical Group, Inc. v. San Diego County Superior Court*,[46] the Supreme Court of California ruled that, under the Unruh Civil Rights Act, religious liberty did not protect the conscientiously objecting physicians from patient claims:[47]

> All persons within the jurisdiction of this state are free and equal, and no matter what their sex, race, color, religion, ancestry, national origin, disability, medical condition, genetic information, marital status, or sexual orientation are entitled to the full and equal accommodations, advantages, facilities, privileges, or services in all business establishments of every kind whatsoever.[48]

On the basis of *Smith*, the California Supreme Court rejected the physicians' Free Exercise claims.

The opinion in *North Coast*, then, suggests that health care professionals in California are not free to follow their consciences when refusing treatment in cases similar to those under discussion. California has enacted conscience protections in matters involving abortion,[49] but it has not protected other conscientious treatment refusals in the context of patient claims based on sexual orientation public accommodation laws.

We advise vigilance on the part of healthcare providers since, one by one, states and local governments have been enacting sexual orientation protections. As of January 2012, twenty-one states and the District of Columbia have enacted statutes of some kind addressing discrimination based on sexual orientation.[50] While not all of these laws necessarily provide a basis for patient claims against clinicians,[51] a trend toward expanding sexual orientation protections to the sphere of public accommodations will likely lead to increased threats against health care rights of conscience.

Part III: The Political Solution

State Conscience Protection Laws Can Safeguard the Religious Liberty Interests of Healthcare Professionals.

Phase One: *Educate your state lawmakers.* Let them know your concerns about escalating threats to the conscientious practice of medicine. Present your state legislators with a "conscience primer:" a clear delineation of the serious harms to the provider, the profession, and the polity when the state fails to protect the legitimate exercise of conscience rights within healthcare.

A Conscience Primer:

Coercing the conscience of healthcare providers produces:

Personal harms:

- To coerce healthcare providers' conscience is to threaten them with the Scylla of professional undoing, should they stand their ground, or the Charybdis of moral corruption, should they capitulate.[52]
- To require healthcare workers to act in a way contrary to their conscience is to strike at the heart of who they are, violating their very person—someone who, by nature, tends to the true and the good and is only fulfilled by doing good and avoiding evil.[53] Doing so deforms their inner moral self (character) with the vicious effects of bad choices, interrupting all the stages of their ability to act humanly (including the capacity to understand the moral principles of human nature, to reason from these principles, to judge according to them, and to choose and carry out these conscientious judgments in concrete acts). In compromising the freedom for excellence that follows from their natural openness to truth, goodness, and happiness, you deny them the right to freely exercise their prudent conscience, an inalienable requirement of human dignity.
- In summation, to coerce religious healthcare providers into acting against their conscience or to prevent them from following their religious convictions so radically defaces their dignity,[54] freedom, and moral

integrity as to imperil their quest for integral human happiness and a life of grace—and even endanger the realization of their final beatitude, the eternal vision of God.

Professional harms:

- To succumb to cooperation in the provision of a treatment they have judged to be immoral means healthcare providers both confirm the patient in his wrongdoing and violate the premier norm of medicine: do no harm.
- Coercion of conscience discourages the affected professionals and their like-minded conscientious objectors from remaining in the medical profession, and new healthcare recruits from entering the field. Elimination of conscientious objectors, "morally serious persons"[55] who are "unwilling to just follow orders,"[56] not only stunts moral diversity within the healthcare field, but also smothers rich moral debate—an oft-cited means toward maintaining the purity of personal and professional integrity in the healing profession.
- Attempts to contravene conscience suppress personal autonomy, forcing the providers to bracket their religious convictions and park their moral beliefs outside their clinic.[57] Suppression of moral autonomy, in turn, causes ethical distress and anxiety in the practitioners as they wrestle with their situation: 'Is protecting my professional standing worth forfeiting my moral integrity?' 'Is keeping my job worth sacrificing conscientious care as the hallmark of my personal and professional identity?' Obviously, anxious clinicians are also distracted ones, spending more time worrying about their own affairs and less time focused on the needs of their patients.[58]
- To practice within an anti-conscience milieu slowly but inexorably breeds callousness within the providers, replacing their wholesome empathy toward patients' vulnerabilities with an insalubrious attitude that "patients do not deserve caring responses from their physicians."[59]
- To ask healthcare providers to contravene their conscientious judgments has a boomerang effect: it provokes clinicians to take a similarly restrictive attitude toward the moral view of their patients, extinguishing, thereby, a key element of provider-patient respect and trust.
- To prohibit healthcare rights of conscience, to constrict healthcare providers' fidelity to core personal beliefs, is to encourage moral laxity toward other general professional responsibilities.

Political harms:

- Denying healthcare rights of conscience violates what national and international human rights proclamations recognize as the basic civil right of every human being:[60] "the right to freedom of thought, conscience and religion," including the freedom to "manifest his religion or belief in teaching, practice, worship and observance."[61]

- Coercion of conscience generates intolerance toward objectors and their system of objective morality.[62] Such intolerance vitiates civic peace and harmony[63] and can even lead to a tyranny of relativism, where every citizen's pursuit of the true and the good is held hostage by relativist and individualist tendencies to a "sly selectiveness" that indirectly suppresses any ideas outside the mainstream of "popular opinion" or elitist political ideology.[64]
- To the extent that laws of the state fail to give primacy of place to free exercise of the conscientious judgments of its citizens, to such an extent has the state overreached its authority, arrogating to itself the right to decide what is good and evil, and failing to secure the fundamental rights of individuals against unjust encroachment by government and the majoritarian view.
- Promoting an anemic sense of conscience and conscientious objection in healthcare (and in other professions) could help to derail even the most liberally enlightened state and push it towards a destructive authoritarianism.[65]
- To coerce healthcare providers' conscience robs the polity, on the one side, of a clear voice for the meaning of sexuality,[66] marriage,[67] and family[68] and imposes on all Americans, on the other, an LGBT "ethic" and legal system.
- Anesthetizing the conscience of healthcare providers means that they and all those in the culture who agree with their moral assessment of homosexual sex and same-sex marriage experience anguish over two things: the fact that the immoral behavior is going on in society, weakening its moral fiber, and the fact that the state appears to have a greater interest in facilitating the amoral behavior than in inhibiting it.[69]

Phase Two: *Convince sympathetic state lawmakers to sponsor appropriate legislation to protect health care rights of conscience.* One option would be to carve out religious freedom and conscientious objection exemptions within: (a) same-sex civil union or same-sex marriage statutes and/or (b) new state civil rights statutes protecting gender, sexual orientation, or marital status *while* the respective laws are being debated. The ideal is to create conscience protection statutes that broaden the right to religious objection beyond abortion and sterilization issues to any sort of medical service that abrogates moral convictions.

A second option would be to draft a stand-alone conscience protection statute. Illinois' Healthcare Right of Conscience Act includes safeguards for a wide range of persons involved in the healthcare delivery system as well as robust protections against liability:

> No physician or health care personnel shall be civilly or criminally liable to any person, estate, public or private entity or public official by reason of his or her refusal to perform, assist, counsel, suggest, recommend, refer or participate in any way in any particular form of health care service which is contrary to the conscience of such physician or health care personnel.[70]

The Act also prevents individuals, public or private institutions, or public officials from discriminating against persons who exercise conscience rights.[71]

Broad conscience protections like these send a strong message of support not only to religious individuals but also to institutional providers of healthcare.[72] These comprehensive safeguards make good legal sense. Healthcare institutions—no less than individual providers—need conscience safeguards that guarantee a participation in healthcare delivery that reflects their moral/religious values. Furthermore, since small or moderately sized healthcare organizations tend more readily to mirror the religious convictions of their proprietors, carving out exemptions for them provides a stage upon which owners and employees alike can integrate their religious beliefs into everyday professional practice.

Phase Three: *Dialogue with members of the gay community, aiming for a win-win resolution to liberty conflicts between homosexual patients and religious providers.* Emphasize that a liberal, tolerant society should not embrace coercion when other means are available.[73] Coercing conscience does not merely harm the healthcare provider. It also harms the patient, encouraging rancor and distrust between two private citizens (the provider and the patient). Dialogue, rather than coercion, is the only path capable of generating progress without inflicting serious harms.[74]

If patient-provider liberty conflicts were to occur in states with robust sexual liberty protections, it is safe to predict the following. The legal risks of noncompliance with sexual orientation public accommodation laws would effectively drive conscientious professionals from the marketplace. And, since gay patients would be spared the embarrassment of treatment refusal and the inconvenience of having to seek out another provider, gay rights activists would probably welcome the departure of conscientious clinicians.[75] Furthermore, the LGBT community would view a reduction in religious healthcare providers as only a short-term inconvenience: compliant providers would simply take the place of those who conscientiously refused to perform treatment.[76] However, such prognostications would ignore other marketplace dynamics that adversely affect all patients.

Homogenization of medical professionals would disenfranchise religious patients who only want to receive medical care from providers who share their moral convictions about life, family and sexuality. Unlike their homosexual counterparts, these religious patients would have few, if any, clinician alternatives. If a state enacts robust healthcare conscience protections, it will guarantee that the diversity of clinicians matches the diversity of the patient population, providing everyone with the care they want from a provider they appreciate.

Private ordering could also reduce any residual “friction” between homosexual patients and religious healthcare providers. For example, the Internet enables patients to research not only their treatment options, but also their provider alternatives and, most importantly, the particular philosophy of medicine that grounds these prospective clinicians. The sharing of information among patients, coupled with the emergence of networks of like-minded physicians, will facilitate citizens’ access to healthcare services that meet their moral/medical needs. In sum, markets can fulfill desires of the entire community without incurring the harms brought on by coercive laws.

Conclusion

Protections for healthcare rights of conscience have not kept pace with expanding sexual liberty interests. Unfortunately, some laws skew the competition between religious and sexual liberty as a zero-sum game. Indeed, when states adopt coercive antidiscrimination laws that favor the interests of homosexual patients at the expense of conscientious providers, one side definitely wins; the other side definitely loses. In contrast, when states enact robust safeguards for healthcare rights of conscience, both sides win. Protecting diversity in the provider community—rather than forcing conscientious providers out of medicine—will maximize liberty and healthcare options for all.

References

1. *Lawrence v. Texas*, 539 U.S. 558 (2003), overruling *Bowers v. Hardwick*, 479 U.S. 186 (1986).
2. As of March 2012, Connecticut, District of Columbia, Iowa, Maryland, Massachusetts, New Hampshire, New York, Vermont, and Washington have enacted same-sex marriage laws; Delaware, Hawaii, Illinois, Maine, New Jersey, and Rhode Island have legalized same-sex civil unions; California, Nevada, New Jersey, Oregon, and Wisconsin (appeal pending) recognize same-sex domestic partnerships and Colorado has legalized "reciprocal beneficiary" same-sex relationships.
3. California, Connecticut, Hawaii, Illinois, Iowa, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New Mexico, New York, Oregon, Rhode Island, Vermont, Washington, Wisconsin, and Washington, D.C. prohibit discrimination on the basis of sexual orientation in public accommodations. See, e.g., Cal. Civ. Code § 51b: "all persons within the jurisdiction of this state are free and equal, and no matter what their sex, race, color, religion, ancestry, national origin, disability, medical condition, marital status, or sexual orientation are entitled to the full and equal accommodations, advantages, facilities, privileges, or services in all business establishments of every kind whatsoever."
4. This clinical scenario resembles circumstances in *North Coast Women's Care Medical Group v. San Diego County Superior Court,* 189 P.3d 959 (Cal. 2008).
5. A physician presented this clinical scenario to the Center for NaProEthics with the goal of discerning the moral dimensions of a treatment refusal.
6. This case resembles the facts of a suit brought by a student who was expelled from her graduate counseling program because of her conscientious beliefs. *See* Ward v. Polite, 667 F.3d 727 (6th Cir. 2012).
7. This case mirrors the situation described in the Delaware statute legalizing same-sex civil unions [13 Del. Code § 207(a)]: "In the case of critical illness of one of the parties desiring to enter into a civil union, the physician attending such party may appear for the ill party and make an application for a civil union license for such party, if such physician first makes an affidavit and delivers it to the issuing officer stating that in the opinion of said physician the party for whom said physician is acting is at the point of death and that this person may lawfully enter into a civil union. The application for the civil union license shall be altered in such case to show that said physician acted as proxy and the affidavit of the physician shall be filed with the application." Although assistance on the part of the attending is discretionary, it is possible that a refusal, allegedly based on sexual orientation, could run awry of a sexual orientation public accommodations statute.
8. Requests for reproductive services from unmarried heterosexual patients may also result in treatment refusals from conscientious providers. It should be noted, however, that in some states marital status is a protected category for antidiscrimination laws. In these states, then, refusing a reproductive treatment to an unmarried patient could present a similar legal liability for the religious medical professional.
9. Ethical licensing and accreditation standards may also present difficulties for these professionals. (See Jill Morrison & Nicole Allekotte, "Duty First: Toward Patient-Centered Care and

Limitations on the Right to Refuse for Moral, Religious, or Ethical Reasons," *Ave Maria L. Rev* 9(2010):167-70.) Nonetheless, the impact of such standards on healthcare rights of conscience is beyond the scope of this discussion.

10. *North Coast Women's Care Medical Group* v. *San Diego County Superior Court,* 189 P.3d 959 (Cal. 2008).
11. Cf. note 3 *supra.*
12. Proposed legislation that enacts federal protections for conscience rights in connection with the Patient Protection and Affordable Care Act includes a finding of fact that "[conscience protections] are deeply embedded in the history and traditions of our Nation and codified in numerous State and Federal laws, including laws on health care." H.R. 1179, § 2 (March 17, 2011); S. 1467, § 2 (August 2, 2011). See also *Gilette v. United States*, 401 U.S. 437, 453 (1971) ("[I]t is hardly impermissible for Congress to attempt to accommodate free exercise values, in line with 'our happy tradition' of 'avoiding unnecessary clashes with the dictates of conscience'") (Citations omitted).
13. See id. at 445 ("It is true that the legislative materials reveal a deep concern for the situation of conscientious objectors to war, who absent special status would be put to a hard choice between contravening imperatives of religion and conscience or suffering penalties. Moreover, there are clear indications that congressional reluctance to impose such a choice stems from a recognition of the value of conscientious action to the democratic community at large, and from respect for the general proposition that fundamental principles of conscience and religious duty may sometimes override the demands of the secular state.").
14. See U.S. Const. amend. I ("Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the Government for a redress of grievances.") Both the Free Exercise Clause and the Free Speech Clause may provide a basis for conscience safeguards. The Due Process Clause of the Fourteenth Amendment ("nor shall any State, deprive any person of life, liberty, or property, without due process of law") as well as the Equal Protection Clause of the Fourteenth Amendment ("nor [shall any state] deny to any person within its jurisdiction the equal protection of the laws") likewise provide a basis for conscience protections from the states. See U.S. Constitution amend XIV, § 1. The Supreme Court has interpreted the Fourteenth Amendment to include First Amendment protections against the states. See, e.g., *Cantwell v. Connecticut,* 310 U.S. 296 (1940).
15. 494 U.S. 872 (1990).
16. Id. at 877.
17. See id.
18. Id. at 879. The Court cited *Reynolds v. United States*, 98 U.S. 145 (1878) in which it rejected a claim that criminal laws against polygamy were unconstitutional when the practice of polygamy was required by religious beliefs: "To permit this would be to make the professed doctrines of religious belief superior to the law of the land, and in effect to permit every citizen to become a law unto himself." (*Reynolds*, supra, 98 U.S. at 166-67). An interesting question: Would a challenge based on more recent cases involving sexual liberty sustain the same result?
19. Id. (citation omitted).
20. 374 U.S. 398 (1963).
21. *Smith*, supra, 494 U.S. at 883-84.
22. Id. at 885 (Citations omitted).
23. Id. at 890.
24. Id.
25. In some cases, pharmacists (and pharmacy owners) have been able to mount successful challenges to state statutes based on facts showing animus against religious providers. See, e.g., *Stormans, Inc. v. Selecky*, __ F.Supp. 2d, 2012 WL 566775 (W.D. Wash. Feb. 22, 2012) (holding dispensing regulations invalid under strict scrutiny); *Morr-Fitz,Inc. v. Blagojevich,* 2011 WL 1338081 (Trial order) (Circuit Court of Illinois, Seventh Judicial Circuit, April 5, 2011) (invalidating Illinois dispensing rules under strict scrutiny). *Morr-Fitz* illustrates the value of conscience protective statutes, as other Illinois laws, including its state version of RFRA and its

Health Care Right of Conscience Act, also provided a legal basis for protecting the conscience rights of pharmacists and pharmacy owners in that case.

26. Pub. L. No 103-141, 107 Stat 1488 (1993), codified at 42 U.S.C.A. §§ 2000bb-2000bb-4.
27. 42 U.S.C.A. § 2000bb.
28. 42 U.S.C.A. § 2000bb-1(b).
29. 42 U.S.C.A. § 2000bb-1(a).
30. 521 U.S. 507 (1997).
31. RFRA, in the Court's view, went beyond the proper scope of Congressional remedial powers under the Fourteenth Amendment. The Court argued that Congress effectively attempted a substantive change in Free Exercise safeguards, rather than merely enforcing existing constitional protections. See id. at 532-35. Among other things, this was thought to entail "considerable congressional intrusion into the States' traditional prerogatives and general authority to regulate for the health and welfare of their citizens." Id. at 535.
32. See *Gonzales v. O Centro Espirita Beneficente Unia do Vegetal*, 546 U.S. 418 (2006).
33. One author counts ten states that have passed their own version of RFRA: Arizona, Connecticut, Florida, Idaho, Illinois, New Mexico, Oklahoma, Rhode Island, South Carolina and Texas. See Patricia Kelleen Forlizzi, "State Religious Freedom Restoration Acts as a Solution to the Free Exercise Problem of Religiously Based Refusals to Administer Health Care," *New England L. Rev* 44(2010): 400. However, a state RFRA may not provide protections as robust as other legislative approaches to conscience rights, especially since the substantiality of a burden and the "compelling" nature of the government's interest are indeterminate and not always productive of the desired protection. "Equal access to health care may be deemed a compelling state interest, but the imposition of a State RFRA and its strict scrutiny mandate will not always result in a victory for equal protection." See id. at 418. For example, in *North Coast*, the California Supreme Court concluded that the antidiscrimination goals of the Unruh Act were sufficiently compelling to withstand even this strict scrutiny requirement. See *North Coast, supra*, 189 P.3d at 968.
34. For example, the Religious Land Use and Institutionalized Persons Act (RLUIPA), 42 U.S.C. § 2000cc-1 et seq., was enacted in 2000 to protect religious freedom in the context of incarcerated persons and zoning restrictions. Although this law constrains state and local laws, it was held to be a valid exercise of Congressional power under Article 1 due to its limited application to circumstances involving federal funds. See, e.g., *Cutter v. Wilkinson*, 544 U.S. 709 (2005) (upholding RLUIPA application to state prisoners where federal funds were involved).
35. See, e.g., H.R.1179, Respect for Rights of Conscience Act of 2011 (March 17, 2011); S. 1467, Respect for Rights of Conscience Act of 2011 (August 2, 2011).
36. See e.g., *Planned Parenthood v. Casey*, 505 U.S. 833, 848 (1992).
37. Id. at 852.
38. Id. at 851 (emphasis added).
39. *Griswold v. Connecticut*, 381 U.S. 479 (1965).
40. See, e.g., *Roe v. Wade*, 410 U.S. 113 (1973).
41. See, e.g., *Lawrence v. Texas*, 539 U.S. 558 (2003) (unconstitutionality of a Texas criminal statute applied to adult males in the privacy of their home) overruling *Bowers v. Hardwick*, 478 U.S. 186 (1986) (upholding a similar statute against constitutional challenge).
42. See note 23, *supra.*
43. See also *Washington v. Glucksberg*, 521 U.S. 702, 788-89 (Breyer, J., concurring) (suggesting that legislatures are superior decision makers about emerging issues when future implications are potentially significant but unknown).
44. In 1961, all fifty states had outlawed sodomy, but by 2003 only thirteen states had retained such laws, and only four states enforced them, and then only against homosexual conduct. See id. at 572. The Court also noted that the European Court of Human Rights had long ago ruled in *Dudgeon v. United Kingdom*, 45 Eur. Ct. H.R. (1981) that a Northern Ireland Law proscribing consensual homosexual conduct was invalid under the European Convention on Human Rights. See id.

45. Marriage is often seen as an important status symbol. Hence, the goal of making it equally possible for both homosexuals and heterosexuals to achieve this "status" has prompted state courts, based on equal protections considerations, to strike down opposite-sex restrictions. See, e.g., *Kerrigan v. Commissioner*, 957 A2d 407 (Conn. 2008) (noting that "consigning same-sex couples to civil unions [ ] has relegated them to an inferior status, in essence, declaring them to be unworthy of the institution of marriage"); *Lewis v. Harris*, 908 A. 2d 196 (2006) (noting that "[u]ltimately, the message is that what same-sex couples have is not as important or as significant as 'real' marriage ...."). Cf note 3 *supra.*
46. 189 P.3d 959 (Cal. 2008).
47. See Cal. Civ. Code § 51(b).
48. Cal Civ. Code § 51(b). It should be noted that during the years at issue in *North Coast*, neither sexual orientation nor marital status were included in the statute. Nevertheless, the California Supreme Court ruled that sexual orientation was a protected category based on other California cases.
49. See Cal. Health & Safety § 123420 (protects a "moral, ethical, or religious" refusal to participate in abortion, including a liability limitation from suits for failure to provide or refusal to participate, and makes it a misdemeanor criminal offense). Note, however, that this law does not apply to "medical emergency situations and spontaneous abortions." Id., § 123420(d).
50. See National Gay and Lesbian Task Force, State Nondiscrimination Laws in the U.S. (January 20, 2012, at www.theTaskForce.org (last accessed 3/6/12).
51. For example, nondiscrimination laws affecting employment or housing would not impact patient care.
52. Blessed John Paul II argued that, when faced with the dilemma either of abandoning the medical profession or of compromising one's convictions, healthcare providers should take the "middle path" of conscientious objection which must be "respected by all, especially legislators" [Address of John Paul II On the Occasion of the International Congress of Catholic Obstetricians and Gynaecologists, 18 June 2001; *Evangelium vitae*, 72-74].
53. Cf. Ibid., 74.
54. Douglas B. White and Baruch Brody, "Would Accommodating Some Conscientious Objections by Physicians Promote Quality in Medical Care?" *JAMA* 305(2011):1804.
55. A morally serious healthcare worker certainly qualifies as "a man of conscience" and, as such, can take as his models Blessed John Henry Cardinal Newman, St. Thomas More, and St. Thomas Becket who, within their professional lives, paid unequivocal "obedience to that truth which must rank higher than every social authority and every kind of personal taste" [Ratzinger, *Values*, 87].
56. White, "Accommodating," 1805.
57. Leon Kass warns that when the ends of medicine are not clearly defined or agreed upon, the practitioner is at risk of becoming a mere "technician and engineer of the body, a scalpel for hire, selling his services upon demand" [*Toward a More Natural Science: Biology and Human Affairs* (The Free Press: New York, NY, 1985) 158]. Benedict XVI encourages healthcare workers to never lose sight of the fact that biomedical sciences are at the service of the human being and counsels them that anesthetizing their conscience will only reduce healthcare services to "a cold and inhuman character" [*Address of His Holiness Benedict XVI to Members of the International Congress of Catholic Pharmacists*, 29 October 2007]. Margaret Somerville argues that denial of conscience in the healthcare setting does a great disservice not only to the individual medical professional but to the medical profession in general, where maintaining respect in the human encounter between healthcare worker and patient is of paramount importance. [MercatorNet, 17 October 2008 (www.mercatornet.com, last accessed 11/20/11).]
58. John Paul II underscores the psychophysical scope of patients' needs and their correlative requisites that healthcare professionals practice not only biomedicine but the "spiritual medicine" of compassionate human contact imitative of the gospel image of the Good Samaritan: the willingness even at great personal sacrifice to help those in need of healing, all the while witnessing "to those higher values which have their firmest foundation in faith" [*Address to a Congress of Catholic Doctors*, 7 July 2000].
59. White, "Accommodating," 1805.

60. Ratzinger argues that when conscience and authority seem to be "locked in struggle with each other," human freedom is rescued in an appeal "to the classical principle of moral tradition that conscience is the *highest norm* which man is to follow even in opposition to authority" ["Conscience and Truth," 8]. Cf. *Dignitatis humanae* #3 and *Gaudium et spes* #79.
61. *Universal Declaration of Human Rights* #18.
62. Loyalty to conscience on the part of Christian believers not only puts them in solidarity with the same quest on the part of their non-Christian fellow-citizens, but also, to the extent that an upright conscience prevails, facilitates just resolutions to societal problems, resolutions that follow from objective truths rather than "blind choice" [*Gaudium et spes* #16].
63. John Paul II fuses societal respect for conscience with "a force for peace." Citizens' right to follow conscience, to judge and to act in accordance with truth, promotes "unity rather than division; reconciliation rather than hatred and intolerance." Seeking the truth together, "with respect for the conscience of others," enables all people "to go forward along the paths of freedom which lead to peace, in accordance with the will of God" [*If You Want Peace, Respect the Conscience of Every Person*, 1 January 1991, XXIV World Day of Peace].
64. Aleksandr I. Solzhenitzsin, *A World Split Apart (New York: Harper & Row Publishers, 1978) 30. NYU law professor Jeremy Waldron's observation that it "infuriates" his fellow liberals that some intellectuals continue "to actually argue on matters that many secular liberals think should be beyond argument, matters that we think should be determined by shared sentiment or conviction" and "to refuse to take the liberal position for granted" is a good example of "sly selectivity." ["Secularism and the Limits of Community," New York University School of Law: Public Law & Legal Theory Research Paper Series, Working Paper no. 10-88, December, 2010, 16-17.]*
65. Ratzinger points out that the source of concern over the blunting of moral sensitivity so rampant under Marxist regimes was "that those who lived in a system of deceit had lost much of their powers of perception. Society had lost the ability to feel compassion, and human emotions had withered away. An entire generation had become impervious to the good and was incapable of human deeds. . . . When conscience falls silent and we do nothing to resist it, the consequence is the dehumanization of the world and a deadly danger" [*Values*, 83].
66. Chai Feldblum, lesbian activist, is unequivocally committed to using government, through the power of its laws, to shape public opinion toward agreement that heterosexuality and homosexuality are equivalent moral goods. She claims that nothing short of this sort of moral equivalency will bring full equality to LGBT people. ["Gay is Good: The Case for Marriage Equality and More," *Yale JL & Feminism* 17(2005):139, 140.]
67. The Congregation for the Doctrine of Faith calls Christians to give witness to the moral truth regarding marriage by avoiding approval of homosexual acts and homosexual unions and by participating in the following discreet and prudent actions: "unmasking the way" that state tolerance, but not explicit legal recognition, of homosexual unions "might be exploited or used in the service of ideology; stating clearly the immoral nature of these unions; reminding the government of the need to contain the phenomenon within certain limits so as to safeguard public morality, and above all, to avoid exposing young people to erroneous ideas about sexuality and marriage that would deprive them of their necessary defenses and contribute to the spread of the phenomenon" ["Considerations Regarding Proposals to Give Legal Recognition to Unions Between Homosexual Persons," Part II].
68. In their evaluation of forty-nine empirical studies on same-sex or homosexual parenting, Robert Lerner and Althea Nagai categorize the surveys' claim—viz., it makes "no difference" whether a child has two heterosexual parents or two homosexual parents (two moms or two dads)—as inconclusive. Quantitative analysis experts Lerner and Nagai, having identified at least one fatal flaw in each of the studies, concluded, for that reason, that the papers: (1) yield no reliable generalizations and (2) "are no basis for good science or good public policy" [*No Basis: What the Studies* Don't *Tell us About Same-Sex Parenting* (Washington, DC: Marriage Law Project, 2001) 3].
69. Robert H. Bork uses this argument in reference to the Supreme Court's decision in *Griswold v. Connecticut*. Even though, in 1965, the Court admitted "the majority finds the use of contraception immoral," it made no effort to inhibit the practice, despite the fact that the ruling

caused "the majority anguish" and impaired their gratifications. ["Neutral Principles and Some First Amendment Problems," excerpt taken from Bork's *A Time to Speak: Selected Writings and Arguments* (Wilmington, DE: ISI Books, 2008) available at: http://www.firstprinciplesjournal.com/print.aspx?article=1190&bc=b&type=cbtp (last accessed 6/13/11).]

70. 745 Ill. Comp. Stat. 70/4. Liability protections are also extended to owners, operators, supervisors, and managers, as well as the health care provider. Id. § 70/9. It should be noted, however, that the Act requires that clinicians have a duty to provide emergency medical care. See id. §§ 70/6; 70/9.

71. See id. § 70/5. Those rights allowed a pharmacist to sue his employer who placed the pharmacist on unpaid leave because he refused to dispense contraception on grounds that it violated his conscientious beliefs. See *Vandersand v. Wal-Mart Stores, Inc*., 525 F.Supp. 2d 1052 (C.D. Ill. 2007) (denying Wal-Mart's motion to dismiss the pharmacist's claims). See also 745 Ill. Comp. Stat. § 70/7 (prohibiting discrimination by employers and institutions); id. §§ 70/10-11 (prohibiting discrimination and denial of aid or benefits to facilities that exercise conscience rights). Payers are likewise protected by provisions tailored to their conscientious convictions. See id. §§ 70/11.1-4.

72. This avoids the potential problem generated by the Washington conscience law (Wash. Rev. Code § 43.065(2)(a)) which extends protections only to individuals and not their employers. See *Stormans, Inc. v. Selecky*, __ F.Supp. 2d, 2012 WL 566775 (W.D. Wash. Feb. 22, 2012).

73. History shows that coercive endeavors do not necessarily have good endings. See, e.g., *West Virginia State Board of Education v. Barnette* 319 U.S. 624, 640-641 (1943), where the Court observed:

> "Struggles to coerce uniformity of sentiment in support of some end thought essential to their time and country have been waged by many good as well as by evil men. Nationalism is a relatively recent phenomenon but at other times and places the ends have been racial or territorial security, support of a dynasty or regime, and particular plans for saving souls. As first and moderate methods to attain unity have failed, those bent on its accomplishment must resort to an ever-increasing severity. As governmental pressure toward unity becomes greater, so strife becomes more bitter as to whose unity it shall be. …. Ultimate futility of such attempts to compel coherence is the lesson of every such effort from the Roman drive to stamp out Christianity as a disturber of its pagan unity, . . . the Siberian exiles as a means to Russian unity, down to the fast failing efforts of our present totalitarian enemies. Those who begin coercive elimination of dissent soon find themselves exterminating dissenters. Compulsory unification of opinion achieves only the unanimity of the graveyard."

Modern examples of coercion to achieve conformity regarding sexual liberty can be found in other Western nations. See Jeffery J. Ventrella, "Square Circles?!?: Restoring Rationality to the Same-Sex 'Marriage' Debate," *Hast. L. Q.* 32(2004-05):713-14 (citing examples of religious persecution in Canada, England, Spain, and Sweden involving dissenting views on homosexuality).

74. As one commentator suggests: you just can't hurry love. (See Andrew Koppelman, "You Can't Hurry Love," *Brook L Rev* 72(2006):146.)

75. For example, in *Stormans, Inc. v. Selecky*, 2012 WL 566775 (W.D. Wash. Feb. 22, 2012) (No. C0705374RBL), the Washington Board of Pharmacy promulgated rules that required pharmacies to deliver all lawfully prescribed drugs, including "Plan B." Since many religious pharmacists refuse to dispense abortifacient drugs, smaller pharmacies owned by persons with these conscientious objections had no choice but to close. The Board admitted it was "well aware of this result when it designed the rule."

76. See id. at n. 6 ("the [State Pharmacy] Board contemplated its rules would result in pharmacies run by religious-objectors being replaced by non-objectors.") See also *Morr-Fitz v. Blagojevich*, 901 N.E.2d 373 (IL 2008) that involved a challenge to an Illinois administrative rule requiring pharmacists to dispense "Plan B" regardless of religious objections. The court noted that then-Governor Rod Blagojevich opined: "pharmacists with moral objections [to dispensing Plan B contraceptives] should find another profession." Id. at 390.

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PALLIATIVE CARE IMPERATIVE: A FRAMEWORK FOR HOLISTIC AND INCLUSIVE PALLIATIVE CARE

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Abstract

Care at the end-of-life in Singapore is fraught with complexities and various subtleties, particularly when one considers the many local mores and beliefs, religious and cultural norms, as well as the specific values and nuanced social expectations of this multi-religious, multicultural, and multi-ethnic island nation. The prevailing ethical frameworks, mostly western in nature, have thus far failed to contend with such variability, particularly within this society. This is not altogether surprising, given the evolving nature of local ethical frameworks that still maintain the idea of the centrality of the family within any consideration but which are also increasingly influenced by western and Judeo-Christian values.

To meet the need for a more flexible and inclusive ethical framework, this paper attempts to meld the prevailing expectations of a deontic-inspired Duty of Palliative Care (DoPC) at the end-of-life with an aretaic-inspired Virtue Ethics framework to better capture the nuances of end-of-life decision making in Singapore. The Palliative Care Imperative (PCI) seeks to accomplish this by imbuing clinical deliberations with a better, more multi-faceted appreciation as well as a holistic assessment of character-based, emotional, spiritual, and motivational facets within the decision making process through the utilization of a multidisciplinary team approach.

Key words: palliative care imperative, end of life, decision making, Singapore, virtue ethics, duty of palliative care, multidisciplinary team

Introduction The Duty of Palliative Care [DoPC]

Care at the end-of-life is frequently complicated, depending upon a number of factors ranging from emotional and spiritual concerns to the medical, social, and financial factors surrounding a particular clinical scenario. These considerations, particularly those pertaining to cultural, emotional, spiritual, and local mores, are not only the express domain of the patient and their loved ones and caregivers, but also apply to the team caring for them—particularly in the attempt to accomplish the central goal of holistic, patient-centred end-of-life care. Here, a coadunation of considerations that both span a variety of personal factors and involve the clinical setting of care, institutional experience, and style of practice combine to play a part within a large care-provision computation. Despite the infusion of evidence-based guidelines and thinking, many eventualities cannot be provided for in legislation, particularly when caring for terminally ill and vulnerable patients. This leaves some Health Professionals [HPs] in the unenviable position of having to navigate these often-difficult clinical situations without much guidance. The situation is made all the more acute when the Principlismbased framework, which has been the guiding ethical structure, struggles to cope in a Singaporean setting, where Confucian-inspired ethical frameworks and Asian 'family centered' thought, rather than Western ethical thought, are the dominant ethical or moral structures. The Duty of Palliative Care [DoPC] took form in an attempt to confront the many nuances of end-of-life care within the Singaporean setting with a focus upon end-of-life support and decision-making.[1,2] This paper is also rooted in such a context.

The Duty of Palliative Care [DoPC]

The idea of the DoPC represents an attempt by Krishna et al to clarify the position of a HP who is caring for those with both shrinking curative treatment options and goals of care that are firmly focused on comfort measures and improving quality of life.[1,2] Within this conception, the overarching duty of a HP involved in the care of patients with attenuated treatment options is firmly focused on comfort measures and improving the quality of life.[1,2] The aim of the DoPC is not simply to bring about the best medical decision for each case, but rather to ensure the best outcome in a holistic sense, based primarily on the best available information within a particular clinical situation.[1,2] Yet, this goal exposes a pivotal flaw, for the DoPC fails to consider the integral issues of emotions, relationships, virtues, and character that play a significant role within the pivotal elements of holistic palliative care. As will be shown in this treatise, the significant shortcomings within the DoPC have paved the way for the proffering of the Palliative Care Imperative (PCI).

However, before proceeding further, it is important to frame and contextualize the position of the DoPC, which will form the scaffolding for the intended PCI, within the remit of care at the end-of-life. This paper will first adopt the World Health Organization definition of Palliative Care in order to define the DoPC further. Palliative care is understood as,

> An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:
>
> (1). Provides relief from pain and other distressing symptoms;
>
> (2). Affirms life and regards dying as a normal process;
>
> (3). Intends neither to hasten or postpone death;
>
> (4). Integrates the psychological and spiritual aspects of patient care;
>
> (5). Offers a support system to help patients live as actively as possible until death;
>
> (6). Offers a support system to help the family cope during the patient's illness and in their own bereavement;
>
> (7). Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
>
> (8). Will enhance quality of life, and may also positively influence the course of illness;

> (9). Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[3]

Within the context of their discussion of the care of the imminently dying, Krishna and Chin suggest that only the first eight factors within this definition are pertinent to the specific considerations of this discussion[1-8], arguing that, given the rapidly decreasing number of treatment options and the imminence of the final outcome, goals of care have irretrievably shifted from cure to palliation of symptoms. As a result, the authors suggest that, during this period of a disease process, the DoPC expound the need for management options to be appropriate to the clinical context of the patient. Hence, clinicians ought to be focused on comfort measures and interventions that are less invasive and that carry less morbidity.

In order to accomplish this task, the DoPC proffers some guidance for the balancing of conflicting moral principles. To begin with, it assigns each duty a specific 'weight' within this period of waning ability to cure or prolong life and increasing duty to maximize comfort.[1,2] Firstly, more 'weight' is placed on the duties that optimize comfort and ameliorate suffering, allowing HPs to override any duty to attempt a cure. Secondly, attention to clinical data allows for further strengthening of these duties and lies within the scope of Evidence Based Medicine, which utilizes best practice guidelines in considering these context-sensitive and case-specific situations. This model underscores the authority of professional judgment and maintains that decisions ought to be made by a team of individuals who have undergone appropriate standardized training within the given specialty and who possess the experience sufficient to be accredited as specialists by a national accrediting board. This will engender standardization of clinical training and practice.[1,2] The DoPC's provision for 'weight' and balancing is also adopted within the PCI.

Within the DoPC, palliative care physicians are also expected to utilize evidence-based medicine [EBM] guidelines, thus keeping clinical practice in step with the nationally and internationally recognized standards.[1,2] Working practices within the DoPC also advocate multidisciplinary teamwork by harnessing the collective expertise and combined experience of a variegated team in order to consider disparate points of view. Any decision is, then, grounded in the wealth of experience and expertise of the various team members.

Palliative Care within the Singaporean Setting

An understanding of the nuances of the palliative structure in Singapore is necessary to a discussion of the PCI. Indeed, Singapore sits at the forefront of palliative care services in Southeast Asia, a fact that is aided by its astute shared-funding approach to health care.[4-14] The recent Economist Intelligence Unit's Quality of Death Index acknowledged local end-of-life care provisions with a respectable standing in its rankings.[4] However, a shared-funding approach to the health care system is not without drawbacks.[4-14] The effects of potential conflicts of interest that arise as a result of this system, one which sees an apportioning of treatment costs upon families who regularly fulfil the role of main decision makers, will be considered in due course.[15-21]

Aside from its novel funding of care, end-of-life welfare in Singapore is also affected by the considerations of multi-ethnic, multicultural, and multi-faith communities.[22] Indeed, though 75% of Singapore's 5.1 million inhabitants are of Chinese extraction, local culture is still influenced by the Malay and Indian roots and traditions that have prevailed from before the influence of the British Empire.[1-2,15-48] Much of the present day Chinese culture has evolved as result of mixture with these various other Asian cultures and also with, especially lately, Judeo-Christian and Western values and thought.[1-2,15-48] Local audit data has revealed that some of the traditional Chinese concepts appear to have evolved and now hold new meaning amongst local families and patients. Some of these evolved forms of traditional Chinese beliefs and practices have also been adopted by all the major races in Singapore. Such findings appear to suggest an evolution in the general perception of terms, beliefs, and values, and an ensuing need for a review of understanding of local practice. These cultural transformations are not entirely surprising, particularly in end-of-life care, given the active propagation of family-centric values by a local government that is focused upon imbuing local thinking with 'Asian values' (albeit drawn largely from Confucian ideals).[23-52] However *rather than resulting in a more homogenous interpretation of traditionally held concepts, local audit data appears to allude to variability in transmission, practice, and understanding amongst the races and even family units.* As a result, the Singaporean social landscape, as well as the medical field, has morphed to meet the particularities of the changing and influential ethic. Of particular interest within this family-centric approach is the idea of *familial determination* or *family decision making.*[5-21,23-54]

Family Decision Making

It has been observed of end-of-life care in Singapore that a critical element of the prevailing family-centric view is family decision making, which lauds familial determination over patient autonomy.[1-2,15-21,40-54] Here, the family acts in unison or designates a member, such as the patient's eldest son, to determine the best course of action on behalf of the patient—sometimes to the detriment of the patient's own knowledge of their illness, prognosis, or treatment.[1-2,15-21,40-75] Cultural, societal, and local mores that place great value upon the preservation of 'hope' have been vital to this posture towards family decision making, as well as social inclinations towards filial obligations, the familial duty of non-abandonment, and local taboos that negate discussions of death and dying.[1-2,15-21,29,30,45,50,53-76,78] Such an attitude is, in turn, underpinned by the belief that 'staving off bad news will feed hope and starve death of an early victory,' which predisposes many towards acts of collusion.[1-2,15-21,55-78] Indeed, collusion in varying degrees remains a proceeding that is widely practiced by many local physicians.[15,18-20,54] One study revealed that the majority of physicians in Singapore prefer to discuss prognosis and diagnosis with the family rather than the patients themselves out of deference to this time honoured custom.[20] The effect of familial decision-making within this context points to two important findings.

The first finding alludes to the fact that familial determination remains a reality of care in Singapore that is unlikely to be either circumvented or changed readily.[1,2,15-21,53-55,75] The second suggests the possibility of compromised decision-making, particularly in the presence of the sometimes-fractious motivations that arise when considering issues associated with the regnant co-payment scheme that regularly impacts the deliberations of local familial decision-makers.[1-2,9,10,18-20,42,43,51-55,75,78] Provision for meeting these personal costs are initially met through an individual medical savings account scheme called Medisave and an insurance-based policy called Medishield.[5-12,14] When this money is exhausted, family members can 'elect' to draw upon their own Medisave accounts in order to pay for the care of their loved ones before the strictly regulated and state sponsored 'safety net,' called Medifund, sets in.[14] It has been observed that societal expectations (local values in the form of filial piety and non-abandonment) and even legal obligations, in the form of the Maintenance of Parents Act of 2010, exert significant expectations upon the immediate family to honor their financial 'responsibilities' to the family.[13,15-17,40-41,58-62,66-70] The presence of such pressures, as well as the fact that cash 'top ups' (or replenishments of accounts) are sometimes required, appear to stoke regnant customs of familial involvement in care determination, but can also cause concern with regards to an underlying conflict of interests.[13-15,40-41,58-62]

The Palliative Care Imperative

In basing the DoPC upon the ideals of a deontological approach, the zeitgeist of biomedical thinking, problems of applicability arise. Such is particularly the case when dealing with end -of-life care, an arena richly permeated with cultural, spiritual, social, and emotional considerations and regularly confronted by conflicts of interests and both ethical and moral conundrums. Here, a detached review of an action (or the deliberation preceding it) that is guided by a duty based [deontic] ethical framework does little to either address the various factors involved or mitigate lingering concerns with regards to the judgment, motivation, and intentions of the HPs and family members involved. Thus, a deontic framework fails to excogitate the affects and attitudes that underpin a person's worldview, for how these individuals deal with ethical dilemmas and their implications is pivotal when considering the ethically complex scenarios presented by end-of-life decision making.[79-82] In a multifaceted setting, clear guidance from Beauchamp and Childress's four principles may not be forthcoming.[81] In order to highlight this point, consider the following three cases.

Yusnisha was a local, 32-year-old Malay lady who had resigned from her post as a care assistant in order to care for her mother, who was suffering from end stage kidney and heart failure. As a result of her sacrifice, her 5 siblings, who lived abroad, and their mother agreed that the family home where Yusnisha cared for their mother would be willed to Yusnisha upon the mother's demise. Not long after Yusnisha moved back into her family home, her mother's health began to deteriorate and she was admitted to a hospital. Yusnisha insisted that her mother not undergo any tests and be administered with comfort measures only. Because Yusnisha had been named as both 'main carer' upon her mother's previous hospital admission and as 'next of kin' by her mother herself, the doctors approached her with regards to plans for the mother's care. The patient, Yusnisha claimed, wished only for comfort measures to be administered. Yusnisha also insisted that she herself was to be the sole spokesperson and surrogate in any decision-making process. As this discussion was taking place, the patient experienced a massive heart attack and passed away. It transpired from later conversations with the rest of the family that, while Yusnisha's mother had wished for comfort measures only, Yusnisha's motivations in carrying out her duty as surrogate decision-maker and in abiding firmly *to her mother's wishes may have been far from creditable. Indeed, her siblings reported that Yusnisha had always been rather selfish and money-orientated. According to two of her siblings (to whom she confided) Yusnisha had only agreed to care for their mother because she felt that it was an easy and potentially lucrative proposition.*

In a similar scenario Naomi, a 40-year-old Chinese woman tasked with caring for her frail and elderly mother (her only remaining family member), who suffered from severe dementia, resigned her post at an eminent design firm. She passed up her chance of fame and recognition, even delayed her forthcoming nuptials, to see out her filial obligations. Naomi, like Yusnisha, insisted that only comfort measures and minimal interventions be employed upon her mother's admission to hospital for worsening sepsis and circulatory collapse. Though her mother had been clear in her wish not to have her life prolonged, Naomi's motivations were ruled by the fear that her mother would die during the forthcoming 'hungry ghost' month.[14-15] *Though Naomi was a devout Catholic, her mother remained a reverent Taoist. Naomi was keen to abide by her mother's faith and felt obliged to comply with her Taoist beliefs. The seventh lunar month of the Chinese calendar is often considered a particularly inauspicious time to die, for souls that pass during this month are believed to be doomed, lost, and carried to hell.*[14-15] *Motivated to protect her mother from an iniquitous afterlife, Naomi chose to respect her mother's stated wishes so that that she would pass on before such a period.*

Geraldine, a 30-year-old Chinese lawyer, found herself in a situation similar to that of Naomi when her mother, her only surviving family member, was taken ill with subacute bacterial peritonitis as a result of an underlying diagnosis of metastatic cholangiocarcinoma. As in the other case studies, Sally, Geraldine's mother, had made her wishes clear: she did not want life-sustaining treatment, having 'progressed through' multiple lines of oncological, radio-therapeutic, and surgical treatments. She had even gone as far as preparing written instructions to this effect. However, Geraldine chose to keep the knowledge of such a living will from her mother's treating physicians, insisting instead upon the administration of maximal treatment options. It has been since suggested that, rather than being concerned with her mother's wishes, Geraldine, who was named as the surrogate decision-maker by her mother, wished to prevent her mother's demise until her wedding to Anand, a local Indian lawyer. Due to the strict Indian customs and beliefs of Anand's family, Anand's mother would not consent to their wedding taking place within a year of the demise of Geraldine's mother. Vishant, Anand's brother, suggested in later conversations with social workers that Geraldine chose to overrule her mother's wishes out of unwillingness to delay her own wedding plans. Only some days after her return from her honeymoon, and in the face of mounting hospital costs, did Geraldine notify physicians of the existence of her mother's will and have her mother's ventilation and circulatory support, the 'extraordinary' medical interventions used in the face of progressive disease and continuing sepsis, cease as per the instructions of her 'living will' and Geraldine's wishes.

Actions speak only of the moment and merely hint at the moral character of a person, their motives, discernment and emotions. A review of an individual's actions, although it may be thorough and multidimensional, still fails to explicate the nature of that individual. The inescapable conclusion to be drawn is that the character of those within a clinical situation is the pivotal need for a holistic assessment of any clinical scenario that includes an evaluation of the actions that have been carried out by various parties.[81,83] In the cases above, the actions of Yusnisha, Naomi, and Geraldine may have been deemed acceptable, even though their motivations are not acknowledged by and even appear to be diametrically opposed to, deontic frameworks. It is this central observation that feeds the undertaking of this paper: that a framework must be found that is more applicable to local values and beliefs and which provides a better understanding of local character, relationships, emotions, moral education, moral wisdom, and motivations.[83-84] In the manner abjured by Hursthouse, the PCI acts to embrace the increasingly blurred ethical confines of deontology and virtue ethics to form a more clinically relevant and culturally sensitive concept.[83,84]

Of primary concern within this paper are the HP, patients, and families in the aegis of palliative care. It would be prudent at this point to provide an outline of some of the specific difficulties facing the practice of palliative care and, by doing so, tease out the importance of specific character traits and a full complement of virtues. Palliative care in its most basic form involves the care and relief of any of a range of symptoms that patients may have, from pain and shortness of breath to the psychosocial and spiritual problems of the dying. Palliative care moves beyond the myopic confines of patient-centred care and seeks also to care for the patient's family and carers through a holistic and multidisciplinary approach. This paradigmatic care approach, which has been shown to be particularly adept to the Singaporean setting, has increasingly been adopted by other medical specialties in order to meet the psychosocial, physical, spiritual, and emotional needs of patients and their families.

For many, the appeal of palliative care lies in the chance it offers to care for the most vulnerable of patients, those whose time is limited and precious. Many who embark on a career in palliative care do so as a result of a strong calling to serve their fellow man and a desire to be in symptom control, providing spiritual, emotional, or psychological support. There is no accompanying 'adrenaline rush' of the resuscitation room, as in TV shows such as *ER,* or 'power of life and death' surgeries such as are found in *Gray's Anatomy.* Nor are there significant remunerations, the 'perks' that one might see in *Royal Pains.* The rewards of palliative care are much more ethereal; they are best found in the eyes of patients, their families and the HPs themselves.

This paper holds that the motivation to participate in palliative care comes from within, fed by the predisposition of one's own character. Such tendencies or predispositions to act in a particular manner cannot be crystallized and divined by averring to one's duty to 'care,' nor can it be solidified by simply invoking the moral value of beneficence which is enshrined in the Hippocratic Oath and its successors. Elucidating what drives the inclinations of HPs to care for others in a field such as palliative care is integral in deciphering their motives—which is, in turn, a task of importance given the strong bearing that motives have upon ensuing actions. The need to understand motive is especially relevant within a field of medicine, such as palliative care, which seeks to assuage the needs of both the patient and their families and loved ones by extolling the virtues of caring and adhesion to familial bonds. Here, strength of character and moral values are pertinent to how a HP might address matters of existential and psychosocial care. The cold, detached, dialectic computations of a deontic framework fail to address the many enmeshed social, emotional, motivational, cultural, and spiritual facets within the milieu of holistic care. Such a situation compels closer scrutiny of 'supratentorial' matters rather than purely matters of sterile logic. The acceptability of a decision (or the motives for an action) must be dependent upon the deliberations of existential facets such as strength and character and moral values, and not only on clinical or technical points.

In the case of Yusnisha, Dr Alwandi, the primary physician, was eager to acquiesce to Yusnisha's requests, for he strongly believed that both the patient's quality of life and her outlook were compromised and bleak. As a proponent of euthanasia, he was motivated by his own strongly held beliefs to meet her needs in this way. To him, euthanasia appeared to be justified, especially as a result of the daughter's (and indeed the patient's) past discussions. While he was not in a position to affect such an outcome, his motivations would nonetheless be important to discern, given their potential impact upon the care of subsequent frail patients. Indeed, a review of some of his cases involving frail elderly patients consistently revealed a tendency to withhold or withdraw care at an earlier juncture than would other physicians. In such a case as this, understanding his track record would have great bearing on the future care of patients.

It is clear that motives cannot be adequately understood from consequentialist or deontological views. Rather, motives require reference to a virtue-based framework to truly discern a thorough character trait analysis.[83-84] This, then, exalts the importance of elucidating the character, motives, and moral wisdom of HPs, as well as those of patients' families and surrogates. To help structure thinking and analysis in matters pertaining to the elucidation of character and the importance of relationships and emotions within moral life, this paper will consider Hursthouse's formulation of virtue ethics [VE], as published within her treatise entitled "On Virtue Ethics."[83-84] The importance of such scrutiny lies in the need to discern the integral role of aretaic factors within complex clinical assessments.

Facets of Aretaic Considerations

To begin with, some characterisation of aretaic elements is required. Character traits, Hursthouse posits, convey the predisposition of the HP to act in a specific manner and are far more than simple habits. On the contrary, they 'go all the way down' and represent a 'disposition that is well entrenched' through habituation and that is, in turn, dependent on a myriad of factors, ranging from culture and religion to the influence of exemplars, parents, and peers.[83]

Virtues are postulated to be 'multi-track,' well entrenched character traits that do not concern themselves exclusively with actions but also with "emotions, emotional reactions, choices, volitions, values, desire, perceptions, attitudes, interests, expectations and sensibilities." These things provide an agent with a "wholehearted acceptance of a certain range of considerations as reason for action" in the practical matters within a specific situation.[83-84] They are assimilated through practice and dependent upon experience, judgment, emotional maturity, and knowledge in order to bring about the best feeling, reasoning, and action, and promote the realization that the best possible outcome within a specific context simply is a means to its own end.[80,83-86] This is in keeping with the pursuit of the aretaic goal of *eudaimonia*, a 'flourishing' or happy and meaningful life that can only be achieved by being virtuous.

Within an aretaic system, a single good action does not define character, but merely hints at it. Kant famously argued that the will of the individual determines the rightness or wrongness of an action.[87] Indeed, good actions may simply reflect obedience to a duty set out by frameworks and guidelines, and not bear witness to the authenticity behind the action. Thus, it is the HP's track record that engenders a better understanding of their character.[83-84] Simply analyzing a single action will not fully crystallize his or her motives, nor will it assign praise or blameworthiness, for the performance of a good act. Instead, imbuing such evaluations with considerations of the character, motivation, and past actions of the person may shed some light upon that person's ethical considerations. The cases of Yusnisha, Naomi, Geraldine, and Dr. Alwandi reflect this point. The assumption is that a moral person, with a track record for being virtuous, is more inclined to act morally, particularly within situations where a distinct line of action is not clear and the options are ethically ambiguous. Such an inclination to act appropriately is then said to arise due to its being part of a person's character.

Simple adherence to deontic ideals, though these ideals may provide specificity and balancing mechanisms within their formulation, is unlikely to delineate a means of proceeding in a clinical setting, particularly in the face of cultural, societal, and religious variability. While not tantamount to moral absolutism or an unwavering perception of right and wrong, deontic frameworks still struggle to provide the flexibility required for such complex and variegated cogitations, especially when balancing competing prima facie obligations that appear to be dependent on agents for their resolution. Resolution of such conflicts requires appropriate elucidation of the processes that undergird them, as well as the inclinations, moral sense, emotional responsiveness, character, and moral insight that feed this process. It is, therefore, particularly pertinent that a firm grasp of the physician's, and indeed the surrogate's, character is appropriately discerned and their motivations garnered, given that ensuing praiseworthiness or blameworthiness of their actions depends upon it. Motivation and intention, especially the subtle differences between these similar terms, play a significant role in the determination of character. Intention aims at a certain *outcome*, while motivation aims at an *action*.[89] The motivation for an action must, as with all facets of the HP and the patient's family and surrogates, be analyzed within its context and placed within a holistic review that can only truly be met through the multidimensional considerations of a specific case.[90] However, good motivations alone do not make for good actions. Being virtuously motivated and, yet, carrying out an action that is not virtuous reflects a deficiency in another pivotal element of aretaic considerations, that of practical wisdom [PW].[83,84]

Hursthouse views PW as "the ability to reason correctly about practical matters" which "anyone can gain in the course of an ordinary life" and which is "available to anyone who really wants it." PW endows its possessor with an objective viewpoint, a situational appreciation within a context, and the ability to recognize the important factors for consideration and to secure real benefits effectively.[83-84] Character and PW take pride of place when contemplating care of patients whose clinical, emotional, social, relational, and spiritual conditions are fluid.[83-84] In such cases, the changeability of a patient's condition is quite unlike the classically presented scenarios envisaged in bioethical case discussions, cases that appear to pirouette upon singularly dramatic and defining moments. In reality, no single 'snap shot' review of a case will fully encapsulate the changing landscape of the patient's or their loved ones' situation. Reality necessitates comprehension an evolving situation's influences and effects when discerning a plan of action. The place of PW in discerning the correct line of treatment (and non-treatment) is imperative to good care provisions and is integral to a wider contextual appreciation of holistic care provision, an appreciation that appears deficient within the deontic framework.

Experience, be it personal, professional, emotional, psychosocial, or spiritual, plays a role in honing PW.[83-84] Work experiences, coupled with life experiences, help many HPs to gain some semblance of insight into clinical environments and discern the intricacies and nuances of decision-making. Experience, in tandem with the perceptions and intuitions of a specific case, can also provide wisdom in communication and treatment of patients from varied social, psychological, spiritual, relational, and cultural backgrounds. Indeed, such wisdom and experience is integral in clinical care.[83-84]

For example, simply gleaning information through verbal assessments and data is clearly insufficient to meet the rigors of holistic appraisals. Rather, sensitivity to body language and other nonverbal cues is also required, as well as ancillary observations and contextual appreciation. It is not only an appreciation of the cultural, religious, spiritual, emotional, and social matters that is required to conduct a holistic appraisal, but also a comprehension of the situation and its impact on and interplay with the patient's own narrative.[83-84] Judgment that is inspired and guided by practical wisdom plays a role in sifting through the relevant facts and determining their contextual relevance. While neither 'cast iron' nor always reproducible or validated, PW-driven judgements do appear able to capture the intricacies of a complex situation and help the HP act in a manner that responds appropriately to the needs of the patient and the family. Surely such evaluation better reflects the reality of clinical decision-making than does the 'cut and dry' appreciation framed by a deontic evaluation. Often ignored by deontic frameworks, experience and narrative-appreciation that aid clinical judgment, reduce errors, and make for a better decision-making processes are certainly given an important position within the cogitations of this more inclusive framework.[91-95]

PW-inspired judgments also consider the consequences of decisions made within the clinical setting. While consequences are not the primary concern of VEs, they cannot be given short shrift, nor can they be completely discounted, especially within clinical practice. Adequate judgment must be used in considering the cardinal elements of PW, and in achieving a holistic appraisal of the consequences from a physical, emotional, psychosocial, moral, motivational, historical, and personal narrative perspective, thus contending in any deliberation with acumen and experience, armed with clinical evidence. In this way, judgement allows for the consequences of one's actions to influence the deliberative process and steer actions toward a specific route or plane of possible undertakings. The values and beliefs of those involved are salient to the consultative process as well, as any prejudices and biases undoubtedly have an impact upon steering deliberations and guiding actions.

On the subject of guidance, Hursthouse concludes that the direction one should take will be forthcoming as a result the discernment of virtues within a specific clinical setting. Such specification makes for very characteristic and idealized rules that arise from context-defined vices and virtues. These emergent rules are referred to as 'v-rules.'[83-84] Defined by the context and specificity of the situation, v- rules offer guidance that is more orientated toward the patient and his or her family and is in keeping with the 'case specific' approach adopted in daily clinical decision making.[89,95] Within the PCI, 'v- rules' are supplemented by deontic core considerations that also shepherd deliberations within distinct moral, ethical, clinical, and legal boundaries. Indeed, within this context, the intersection of the two disparate ethical frameworks, we arrive at the rationale for creating the PCI. The combination of deontic and aretaic models better meets the goals of a clinically relevant, ethically sensitive, and culturally and religiously cognizant framework of decision making for HPs who care for patients at the end-of-life. The coadunation of these two thought processes best reflects the realities of clinical decision making within the Singaporean context and provides a better provision of guidance in resolving moral dilemmas at the end-of-life.

The complexity of care within the Singaporean setting, as elaborated by the cases presented earlier, certainly attests to the need for such a combined formulation. Moral intuitions are sometimes in conflict with social, cultural, or even religious demands, and a framework that shows appreciation for both considerations would be useful in balancing these conflicting motivations. Such problems appear magnified within the local context of multiculturalism and multi-religiosity, for the identification of pertinent virtues is often believed to be religiously, culturally and socially defined. Judgment is pivotal, corralled and supplemented by the insights and the deontic obligations of the many professionals contained within a Multidisciplinary Team [MDT] and tempered, as I will argue, whenever possible by the patient's own input and those of his carers and loved ones. As will be discussed later, the MDT as a whole, replete as they are with the cultural, social, religious, and narrative-based considerations of the clinical context, will aid delineation of the overriding virtues and obligations within a multifaceted setting.

It is within such settings that we also see another pivotal facet of human nature that is frequently ignored by deontic frameworks and which should take pride of place within any judgment. Emotional sensitivity plays a significant role in how an agent chooses to approach a patient.[80,96] It aids in the initial assessment of both clinical situations and the repercussions that follow the action taken. Its place is also imperative to good clinical care and must be taken into account within any deliberation.

Emotional sensitivity, perception, and PW also occupy pivotal roles in the perception and appreciation of the many and various facets which may be influenced by an action, including a patient's autonomy, quality of life, motivation, confidence, emotions, goals, and values, as well as the effects which an action will have upon those near and dear to the patient. Appreciating all of these factors is certainly not easy, but doing so but has a major impact upon both the care that is required and what measures can realistically be provided. In Singapore, where cultural and religious mores take on an added dimension and where bonds formed between HPs and patients and their families are given appurtenant reflection within the deliberative process, such emotional sensitivity and appreciation of the situation illuminate and supplement evidenced based practices.[96] Furthermore, emotions that are attuned to societal rules and mores will allow for the 'authenticity' of both a HP's and a family member's actions to be crystalized—which will, in turn, help characterize traits and elucidate worthiness for commendation.[97]

Indeed, the benefits of judgment are multiplied in the face of the multidisciplinary approach adopted within the palliative care model. Experience with complicated and taxing situations can be drawn upon when needed and can make the provider more responsive to evaluations within the inevitably changeable situations that take place in a patient's care.98 Similarly, maturity, expertise, and experience within a multidisciplinary team will create flexibility in the decision-making process, allowing for the better utilization of discretion where case-specific considerations are involved. This discretion facilitates better action-guidance for HPs facing difficult decisions at the end-of-life, with the concurrent utilization of the PCI further substantiating this position. The experience gained from the interactions between experienced HPs also confers personal benefits to HPs within the multidisciplinary setting. Members of the multidisciplinary team can act as exemplars for the more junior members of the team by instilling and cultivating virtues, developing and honing PW, and providing a wealth of knowledge upon which junior members can draw. Guidance, experience, and habituation of good practice through such a work ethic can only aid moral goodness within HPs.89,99-100

Concerns with Regards to Virtue Ethics

While, on the surface, much can be said for the enrichment of the DoPC through the addition of a system of virtue ethics [VEs], concerns remain about its applicability and viability within the clinical setting. These concerns relate to the discernment of the various facets of VE's triumvirate of key components, given that little is made of how and when they are attained. Such a lack of guidance in this area is particularly stark when considering the issue of PW. Despite the existence of a set-out list of PW's components, no 'detailed specifications of what is involved in such knowledge or understanding has yet appeared in literature.'[83-84]

The discrepancy between the need for VE in their practice and the inability to properly understand how PW comes about (and at what point PW is fully attained) leaves HPs in as much a quandary as they began with. There is much to be said with reference to PW's many constituents, but little, if anything, to be said concerning how each of these constituents is garnered when a HP has gained sufficient value to be considered ready for PW. What is clear, however, is that despite Hursthouse's exaltations that PW can be gained through 'just plain worldly knowledge,' from the *nous* that comes as a result of previous experience and lessons learned by adopting a holistic view of considerations rather than 'mother's knee' rule,' there still remains a significant gap in understanding the method for acquiring PW.[84] This understanding is particularly cogent given that PW appears to be an all or nothing element. The problem reverberates even further when one contemplates exactly how PW works, either as a master virtue or a compositional element of each and every virtue. Within this latter formulation, a virtue is composed of base parts. For instance, the virtue of courage is composed of moral goodness, PW, and courage. The compositional view instills the notion that PW provides particular guidance for a specific virtue, the fact that working in concert with the other elements enables a virtue to reach its target. The master virtue view, on the other hand, addresses PW as an overarching virtue that guides all of an agent's virtues towards the target of *eudaimonia* (human flourishing) as a bow guides its various arrows towards a target. In contrast, the compositional view presents PW as many bows, each specifically trained on a given virtue.

It is only in the discernment of the intrinsic nature of PW that an agent who seeks a virtuous life can come to comprehend the task set before him or her. Though it is beyond the remit of this paper to synthesize a cogent view of PW, the merits of both camps are clear. The strengths of the compositional view, for instance, lie in its ease of comprehension. This concept is more manageable and more attainable simply because it is, for the most part, more explicit and circumscribed. Conversely, a master view gains strength from the synergistic, non-linear and additive experiential effects of the various components of PW as they come together within a 'pool' of knowledge, experience, emotions, values, ethics, and personal views that are specific for the agent and which unquantifiabley change with agent's changing perspective and attitude. Such affects will, undoubtedly, produce changes in the agent's cognition and consciousness that may not be initially felt. Much like a ripple, the full result of these unquantifiable changes may not be felt immediately.

Because the appositeness of both formulations is called into question when one considers the variances within the definitions and the disparate understandings for the various virtue and *eudaimonia* concepts, problems persist in the interpretation of both the component and master views of PW. Certainly, situational appreciation of the relevant cultural, societal, and religious mores becomes complex within a multicultural society, and even more so within a multi-religious, multiethnic family. Such families are becoming increasingly common in Singapore.[14-15,101] To be clear, it has been observed that many palliative care patients are becoming increasingly immersed in many religious views, notably supplementing Christian beliefs over and above prevailing Hindu, Taoist, and Buddhist values. Cultural and sub-cultural variances have also taken root in Singapore, and a true appreciation of their beliefs will certainly require a good grasp of local and personal ideas and thinking. This fact is particularly important given, as Macintyre posits, the appreciation of such specific goals of life can only be applicable with like-minded individuals and within an increasingly bureaucratic and individualist society, for the understandings of what constitutes a moral life and a moral good will differ.[87] Once more, the role of the supplementing input from the MDT to perceive such personal and varied differences from a patient's point of view becomes vital.

Similar problems also arise regarding the authenticity of actions, the multi-track nature of a HP's character (and the discernment of this character upon a background of emotional and psychosocial elements), the true, viable, place of a VE system in realistic clinical considerations. All such aspects need clarification if VE is to be useful within the clinical setting. The solution, however, may already exist within the workings of modern palliative care teams.

The Value of the Multidisciplinary Team [MDT] Approach

Hursthouse has declared that perfect virtue is rare, alluding to the need for exemplars and guidance in both deliberations and actions.[83-84] In an arena like Singapore, which boasts such socio-cultural and religious diversity, the need for guidance and support becomes particularly evident. Influenced by the British and Canadian palliative medicine models, and in line with the central tenets of evidenced based medicine and holistic care, multidisciplinary teams [MDTs] have been integrated into the developing palliative medical practice in Singapore. The teams seek to meet the needs of morally continent HPs as they attempt to effectively and appropriately discern the overarching duty and pivotal virtue of each situation within the milieu of the individualized clinical settings.[83-84]

An MDT is defined as a "group of people of different healthcare disciplines, which meets together at a given time [whether physically in one place, or by video or teleconferencing] to discuss a given patient and who are each able to contribute independently to the diagnostic and treatment decisions about the patient" as well as to elaborate upon the various bio-psychosocial, spiritual, and cultural aspects that may be relevant to the provision of care and support of patients and their families.[102] In utilizing expert knowledge that encompasses a myriad of specialties (such as nursing care, psychological and pastoral support, occupational therapy, physiotherapy, financial advice, and social support) palliative care teams are better able to minister to the various aspects of physical, spiritual, psychosocial, and cultural elements that constitute a holistic approach to patient and family care. This multifaceted, multitalented, and multi-trained complementary and interdependent approach has been validated in a number of settings and found to be effective in meeting the goals and complex needs of palliative care patients and their families.[102-4]

To actualize such an individualized and thorough approach to care of the patient and family requires a wide remit of concern and a deep understanding of the intricacies of each individual clinical case that is unlikely to be met by a singular health care professional. Much like putting snapshots together to produce a collage, the wider considerations which are called for in any holistic care consideration can be met in the different angles, opinions, and perspectives that are proffered by the MDT. Such a system will enrich palliative considerations and prevent relevant material from slipping between the cracks that inevitably arise when a single individual handles such decisions. Furthermore, specialists in medicine and allied fields will further imbue ongoing assessments of emotional, spiritual, and cultural elements, as well as character analysis of the persons involved, into the clinical scenario. The wider assessments of the situation that they provide will be added to the input of all the other members of the MDT, thus producing the best possible holistic assessment, given the constraints of modern medical practice.

It is, therefore, unsurprising that a good palliative care approach can be carried out by a team of professionals with clear knowledge of the mandates of their roles and obligations. Through the appropriate consideration of clinical and psychosocial issues, as well as the cultural and spiritual values relevant to the patient, decision making and care provision will move beyond a purely clinic-orientated approach into one that is in keeping with the central tenets espoused by palliative care. Furthermore, open discussion within clearly defined professional parameters advocates a platform for the building of consensual flexibility, responsiveness, and engagement rather than a dependence on the sole influence of a single element, consideration, individual, perspective, or framework. Such a multidimensional approach also ensures agreement upon the overriding duty and pivotal virtue that must be addressed within changeable conditions, such as those seen within end-of-life care.

In an MDT approach, objective determination of virtue and overarching duty are reached by balancing each of the competing duties and virtues that have been raised by the members of the MDT, as well as the 'weight' coordinates, against the importance of duty and virtue that is determined consensually by the MDT within the specific context. Each aspect is then weighed up against the particularities of each individual case, balanced, and a consensus decision taken. It is important that the 'weight' of any element within the discussion is determined after a close consideration of the patient and the family's situation, the clinical, psychosocial, and spiritual context, rather than by the seniority of any member of the MDT. Such a consensus-driven approach would also displace suspicions that, despite this confluence of various specialists, technical or medical perspectives would continue to take precedence over moral, ethical, emotional, and spiritual matters. The presence of psychologists, medical social workers, spiritual advisors, and experienced nursing staff ensure that all deliberations are tempered by the essential ingredients of patient-centred care that remain the pillars of the palliative care approach. Given the varying 'bases,' the starting points of considerations, biases and perspectives upon which elucidation of virtues can begin, the MDT setting allows differing view points to be drawn together. A single-voiced approach might be likened a solitary photograph of an event or multiple pictures of an action from a single vantage point, while the MDT approach provides multiple pictures from multiple sites of the same event, as well as pictures associated with and relevant to the events. The result is an effective facsimile of the setting in 3D, also includes the background information leading up to the event. Any incongruent evaluation of the situation is reviewed and considered appropriately, while simultaneously being infused with the moderating and nurturing influences of the skills, insights, and intuitions of the various HPs in the MDT.

The wide-angled view provided by MDTs can also include evaluations over a period of time. Discerning the character of the patient is integral to the determination of the overarching duty and pivotal virtue in any specific case, especially in divining the goals of care and the best interest determinations of frail and, sometimes, incompetent patients at the end-of-life. An appreciation of a person's background, as well as their track record, will hint at their predispositions to act, their motivations, intentions, and (especially) their character in the face of evolving disease or psychological conditions. Many palliative care patients, as we have observed, are both emotionally and psychologically affected by ongoing disease processes and are frequently left incapable of making competent appraisals of their conditions, let alone asserting their wishes, in such cases. Appraisal over time, as well as an understanding of the patient's history, provides critical input to the decision-making process that is aimed at protecting the patient's best interests.

This is not an attempt to suggest that simply discerning a patient's track record of behaviour is sufficient to tease out their character, but it does hint at such character. In such cases, multiple evaluations, some simultaneously and in tandem with other HP, others individually at different times, and still others (as is especially the case with nursing, occupational, and physiotherapists) over a length of time, will confer the MDT with a better appreciation of the patient's behaviour in various contexts and under the influence of different levels of emotional and psychological inputs. This rounded view of the patient provides a distinctive awareness of their decision-making history, thus better informing the MDT of the motivations and inclinations that play a part in the clinical decision-making process.

From a practical point of view, it would appear that the MDT may be as close to a virtuous agent as is possible and, as such, may be the best chance of meeting the goals of a VE-inspired and practical-evidence-based ethical framework. Governed by the deontological pillars upon which the PCI is moulded, the general obligations of each member of the MDT and the specific obligations of the MDT as a whole complement the 'v- rules' in ensuring that any action taken will be within the boundaries of acceptable practice and will be guided by both clinical guidelines and the legal system. Fears of a moral ambiguity towards moral rules and an apparent lack of absolute prohibitions, particularly within the vulnerable setting of care for the dying, are thus allayed. In the specific confines of end-of-life care, specific duties continue to act as boundaries to acceptable practice over and above the simple observance of laws. In such boundaries, there is 'safety' in imbuing considerations with cultural and societal mores and religious beliefs in order to balance the various ideas, opinions, and perspectives that are involved in a patient's care without concern that any one part will overwhelm the decision making process. Thus, the well considered, equitable, effective, accountable, and focused interface that is provided by MDTs, in which group experience and *nous* are given voices, may be as close to a virtuous agent's objective determination of primary goals and virtues as is practically feasible.

Conclusion

The DoPC that complies with the impartial and unwavering machinations of a deontic framework fails to contend with the admixture of emotional, social, and spiritual contingencies inherent in care for the terminally ill and their loved ones. With this in mind, the supplementation of a deontic system to a Virtue Ethics [VE] framework appears to be a logical evolutionary step, which initiates a larger idea of ethical conceptions and brings about the metamorphoses of a more holistic stance, one that is consistent with the ethos of palliative care. This evolved model of the Palliative Care Imperative [PCI] broadens understanding and appreciation of the wide context of decision making at the end-of-life. Imbued within this conception is an agent-specific viewpoint that is enriched by emotions, intuitions, motivations, judgments, and moral perceptions, providing a legitimate platform for the integral factors within deliberations. Similarly, the evolved model of palliative care allows for the appropriate and necessary infusion of religious, social, and cultural mores into its complex reckoning.

Such a model also allows for circumstantial and temporal appreciation of an evolving clinical, emotional, psychological, social, and spiritual situation and the ensuing changes in goals and preferences that follow. The adaptability thus provided better mirrors the reality of clinical decision-making that does not succumb to a rigid set of considerations. This is particularly significant within the multicultural, multi-faith, multiethnic backdrop of Singaporean clinical practice. The variability inherent in the evolved model of the PCI also serves to highlight the importance of motives and emotions in exercising actions that are in keeping with the HP's character and which meet the criteria of the rules and obligations placed upon them. The weights of discernment and of the balancing of consequences lie upon the cultured coadunation that occurs within a rich admixture of religious and local mores, cultural sensitivity, and clinical and moral judgment.

The PCI gives value and balance to an appreciation of the patient and their family's wishes and goals, avoiding a merely technically led discernment of care for the dying in favour of a system which better frames patient care within the specifics of a clinical context. This is particularly pertinent given the dearth of evidenced-based medicine in palliative care and the continued dependence upon interventions that are, at best, experienced based, best opinion led, or simply dependent upon intuition.

The PCI addresses the shortcomings of a universal, rational, and impassive deontic framework that chooses to neglect the nuances of the individual. In addition, it does not succumb to the allure of an overly individualistic moral framework; fighting this allure by utilizing the specific duties set up within the DoPC to reign in expectations. Balance is attempted by considering both clinical and technical aspects, as well as personal and character-based regards, upon an equal footing. Both aretaic and deontic ideals highlight differing aspects of a holistic appraisal of the clinical situation, which holistic approach better succeeds in proffering a flexible, universal, and overarching ethical framework for care of the dying. Together, within the PCI, aretaic and deontic ideals are better able to consider both the pivotal moments in decision making and the fluid state of change in the clinical setting, thus freeing them of restriction to simply the disease, and allowing them to take into consideration the people involved.

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BOOK REVIEWS

Recognizing Transsexuals: Personal, Political and Medicolegal Embodiment

Zowie Davy. Farmham, England: Ashgate Publishing, 2011.

ISBN 978-1-4094-0565-8; 195 PAGES, CLOTH, £55.

What is the meaning of embodiment? How do our biological bodies relate to our gender? What constitutes personal and gender identity? These questions arise from reading *Recognizing Transsexuals: Personal, Political and Medicolegal Embodiment* by Zowie Davy—a revealing book about the recognition and non-recognition of individuals who desire to live out a sexual identity that is different from their biological sex. Davy explores trans people's embodiment and bodily aesthetics through the conceptual framework of recognition, using a multi-faceted grid that encompasses self-, other-, and medico-legal recognition. Her study, grounded in the works of Heidegger, Merleau-Ponty, Foucault, and Bourdieu, examines embodiment through the heuristic devices of the phenomenological, social, and sexual bodies of trans people. She argues that, as a cultural construct, gender is merely a way of donning one's body; it is a fluid process involving trial and error. Hence, transsexual embodiment cannot be captured by a strictly dimorphic body paradigm and culturally defined set of hetero-normative behaviors. Rather, transsexuality deserves to be recognized for the diverse phenomenon that it is.

After an introductory chapter establishing her argument, Davy examines the current legal and procedural milieu of the UK with respect to transsexuals—the Gender Recognition Act. She then moves to the heart of the book, a sociological exploration of the process of transitioning that addresses the phenomena of male (FtM) and female (MtF) "body projects" separately. Such projects are not understood to be manifestations of an ontological identity, but agentic negotiations of medical and legal "binary norms" by which transsexuals "construct, deconstruct, and reconstruct . . . narratives of authenticity" that will enable them to acquire the recognition and resources required for their projects. (125) This authenticity, however, has no relation to fact or truth, but only to phenomenal reality—what "feels" real. Davy's final chapter is a critical analysis of the work by various trans-community organizations that promote "trans bodies," both politically and culturally.

Postmodern, poststructuralist, and queer gender theories are foundational for Davy's promotion of non-normative gendered living. Accordingly, there is no "core gender," only a bodily aesthetic that holds intrinsic meaning; personal, social, and sexual meanings are contextually determined. Davy maintains that such body projects are realized through clothing, make-up, and hormones as well as the creation and destruction of genitalia. In true postmodern fashion, all is text, including the body, and it is the "reader" who determines the meaning of the bodily aesthetics and whose "response" is sought.

Three goals mark Davy's agenda: to affirm the diverse manifestation of trans people; to assert the primacy of transsexual embodiment over gender identity; and to depathologize the phenomenon of transsexuality. However, only the first of these goals is realized. Davy argues that a transsexual body project is not the result of gender identity but constitutes it. Yet, the very fact that she refers to trans body and bodily aesthetics as "projects," affirms the primacy of gender identity over embodiment. Secondly, she claims that "transsexualism is not a medico-pathological condition . . . but an agentic self-diagnosis." (104) However, Davy recognizes that body modification projects require medical resources that are only available by way of a pathological diagnosis: gender dysphoria. While there is a personal cost to pathologization of transsexuality, there is an economic cost to de-pathologization, namely loss of free access (in the UK) to resources required for body projects. This need places Davy in the proverbial space between a rock and a hard place. Furthermore, while Davy speaks of the importance of relationships and communities for trans people, she focuses, narrowly, only on supportive sub-cultural communities, glossing over the issue of regret (mentioned briefly on page 26) and never speaking of the impact transitioning might have on transsexuals' non-trans family members or on their own children.

As our culture progressively normalizes previously aberrant behavior in the name of individual self-expression and self-fulfillment, the notion of "normativity" becomes increasingly deconstructed and diminished. Ultimately, we are being called to deny our binary beginnings as well as any binary understandings of sexuality and gender. Self-understanding must succumb to self-creation. Problematically, with greater recognition of trans people (for which Davy argues) comes greater demand, in this case, for body modification therapies. The US, which is currently facing significant changes to its healthcare system, will also be faced with the question: what responsibility do societies have to provide medical resources in order to treat desires (which Davy clearly states that these are)? How will we accommodate demands for body modification therapies, whether for transsexuals or apotemnophiliacs?

This book is an important read, not only for the insight provided into the lives of trans people and transsexual embodiment, but also for the social, cultural, and economic impact these ideologies will have on our own understanding of who we are as male and female, both, or neither.

Reviewed by Susan M. Haack, MD, MDiv, MA (Bioethics), FACOG, who is a consultative gynecologist at Hess Memorial Hospital and Mile Bluff Medical Center in Mauston, Wisconsin, USA.

Bioethics and Beatitude: An Introduction to Catholic Bioethics

Nicanor Pier Giorgio Austriaco. Washington, DC: Catholic University of America Press, 2011.

ISBN 978-0813218823; 327 PAGES, PAPER, $24.95.

For many Protestant Christians, studying Roman Catholic ethics or moral philosophy can seem like learning a foreign language with new vocabulary, syntax, and grammar. Moreover, for many Catholics, justification of a Catholic bioethical position is often unknown and/or not understood. The recently published work, *Biomedicine and Beatitude: An Introduction to Catholic Bioethics,* adds another book to the list of introductory books on Catholic bioethics, filling a need for Protestants, Catholics, and non-Christians alike.

Nicanor Pier Giorgio Austriaco, a biology and theology professor at Providence College, is the lead author of the work. As stated in the introduction, this book "narrates a bioethics that emphasizes the pursuit of beatitude in the lives of those who are confronted by the moral questions raised by the biomedical and the other life sciences, and the dynamic interplay of faith and reason that characterizes the Catholic tradition." (1)

Although organized into 8 chapters, the book contains three main sections. Chapter one, entitled "Bioethics and the Pursuit of Beatitude," gives "an overview of the Catholic moral vision that places bioethics within the context of each individual's pursuit of beatitude." (7) In this chapter, the writer examines both the way that bioethics intersects the Christian life and the manner in which Roman Catholics justify the rightness and wrongness of actions.

The second major section of the book is organized around a life cycle theme, with chapters on the beginning of life (chapter 2), human procreation (chapter 3), the clinical encounter (chapter 4), and the end-of-life (chapter 5). In each of these chapters the author examines contemporary Catholic and oppositional perspectives on relevant ethical issues, including abortion, in-vitro fertilization, euthanasia, and more.

The third major section covers miscellaneous issues, with chapters on organ donation and transplantation (chapter 6), research bioethics (chapter 7), and bioethics in a pluralistic society (chapter 8). Again, the writer offers both a fairly traditional Catholic position and common objections in each of these areas.

The work distinguishes itself from other books that introduce Catholic ethics in the way it attempts to relate bioethics to the Catholic Christian faith journey. Chapter one discusses important Catholic moral virtues that are involved in bioethical dilemmas, including prudence, justice, fortitude, and temperance, as well as important theological virtues such as faith, hope, and charity. Each subsequent chapter concludes with a discussion of how these virtues of the Catholic faith walk might relate to the subject matter contained in that chapter. The inclusion of these discussions adds a new and helpful element to the literature on introductory Catholic ethics.

The book contains many references that tie its teachings back to papal writings, Catholic hospital directives (ERDS), *The Catechism of the Roman Catholic Church*, and other contemporary and historical Catholic sources. Unfortunately, there is virtually no discussion comparing Catholic teachings on these ethical issues to those of either Liberal/Progressive Protestants or Traditional/Reformational/Evangelical Protestants. Even so, this work can benefit Protestants, Catholics, or secularists who want to learn more about Catholic bioethics.

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