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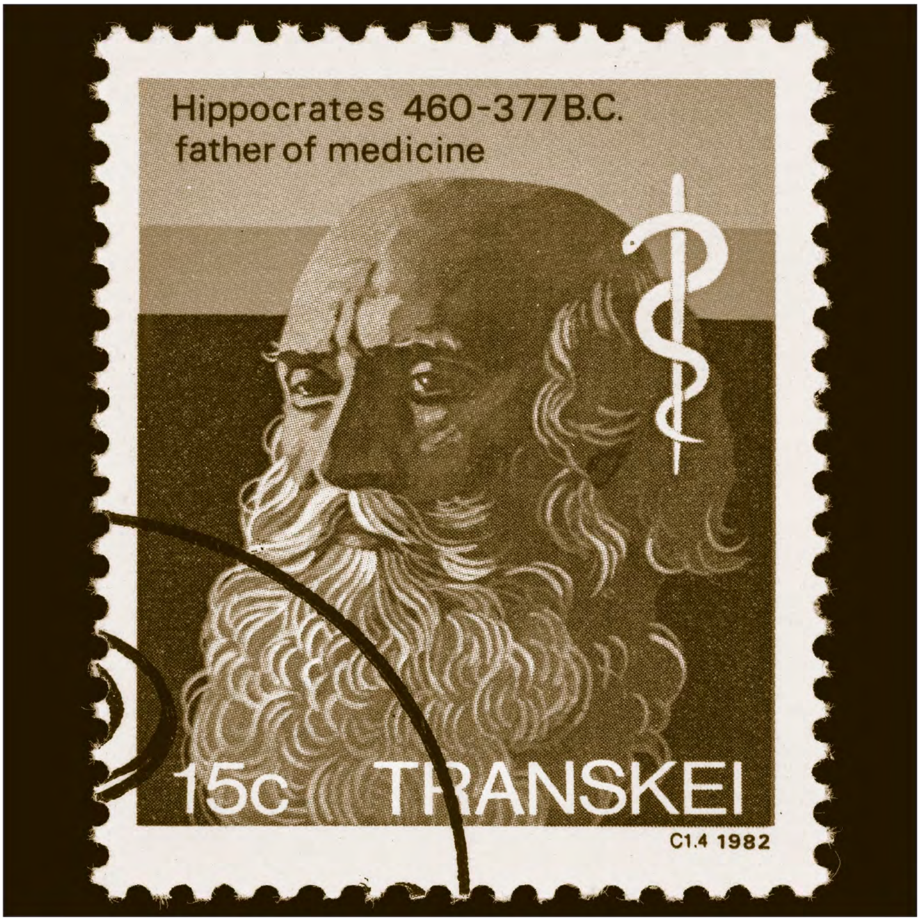

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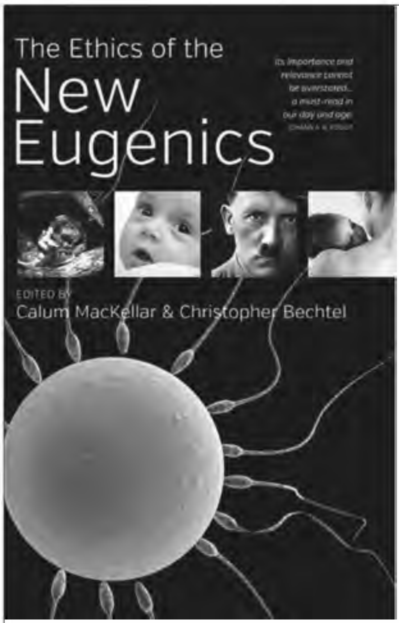

THE ETHICS OF THE NEW EUGENICS

Edited by Calum MacKellar and Christopher Bechtel

"The book is clearly written, easy to follow, well-structured, and well-researched. A lay audience will easily access and understand the debate and realize what is at stake with the new eugenics. Medical procedures and technical concepts are well explained … [Its] importance and relevance cannot be overstated … a must-read in our day and age, especially when biotechnology and the new eugenics can be a threat to all of humanity." • **Johann A. R. Roduit,** Institute of Biomedical Ethics, University of Zurich

Strategies or decisions aimed at affecting, in a manner considered to be positive, the genetic heritage of a child in the context of human reproduction are increasingly being accepted in contemporary society. As a result, unnerving similarities between earlier selection ideology so central to the discredited eugenic regimes of the 20th century and those now on offer suggest that a new era of eugenics has dawned. The time is ripe, therefore, for considering and evaluating from an ethical perspective both current and future selection practices. This inter-disciplinary volume blends research from embryology, genetics, philosophy, sociology, psychology, and history. In so doing, it constructs a thorough picture of the procedures emerging from today's reproductive developments, including a rigorous ethical argumentation concerning the possible advantages and risks related to the new eugenics.

Calum MacKellar is Director of Research of the Scottish Council on Human Bioethics, Edinburgh, and Visiting Professor of Bioethics at St Mary's University College, London, UK.

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EDITORIAL

On the Role of Physicians and Goals of Medicine

C. BEN MITCHELL, PHD

In the preface of his benchmark work, *The Patient as Person*, the late Paul Ramsey reminded us that the problems in medical ethics that are most urgent today are not problems upon which only the experts may have an opinion. “They are rather,” he said, “the problems of human beings in situations in which medical care is needed. Birth and death, illness and injury are not simply events the doctor attends. They are moments in every human life. The doctor makes decisions as an expert but also as a man among men; and his patient is a human being coming to his birth or to his death, or being rescued from illness or injury in between.”

Historically, the role of physicians has fallen under a variety of metaphors. In the earliest days, the physician was father. This was not only the case because it would be nearly impossible to find a physician who was not male, but because of the overweening *pater*-nalism of the tradition. After all, one of Hippocrates’s famous *Aphorisms* was the following: “Life is short, and the Art long; the occasion fleeting; experience fallacious, and judgement difficult. The physician must not only be prepared to do what is right himself, but also to make the patient, the attendants, and externals co-operate.” Under this model, the physician clearly called all the shots. He is the one who “makes” others, including the patient, cooperate.

Alternatively, physicians have been seen as military leaders, battling the great evils of illness, disease, and, especially the *summum malum*, death. Unlimited, unconditional war framed the practice of medicine in its aim of conquering the great physical, emotional, and spiritual maladies of humankind. The medical armamentarium was at the disposal of the fearless general who led the troops into the theatre of war, including the surgical theatre.

More likely than not, today’s doctor is viewed—and may view herself or himself—as a technician. Technological innovation is the way of life. The interpretation of lab values is more important than palpation. An iPad may be more useful than a stethoscope. And a diagnosis like psoriasis becomes what the novelist John Updike once called, “a twisty Greek name it pains me to write,” rather than a patient’s own narrative. Here is Updike’s description of how a character in one of his stories experiences his dis-ease:

> I am silvery, scaly. Puddles of flakes form wherever I rest my flesh. Each morning, I vacuum my bed. My torture is skin deep: there is no pain, not even itching; we lepers live a long time, and are ironically healthy in other respects. Lusty, though we are loathsome to love. Keensighted, though we hate to look upon ourselves. The name of the disease, spiritually speaking, is Humiliation.

Commenting on this description in her wonderfully helpful volume, *Medicine as Ministry: Reflections on Suffering, Ethics, and Hope*, Margaret Mohrmann, MD, says,

> It is important to get diagnoses right: to recognize psoriasis and lupus, cancer and schizophrenia, AIDS and alcoholism. However, it is no less important to get the name of the illness right. It is no less important to recognize that for the sufferer the name of the disease, spiritually speaking, is humiliation or fear or malaise or endless pain or loneliness or despair or the end of a career or the end of a life. It is no less important to recognize that this is a human being to whom a terrible thing is happening and, whatever other name this terrible thing bears, its name is tragedy.

However tempted we may be to see contemporary biomedicine as primarily a technological enterprise, we must resist. It is primarily a human enterprise with technology sometimes as an aid. By all means, robotics may assist in surgery. Of course, increasingly sophisticated scanning technologies may be helpful tools. No one knows what the next great breakthrough medical technology may be. But at the end of the day, it is human beings who are being treated. It is not even suffering that is being treated; it is a sufferer—one who has a life, a story, hopes, dreams, and passions. Getting the twisty Greek name right is not as important as being treated as a person. **E&M**

GREY MATTERS

Ethical Assessment of Personal Health-Monitoring Technologies That Interface with the Autonomic Nervous System

WILLIAM P. CHESHIRE, JR., MD

Dysautonomias are virtually always "mind-body" disorders. – David Goldstein[1]

Abstract

Access to medical technologies is no longer limited to clinicians and researchers. Increasingly, patients are availing themselves of biosensor technologies to monitor their health. Devices designed to sense cardiovascular functions, for example, display information about changes in heart rate and blood pressure that are coordinated by the autonomic nervous system and normally occur below the level of conscious awareness. Once awareness is attained, choice becomes possible, and with increased knowledge comes increased responsibility. This responsibility is best shared by patients and their healthcare professionals. Accordingly, ethical assessment of health-monitoring technology is needed so that it may be used in ways that promote health and well-being while avoiding harm.

Introduction

The past few decades have witnessed significant advances in technologies that allow patients to monitor their own medical data. Home monitoring of glucose and blood pressure, for example, has empowered patients with diabetes and hypertension to participate more directly in their medical care and has improved treatment adherence and clinical outcomes.[2] Patient access to health data continues to accelerate as clinical practice advances toward the dream of personalized medicine. Widespread implementation of electronic medical records has introduced digital portals, whereby patients can view online their own laboratory results and imaging reports.[3] Some direct-to-consumer genetic tests disclose information about an individual's disease risk or responsiveness to certain drugs without having to visit a physician.[4] Further, whole genome sequencing has begun to enter into the clinical arena and promises to supply not only physicians but also patients with unprecedented amounts of personal genetic information relevant to health and disease risk.[5]

The common aspect of these technologies is that they supply medical data directly to patients where such information was not previously accessible or in some cases even knowable. Two clinical cases illustrate some of the ensuing medical and ethical challenges.

The Case of the Panicky Palpitations

A 28-year-old woman who recently filed for bankruptcy awoke one morning from a restless night's sleep with palpitations. Feeling terrified by the sensation of her heart racing, she went directly to a nearby emergency room, where electrocardiography, troponin levels, and chest CT were normal, and she was discharged with a diagnosis of anxiety. Thereafter, she continued to experience episodes in which she was aware of her heart racing or pounding in her chest along with feelings of agitation, restlessness, and apprehension.

To track her situation more closely, she purchased a two-inch long, battery-operated, photoplethysmographic heart rate monitor that, when clipped onto her finger tip, continuously displayed her heart rate and a colorful graphical tracing of her pulse. Each time she felt uneasy, she would pull the monitor from her purse and check her heart rate. On occasion the device displayed rates of 120-130 beats per minute, which made her feel more alarmed, at which point her heart rate would rise even further to 140-150 beats per minute. Rather than feeling reassured that most all of the readings were well below 100 beats per minute, she worried about missing an abnormal reading and checked her heart rate with increasing frequency. She began to feel, as she put it, "hyperaware" of everything in her body and was afraid to go to sleep at night, so worried was she that her heart might misfire and she would not be awake to notice it. Concerned about possible autonomic instability, her primary care physician referred her for neurologic consultation.

Physical examination, complete blood count, and thyroid function testing were normal. Autonomic reflex testing demonstrated normal adrenergic responses including a normal heart rate response to postural challenge. Continuous ambulatory cardiac monitoring disclosed consistently normal sinus rhythm with an average heart rate of 67 and a range of 53-113 beats per minute. Entries in her symptom diary correlated with normal heart rates in the 70s.

In conclusion, the patient's self-reported heart rates, which were much higher than those recorded in the clinic and during ambulatory monitoring, had been selected by the patient and were not truly representative. She was diagnosed with generalized anxiety disorder and panic disorder and reassured that her heart rates were indubitably normal.

The Case of the Paroxymal Pressure

A 38-year-old woman presented with a 7-year history of resistant and labile hypertension. Despite trials of numerous medications, she reported recurrent blood pressure values as high as 200/110 mmHg, which had prompted dose increases or drug changes, and values as low as 80/60 mmHg, which each time had prompted discontinuation of the most recently added drug. Every category of antihypertensive agent had been exhausted in what seemed a futile search to find a regimen that would stabilize her blood pressure. She was referred for neurologic consultation to assess for possible autonomic instability.

Autonomic testing demonstrated normal adrenergic responses. Secondary causes of hypertension were excluded on the basis of no history of alcohol or stimulant use and normal serum potassium, aldosterone/renin ratio, urinalysis, urine metanephrine and catecholamine levels, renal ultrasonography, and renovascular magnetic resonance angiography. Normal optic funduscopy, serum creatinine, urine microalbumin, electrocardiography, and cerebral magnetic resonance imaging indicated no evidence of hypertensive end-organ damage. 24-hour ambulatory blood pressure monitoring showed mild, incompletely controlled hypertension and blunted diurnal variation. Informed by the ambulatory blood pressure profile, her nephrologist made some minor adjustments in the dosage and timing of her antihypertensive medications, which then brought her blood pressure under satisfactory control.

In conclusion, the patient's hypertension was not nearly as out-of-control as she had feared. The explanation for the discrepancy, as it turned out, was that treatment decisions had been based mainly on the patient's journal of blood pressure measurements from a wrist oscillometric sphygmomanometer that she had purchased to track her blood pressure at home. She had not taken her blood pressure in a consistent manner, but only when she had symptoms of pain, anxiety, or dizziness that made her think that her blood pressure must be too high or too low, and she tended to write down or remember selectively the most abnormal values. Based on her self-obtained blood pressure values, she had autonomously changed how she took her medications on a day-to-day basis. She had increased a dose here, skipped a medication there, and on other days dropped a drug altogether, all of which resulted in wide swings in blood pressure control.

Commenting further on the second case, home monitoring of blood pressure overall has had a positive influence on health.[6] It is sometimes appropriate, when instructed by a physician, to hold or take an extra dose of medication if the home blood pressure value is above or below a predetermined limit. Accurate blood pressure measurements and consistent adherence to the prescribed medication regimen are essential to avoid developing pseudoresistant hypertension, which only seems to resist treatment, or withdrawal syndromes following cessation of antihypertensive drug therapy.[7-10]

Disambiguating Dysautonomia from Dysautonomy

The personal health-monitoring technologies in these cases interfaced with autonomic cardiovascular responses. The autonomic nervous system is that which governs "fight or flight" and "rest and digest" responses, among many other bodily functions. It comprises sympathetic, parasympathetic, and enteric divisions as well as networks in the brain that together maintain a constant internal milieu and preside over the complex physiologic responses to stress, including the cardiovascular responses manifest in moment-to-moment changes in heart rate and blood pressure. The term "autonomic" denotes its autonomous operation below the level of conscious awareness. Dysfunction of the autonomic nervous system is known as dysautonomia, which is a broad clinical term encompassing a diverse spectrum of disorders in which there is paroxysmal or sustained hyperfunction or hypofunction of parts of the autonomic nervous system.[11]

The technologies utilized by the patients in these two cases brought cardiovascular autonomic signs that normally escape notice into conscious awareness. Once the patients had knowledge of their heart rate and blood pressure data from their portable devices, they interpreted and acted on that data as empowered participants in the management of their own health. Problems arose because, although they exercised their autonomy of personal agency, it was not a sufficiently informed autonomy. Theirs was a misdirected autonomy, a "dysautonomy."

An analogy for misinformed autonomy from neurology is deafferentation, which means loss of sensory input to the central nervous system. This sometimes occurs in Guillain-Barré syndrome, in which destruction of the myelin insulation of peripheral nerves deprives the brain of incoming sensory information needed to regulate heart rate and blood pressure. Such patients may exhibit episodes of unrestrained, profound tachycardia or hypertension.

Another example is baroreflex failure. In healthy individuals, mechanical sensors in the wall of the carotid sinuses in the neck sense the blood pressure with each heart beat and relay this information to autonomic centers in the brain stem that coordinate sympathetic nervous system outflow. Changes in sympathetic outflow in turn regulate cardiovascular function, including muscle tone in the walls of blood vessels and the rate and force of cardiac contractions. In this way the baroreflex system buffers changes in blood pressure to ensure a steady flow of pulsatile blood to the vital organs. Patients in whom the carotid sinus baroreceptors have been destroyed will develop volatile changes in blood pressure, which alternates between very high and very low levels. Deprived of vascular sensory input, the brain stem lacks vital information from the carotid sinuses needed to decide what signals to send to the cardiovascular system, with the consequence that blood pressure regulation fails.

These afferent dysautonomias behave like a car without a steering wheel careening down the highway. Similarly, medical and ethical decisions without the benefit of accurate information or moral guidance are more likely to go in wrong directions.

Interpretative Pitfalls

Technology that supplies information has a dual aspect. More information can empower users by making better informed choices possible. More information can also introduce burdens, because data is seldom complete and, to be useful, must be interpreted. The tasks of absorbing thousands of facts and identifying relevant information from among countless details and ambiguous trends can be difficult and prone to error. Several errors in judgment stand out in these two cases.

First, the patients, through no fault of their own, lacked the medical knowledge to interpret correctly the numbers delivered by their automated devices. Medical devices are invariably subject to artifacts. Pulse oximeters, which measure capillary oxygen saturation as well as heart rate, can give incorrect readings if, for example, the finger inserted into the device is covered by nail polish or presses too firmly. Factors that can render blood pressure measurements falsely high include caffeine, a full bladder, a cold room, an uncomfortable posture, exercising before measuring, positioning the arm below the level of the heart, or a "white coat" response in a medical setting.[12] These are some of the reasons why over-the-counter health devices typically are posted with a label warning that nonmedical individuals should not use them for purposes of medical diagnosis.

They also lacked the medical knowledge to distinguish abnormal values from healthy variability in heart rate and blood pressure. This resulted in inappropriate changes in medication, unnecessary anxiety, and increased utilization of healthcare resources. There are costs to pursuing the unanticipated and incidental findings that more data generates. Patients utilizing biosensor technology require not only information but also medical guidance.

Secondly, not all individuals are trained in interpreting scientific data. When presented with a scatter of numbers, there is a psychological bias to notice the exceptional values. When shown a plotted graph, the eye may be drawn to the peaks or valleys while failing to see the mean. Such numerical outliers are not necessarily statistically significant or physiologically meaningful. Individuals who lack scientific training may also be more likely to mistake correlation for causation and draw incorrect conclusions. Even valid data analysis often leaves intractable uncertainties, which can provoke anxiety.[13-15] In each of these clinical cases, the patient interpreted her data selectively. Her beliefs and preconceived suspicions biased whether she took notice of and recorded the numbers registered by her device. This prejudice skewed the information on which medical decisions were made.

Thirdly, attaching electronic devices to the body to gain information about its function has the potential to foster neuroticism in patients who are predisposed to anxiety or obsessive thoughts. Catastrophic thinkers will find in such devices new signals at which to feel alarmed. Even the healthy obsession that strengthens the motivation to exercise has been evident in some users of contemporary fitness biosensors.[16]

Further advances in biosensor technology applications for health and medicine may cause the seam between human bodies and their technological appendages to appear to vanish. Abandoning the conceptual distinction between human organism and machine would have intriguing implications for human self-perception and the sense of personal identity. Technologies that blend in with the body might cultivate a way of thinking that equates the body with technology, i.e., matter to be commanded and reshaped according to the will. Considering how human neurotic tendencies play out already in attitudes toward body weight, body proportions, height, hairstyles, and complexion, the human capacity for technological neuroticism toward devices that interface with the body may have barely begun.

Why Heartbeats Are Almost Silent

Being self-aware is an essential aspect of what it means to be human, but humans are not aware of their entire biology, which is as it should be. Procreation does not require an explicit knowledge of the human genome, nor that parents recite correctly all three billion base pairs in their individual genomes to produce children. If as a condition of life every heart beat had to be intentional, if every breath had to be a conscious act, then every moment would be laborious.

The autonomic nervous system operates below the level of conscious awareness for a reason. Having a mind free from having to attend to the innumerable mundane bits of information and decisions that autonomic reflexes take care of efficiently, silently, in the background, is liberating. A mind unburdened by minutiae is free to reflect on larger questions, such as ethics, and to ponder higher meanings.

Conclusion

Technology, though able to measure physical parameters of bodily function, fundamentally lacks the capacity to detect and evaluate moral principles, which remain the jurisdiction of the mind. The discipline of ethics is indispensable to the mind, which interprets and often misinterprets both physical signals and moral principles. Medical ethics brings values and principles that are relevant to health into conscious awareness so that thoughtful decisions can promote human flourishing.

References

1. Goldstein DS. *Adrenaline and the Inner World: An Introduction to Scientific Integrative Medicine*. Baltimore: The Johns Hopkins University Press, 2006, p. 182.
2. Taylor JR, Campbell KM. Home monitoring of glucose and blood pressure. *Am Fam Physician* 2007; 76: 255-260.
3. Goldzweig CL, Orshansky G, Paige NM, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann Intern Med* 2013; 159: 677-687.
4. Burton A. Are we ready for direct-to-consumer genetic testing? *Lancet Neurol* 2015; 14: 138-139.
5. Hayes DF, Markus HS, Leslie RD, Topol EJ. Personalized medicine: risk prediction, targeted therapies and mobile health technology. *BMC Med* 2014; 12:37.
6. Cappuccio FP, Kerry SM, Forbes L, Donald A. Blood pressure control by home monitoring: meta-analysis of randomised trials. *BMJ* 2004; 329: 145.
7. Burnier M, Wuerzner G. Ambulatory blood pressure and adherence monitoring: diagnosing pseudoresistant hypertension. *Semin Nephrol* 2014; 34: 498-505.
8. de Oliveira-Filho AD, Costa FA, Neves SJ, et al. Pseudoresistant hypertension due to poor medication adherence. *Int J Cardiol* 2014; 172: e309-e310.
9. Myers MG. Pseudoresistant hypertension attributed to white-coat effect. *Hypertension* 2012; 59: 532-533.
10. Karachalios GN, Charalabopoulos A, Papalimneou V, et al. Withdrawal syndrome following cessation of antihypertensive drug therapy. *Int J Clin Pract* 2005; 59: 562-570.
11. Cheshire WP. Autonomic disorders and their management. In: L Goldman and AI Schafer, editors, *Goldman-Cecil Medicine, 25th Edition*, Philadelphia: Elsevier Saunders, 2016, pp. 2517-2522.
12. Badeli H, Assadi F. Strategies to reduce pitfalls in measuring blood pressure. *Int J Prev Med* 2014; 5(Suppl 1): S17-S20.
13. Fischhoff B, Davis AL. Communicating scientific uncertainty. *Proc Natl Acad Sci USA* 2014; 111 Suppl 4: 13664-13671.
14. Fergus TA. Cyberchondria and intolerance of uncertainty: examining when individuals experience health anxiety in response to Internet searches for medical information. *Cyberpsychol Behav Soc Nets* 2013; 16: 735-739.
15. Fuchs J, Werner S, Scheunpflug C, et al. Excessive medical information increase in package inserts. *Int J Clin Pharmacol Ther* 2010; 48: 781-790.
16. New C. Fitbit obsession builds as some need “strong motivation.” *Huffington Post*, April 23, 2013.

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RESPECTING THE WISHES OF INCAPACITATED PATIENTS AT THE END OF LIFE

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Editor's note: Although the mission of Ethics & Medicine *is focused on Christian Hippocratism, the journal is open to learning from other voices, especially those which help clinicians and others understand the perspectives of their patients.*

Abstract

Decision-making at the end of life in Confucian-inspired societies continues to be defined by the belief that personhood is inextricably entwined and defined by the family unit. It is thus the interests of the family rather than the individual that takes precedence in care determinations. Emergent data on the manner in which personhood is considered amongst terminally ill patients, however, reveals a more holistic perspective that extends beyond the dominant family-centric perspective. Krishna's Ring Theory of Personhood suggests that personhood is defined by Innate, Relational and Individual domains and domain-specific interests. Interests arising from the Individual and Innate domains are not seen as secondary to those of the Relational Ring, negating their relegation in favour of familial interests in care determinations. Krishna's Ring Theory of Personhood affirms a holistic and balanced view to the interests of the individual and better facilitates the protection of individual interests and autonomous choice.

Introduction

Compromise of the Principle of Respect for Autonomy is well-documented in Southeast Asian nations.[1-40] Here, the continued employment of family determination in end-of-life care decisions, the persistent use of collusion in dealing with end-of-life care issues, and the common practice of avoiding direct patient involvement in the management of the patient's own end-of-life care have been attributed to the continued dominance of family-centric and Confucian-inspired conceptions of personhood. These conceptions portray the individual not as an autonomous entity, but rather as a reflection of their identity in their respective families and sometimes as a vehicle for the advancement of the interests of the family as a whole.[1-37] Interest in better understanding these practices has increased with recent reports regarding the manner by which the wishes of an incapacitated patient are respected within the Southeast Asian care setting. There is also increasing data suggesting that the influence of the view that the individual is inseparable from his or her familial identity has begun to wane.[1]

Foo et al.'s findings—that many physicians in Singapore would overturn the previous wishes of an incompetent patient in favour of completely conflicting wishes of the patient's family—appear increasingly discordant with progressively atomistic practices. These practices differ significantly from Confucian-inspired, family-centric views of personhood that conceive a patient as being defined by elements of individual and familial identity.[41-46] The horizontal dimension or familial identity is defined by relationships within a complex and interrelated familial network.[41-46] The individual's vertical dimension of personhood, on the other hand, affirms the presence of unique individual characteristics and autonomy.[41-46] It has been noted that it is the horizontal dimension that dominates considerations, particularly when the patient is left irreversibly incompetent at the end of life. In such circumstances, unsurprisingly, the family makes decisions to ensure that the patient is cared for in a manner that is consistent with the identity and wishes of the family. Clinical data, however, would suggest that patients rarely subscribe to such views.[5,6,8,10-20,31-40]

Furthermore, Krishna has argued that, despite the widespread use of Confucian centric thinking in Singaporean social, legal, educational, and financial frameworks, the manner in which personhood is perceived locally amongst oncology patients takes a more holistic perspective.[1,7,11-12,19,23,26-27,32,34-35,47-63] Employing Krishna's evidenced-based concept of the Ring Theory of Personhood (Ring Theory), this paper will argue that, from a holistic perspective of personhood, the interests of the individual, which extend beyond concern for the family's interests and advancement, ought to be respected.[38-40]

Case Presentation

Consider the case of A, a 74-year-old Chinese gentleman who suffered a relapse of Stage 4 Diffuse Large B Cell Lymphoma (DLBCL) 6 months after being declared to be in remission following aggressive chemotherapy. Presenting with bone marrow and cerebral involvement, A deteriorated rapidly and was deemed not suitable for further chemotherapy.

As A continued to deteriorate and as his food intake began to decrease, his family approached the doctors to request that A be provided with artificial nutrition and hydration. The family were keen to have either a nasogastric tube (NGT) or a percutaneous endoscopic gastrostomy (PEG) feeding tube inserted so that they could also administer Traditional Chinese Medicine (TCM). However, A refused both as well as any form of intravenous and subcutaneous fluids as he was fearful that these interventions would be both uncomfortable and likely to prolong his life.

After discussions with the physicians, the family reluctantly accepted A's decision but continued in their attempts to convince A to reconsider his decision. Underpinning A's family's position were a number of issues. These included the belief that A would starve to death, and this would not only result in A becoming a "hungry ghost," but it would also reflect badly upon the family as they would be seen to have failed in their filial obligations. The family was concerned that failure to fulfil their filial obligations would be construed by both the patient and the wider family unit as a sign that they had simply abandoned or "given up" on the patient and that they did not care for him.

As A deteriorated further and became uncommunicative, the family became more distressed and increased their efforts to have the physicians insert the NGT. Following a number of family meetings, the NGT was inserted and the family was taught how to feed the patient. This also enabled them to commence their TCM treatment.

Outcome

Whilst there was little evidence to suggest that the NGT changed the course of A's disease, the act of overturning his consistent wishes, which he made whilst competent, does raise concerns. Here, part of the argument in favour of overturning his wishes was the fact that A was known to hold very conservative ideas, drawn from his Confucian-inspired heritage, and he often did make decisions in keeping with these beliefs to place the interests of the family before his own. The family argued that had he been aware of their increasing distress he would have relented and agreed to their request for an NGT. A further reason for their position was that, had A been aware of the external pressures that they as a family faced from the extended family unit for the perception of their failing in their filial duties, he would have reversed his repeated refusal of a NGT. The strongest argument for allowing the family to determine the employment of the NGT, however, was their maintenance that A held strong Confucian beliefs and therefore accepted that he would be considered part of the family unit and, when ill, would be cared for in keeping with the family values and wishes.[10]

A's condition, in effect, negated his vertical dimension of personhood and reduced his personhood to its horizontal dimension.[11,41-46,64-67] A's enduring interests in maintaining those facets that defined his vertical dimension were neglected as a result of the family now deciding upon his care.

Discussion

To proceed to discuss the issues pertaining to A's treatment and consideration of his enduring interests, a better understanding of the Ring Theory is required.

Ring Theory of Personhood

Krishna et al.'s Ring Theory of Personhood consists of the Innate, the Individual, and the Relational domains that are represented as interrelated rings (Figure 1).

Innate Personhood

The Ring Theory of Personhood is built upon the Innate Ring. The Innate Ring depicts Innate Personhood and contains two aspects of concern: the Core and the Secondary Elements of Innate Personhood. The Secondary Elements of Innate Personhood are portrayed within the Secondary Ring that encapsulates the Core. The Core exists in all living persons from the moment of conception (Figure 2).

Unlike the Core elements, which are unchanging till death, the Secondary Elements of the Innate Personhood may alter. These include the patient's cultural and familial descriptors that they were born into as well as their name and gender. Changeability of the Secondary Elements of the Innate Personhood is affected by the patient's degree of adherence to their familial beliefs and practices as well as to the culture into which they are born.

Consider Patient A, who was born a Taoist but embraces Islam following his marriage to a Muslim. As a result, his cultural leanings, his name, his familial beliefs, and even his links with his family may change. Just like an individual who chooses not to maintain the cultural and familial traditions that he or she grows up with, the constituent factors of his Secondary Elements of Innate Personhood are reduced, attenuating the size of the Secondary Ring. Conversely, embracing one's cultural and familial roots will have the opposite effect upon the Secondary Ring. These considerations illustrate the flexibility of the Secondary Ring.

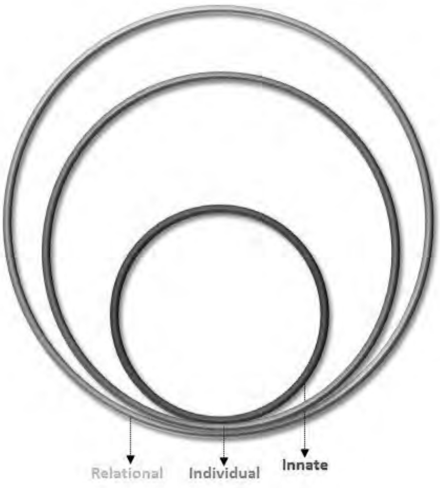

Figure 1. The Ring Theory of Personhood

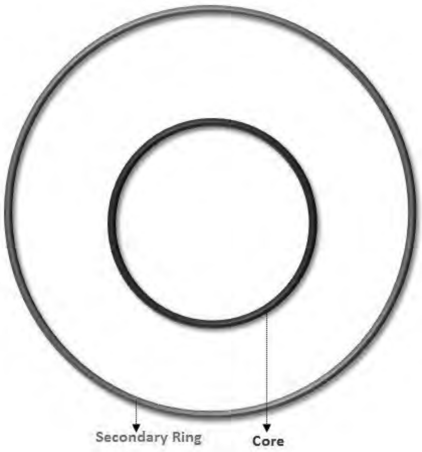

Figure 2. The Constituents of the Innate Ring

Individual Personhood

The second domain of personhood, Individual Personhood, is defined by a patient's potential to learn, to communicate, to think and rationalize, the ability for self-determination, the capacity for moral and ethical beliefs, and the capability to carry out one's family obligations and duties. Other considerations within the Individual Ring that represent Individual Personhood include those features that define the patient as a distinct individual. This would include roles within the family, hobbies, occupation, education, achievements, mobility, religion, and moral or ethical beliefs.

Whilst there is recognition that Individual Personhood can be affected by illness and lost in unconsciousness, data is clear that such an event does not result in a loss of a patient's personhood. A loss of the Individual Ring leaves personhood defined instead by the patient's Relational and Innate Personhood, reaffirming the inter-relationship between the rings and highlighting the relative importance of sentience in defining personhood.

Relational Personhood

Relational Personhood is understood to be both endowed by the family and built upon the relationships that the individual forms throughout his life. It is the significant mutual personal relationships considered important by the patient that play a part in defining this element of personhood.

The presence of relational ties within the Relational Ring has significant effects on how personhood is perceived. Our respondents report seeing their personhood extending beyond the concerns of their individual selves to encapsulate the welfare and interests of those individuals who are seen to inhabit the patient's Relational Ring. This most commonly, but not exclusively, refers to family members and gives rise to the concept of "synergistic dualism." This concept, which is widely endorsed by the various local races, religions, and cultures, highlights the inseparability of individuality within a wider familial identity.[12-13,68] Under this concept, the patient sees himself simultaneously as a distinct autonomous individual and as a member of a family who must protect and advance familial interests. This concept of two inseparable identities challenges conventional ideas of personhood that are confined to the physical self.

There are a number of considerations that arise from a synergistic dualism view of personhood. However, focus for this article will be in considering the conception of surviving interests of these patients. To do so, a review of the influence of the family within the said concept of personhood is required.

The Role of the Family

The concept of family requires some clarification. Patients are clear that the term "family" within the Relational Ring does not refer solely to those persons who share familial bonds but instead encapsulates those persons with whom the patient considers himself to have close personal relationships. This may include friends and even paid caregivers, while it does not necessarily involve those who are traditionally considered key members of the family, such as spouses, children, siblings, and parents. It is in acknowledging this fact that the final ring of the Ring Theory of

Personhood is termed the Relational Ring rather than the Familial Ring. However, despite the specificity to membership of the Relational Ring replete with its wide-ranging influences upon the other rings, patients are clear that this does not allow the Relational Ring to be superior to the other rings in any care determinations. Krishna et al.'s data does clearly illustrate equal importance attributed to all three identified dimensions of personhood.[38-40]

From Krishna et al.'s data, it would seem that the links between the patient and the individuals within the patient's Relational Ring display features of reciprocity.[38-40] This suggests that the ties patients share with members of their Relational Ring are reciprocated by each individual within the Relational Ring having the patient in their own Relational Ring. This is illustrated by an overlapping of the Relational Rings of the various members of the patient's Relational Ring and the Relational Ring of the patient. Such close associations have significant repercussions and give rise to the widely held belief of entwined fates or that the fate of the patient affects those within their Relational Ring and vice versa.[12]

Reciprocity of Personhood

To highlight the reciprocity of personhood between the patient and those within their Relational Ring, we present the example of Patient A and Family Member B where Family Member B is a family elder and Patient A is a young adult. In Patient A's case, the Secondary Elements of his Innate Personhood are conferred by Family Member B's Relational Ring. Therefore his Secondary Ring overlaps with that of Family Member B's Relational Ring. Patient A's Core is derived from the evaluation of Family Member B's assessment of his status as a human and alive. Similarly, there is contact between Patient A's Individual Ring with Family Member B's Relational Ring highlighting the influence of elders such as parents in cultivating the Individual Personhood of the younger members of the family (Figure 4).

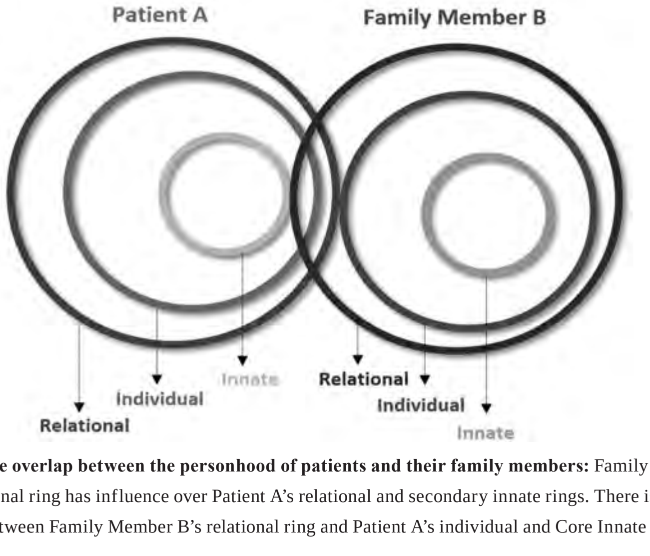

Figure 4. The overlap between the personhood of patients and their family members: Family Member B's relational ring has influence over Patient A's relational and secondary innate rings. There is also contact between Family Member B's relational ring and Patient A's individual and Core Innate rings.

This overlap of Relational Rings is not unidirectional in its effects, and the deeds and conduct of Family Member B may also affect the status of Patient A in the eyes of society. Such perceived interrelatedness means that the misdeeds and failures of any individual within the family reflect negatively upon the rest of the family, resulting in a “loss of face” or a reduction in respect and prestige for the whole family in the eyes of the wider society.[5-6,10-12,17-18,20-22,42,69] This view of interrelated Individual and Relational elements within personhood validates Tsai’s two-dimensional view of personhood, of the autonomous individual existing within a network of social and familial interconnectedness.[43] This finding is not particularly surprising within the local Singaporean society that prides itself upon its Confucian and family-centric views.[5-6,17-18,20-22,60,69]

Realization of the presence of an entwined fate entreats a lifelong interest in maintaining one’s own and one’s family’s reputation and good social standing.[70] These interests are referred to as Individual Interests (IIs), and are deemed to be integral in defining what makes a person a unique individual rather than simply a reflection of his or her family identity, roles, or societal position as the local concept of “synergistic dualism” would suggest.

Individual Interests (IIs)

The concept of synergistic dualism as it is understood in the local setting holds that patients accept that it is not only their personal interests that must be protected but those whose “fate” is tied to theirs if their interests are to be advanced. IIs, then, are held to include considerations about bodily integrity, personal reputations, and family interests, and are said to be present throughout life as a result of cultural, societal, familial, and formal teaching within the Singapore setting. [23,47,60,71-72] Synergistic dualism also creates reciprocal obligations amongst those within the patient’s Relational Ring to maintain and protect the interests of the patient. This is a part of their obligation to someone who is both a member of the family and an influential person within their own Relational Ring, as well as a result of their own self-interests, given that it is they who will experience any harm that should befall the unconscious or dead patient.[10,43,45,73-81]

The implications of this concept are vast both to the general concept of personhood and also to what makes an individual unique. The data forwarded by Krishna et al. shows that rather than be defined solely by a synergistic existence with one’s family and one’s family identity—personalized somewhat by the role and position that one may have within the family unit—IIs show that conceptions of both personhood and what makes someone a unique person have multidimensional considerations.

It is also clear that IIs continue throughout life and even after death. Whilst holistic review of the patient’s best interest are a matter of practice in determining the manner of care of unconscious patients managed by palliative care teams, respecting and indeed protecting the interests of the deceased is a little more complicated.[82-84] We will not take up discussion of best interests at this point given that it has been argued elsewhere that the best interests principle under review of a Multidisciplinary Team represents the most practical means of holistic appraisal of a patient’s situation.[36-37] We will therefore focus our discussion upon the place of IIs after the patient’s demise.

Individual Interests after Death

Some patients do subscribe to the concept of posthumous harm. Harm within this conception is both how surviving members of the patient's Relational Ring determine it, based upon the holistic appreciation of the psychosocial, physical, and existential framework of the observer, as well as how the patients themselves perceive it. Patient-based descriptions of harm are best exemplified by local Chinese and Indian patients who practice ancestor worship. For these patients, maintaining one's esteem and affection within the family ensures the continued offerings by the family for their existence in the afterlife. For those who hold to such beliefs, harm to their interests may extend beyond their moment of death.

Whilst the family members themselves are obliged by familial, cultural, and societal expectations to protect the individual aspects of the IIs of patients beyond simply promoting familial interests, the question that inevitably arises is what aspects of IIs are preserved.[11-12,82-90] There is an expectation by patients that the preservation of IIs moves beyond the simplistic protection of the social, cultural, and familial identities that are congruent with the patient's psychosocial background to a patient-specific plane of consideration of their personal values, beliefs, and identity. Do these expectations, which are variously policed by the family members themselves, provide the deceased with rights? If there are obligations to be enforced or to be waived, it would be the family members themselves that would have to enforce them, raising concerns about how they might do so. Thus, having the interests of the individual well-established within the interests of the family and amongst the obligations of the remaining family members may be seen as an effective way of ensuring one's interests are protected. However, how conflicts between the person's IIs and those of the surviving family interests are resolved remains unclear.

Consider the case of the gay activist who, when he was dying, had hoped that his work advancing gay rights in his community would be remembered and that his relationship with his long-term partner would be respected. However, neither his homosexuality nor his long-term goals of fighting for gay rights within his community contributed to the family interests. Indeed, homosexuality is frowned upon and even proscribed in many Southeast Asian societies. How are the rights of the individual then protected when the family members, who must both police and carry them out, are not willing to do so?

Policing Respect for IIs

There are thus only specific elements of IIs that are protected simply by being part of a family and a group of close-knit friends who share overlapping Relational Rings. The content of these IIs therefore does attenuate as a patient proceeds through the dying phase. From the present data, it is difficult to explain how such shedding of considerations within IIs occurs beyond a central focus on maintaining the family interests. Krishna et al. note that within their study all patients relied upon their families to maintain their personal identity.

Recognition of this fact encourages patients to make amends and even change their lifestyles and behavior, if only to ensure that they retain some control of their surviving interests. This in turn affects the manner in which patients choose to live their remaining lives. Consider once more the dying gay activist whose family now cares for him. He hopes that his family will not only allow his partner to be a part of the care process but also that his new religious beliefs will be respected. Thus he attempted to assimilate his family to his religious views whilst pragmatically adapting his own lifestyle to be more “acceptable” with those of his family’s.

Similarly, many family members adhere to the belief that failure to carry out the wishes of the patient after they are no longer able to do so themselves is “disrespectful.”[11-12] Family members and patients believe that this failure to meet their filial duties and social obligations reduces patients to objects that are of no real value, denying their previous importance and their continued place in the hearts and minds of those who survive them. Failure to preserve the interests of the patient by the family is also held to trivialize the patient’s social and familial links and, at best, to leave them as mere “caricatures” of their past selves, simply remembered by the roles that they played in the family and society. As one patient pointedly stated “I am more than someone’s son, someone’s husband, someone’s father, a physician, a friend, a brother! I am me and I don’t wish to be remembered for what I have done or who and what I was associated with but for being me. It is also about respecting my choices and way of life.” Many patients and family members do hold to the importance of maintaining the memories of the person, their experiences, and their accomplishments, if only as a means of enriching their own historical links and their cultural heritage, whilst others believe that failure to care for the patient and their surviving interests reflects a failure to respect cultural, societal, and familial norms and values.

There is also a prevalent sentiment amongst family members and patients acknowledging the idea that “we live our lives, preparing for our deaths. To fail to respect our beliefs when we are gone is to dismiss the practices and values that gave our lives meaning and direction.” As one family member adds, “what message does that send to those that also share my wife’s faith, her values and beliefs when the people who knew her best cannot respect the values and beliefs that meant so much to who she was?” Acceptance that the way patients are treated after they are unconscious and after their demise does impact the living also provides rationale for families and health care professionals to strive to respect and protect these interests. “Remember how they say no man is an island, yet we seem to believe that we become precisely that when we are dying or dead. Well, all I can say is remember Krakatoa. Even the dying throes of a desolate island in the middle of nowhere can be felt all over the globe.”

Other patients and families hold that circumnavigation of due respect for the deceased and the unconscious does not bode well for their own inevitable deterioration and demise. There is a sense of “do unto others as you would have them do onto you” that inspires families to meet these expectations.[68] For family, failure to accomplish these duties of maintaining hope, carrying out their filial duties, and seeing to the wishes of their deceased family members is seen to reflect negatively upon them and their family or, within the context of local understanding, to “lose face.”[82-90]

The repercussions of this position are felt widely within end-of-life care with families keen to prolong life of their loved ones through the use of treatment options that may be considered burdensome or potentially futile. An example of this includes the manner in which families choose to persist employing nasogastric feeding even at the end of life.[34] This position also informs clinical and legal practice—for example, the stipulation to persist with feeding in Singapore's Advanced Medical Directive Act 2007.[49] The presence of such legal requirements and social expectations highlights the ingrained nature of IIs within prevailing culture.

Conclusion

The implications of synergistic duality and IIs extend to all elements of care provision. With the complexities of end-of-life care determinations involving those families that subscribe to a synergistic dualist concept well-documented across the world, the Ring Theory of Personhood provides a better framework for understanding and working with patients and their family at all levels of the disease trajectory. Concurrently, a better understanding of IIs ensures that patients continue to be regarded as individuals in their own right even when they are irreversibly incompetent.

Indeed, the implications are vast, not least in the manner in which unconscious patients are regarded locally.[1] Envisaging oneself as being part individual replete with interests to maintain the specific elements that make us who we are as individuals and part of a wider entity—that is, the family unit and the close circle of friends and loved ones—creates specific considerations in the manner that autonomy is viewed. Whilst platforms to envisage a wider concept of autonomy namely through feminist concepts of Relational Autonomy and personhood already exist, synergistic duality pushes the boundary of what autonomy ought to look like, far beyond existing concepts that are tied to an individualistic notion of the personhood. Understanding that patients see their family and loved ones as part of their identity and personhood enables healthcare professionals to expand and redress their discomfort with having family units make decisions with regards to the care of an otherwise competent patient or accept the practice of waivers of informed consent that seem to dominate care determinations within the Asian setting. The Ring Theory will also aid in shedding light on the practice of a family-centric approach to care determinations.

However, rather than simply reemphasizing the concept of familial-centric thinking when addressing care of Asian patients at the cost of respect for the individual's beliefs, values, and aspirations, the Ring Theory asserts the need to assess patients upon their own merits in a holistic manner. This negates the need for a two-pronged approach to care of patients, as appears to already exist locally. One approach applied to family-centric family situations would respect a dualistic outlook and accept the practices of collusion and the circumnavigation of direct patient involvement in the deliberative process. Another respects an atomistic perspective. All patients can have all their concepts of personhood addressed holistically and their IIs respected and protected in accordance to their specific beliefs. The notion of family interests always trumping those of the individual is rendered null.

Knowledge of the complex interplay of factors within the family-patient dyad will also allow for better arbitration of differences and strengthening of the healthcare professional's relationship with the family and the patient. Furthermore, it will aid in the better provision of bereavement support, particularly when considering the concerns surrounding the patient discussed earlier, whose values and beliefs ought not to succumb to familial or societal pressure nor see the needs of his partner and his own individual IIs neglected. The Ring Theory ensures that healthcare professionals maintain a clear understanding of the particular needs and values of the patient.

It is clear that the impact of the Ring Theory of Personhood moves beyond considerations about IIs and raises far more complex issues, such as the manner in which autonomy ought to be viewed, particularly in a society that practices family-led care determination.

Whilst further detailing of this concept is required, we hope that the Ring Theory of Personhood provides a new, clinically-relevant, culturally-sensitive framework for deciphering how local—and indeed, many—Asian patients view their Individual Interests.

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Table 1. Summary of main concepts

Learning Points
1. Asian patients, even those from family-centric or Confucian societies, do not always see their interests being secondary to those of their families.
2. Most patients have individual interests that extend beyond the interests set out by their families, and every effort ought to be made to elucidate them.
3. Increasingly, the interests of the family may not be congruent with those of the patient, and a holistic review of the patient's situation and interests must be carried out.

References

1. Foo WT, Zheng Y, Yang GM et al. Factors considered in end of life decision-making of health care professional. Am J Hos Pall Med online first 2012, July 16 2012
2. Kuo ECY. Confucianism and the Chinese family in Singapore in Confucianism and the family Slote W, De Vos GA [eds] (SUNY Series in Chinese Philosophy and Culture) pg 231-248
3. Kou ECY, Wong AK. Some observations on the study of family change in Singapore in The Contemporary Family in Singapore 1979 Kou ECY[ed] Singapore Uni Press. Singapore pg 3-17
4. Thomas E. Filial Piety, Social Change, and Singapore Youth. Journal of Moral Education, 1990;19[3]:192-205
5. Ong JK, Back MF, Lu JJ et al. Cultural Attitudes to cancer management in traditional Southeast Asian Patients. Australasian Radiology 2002;46(4):370-4
6. Khalik S. Dying patients have less of a say in their care than their families do. Straits Times 5 Sept 2011
7. Yang MG. Kwee AK. Krishna L. Should patients and family be involved in "Do not resuscitate" decisions? Views of oncology and palliative care doctors and nurses. Indian J Pall Care 2012;18(1): 52-8
8. Ho ZJM, Krishna LKR, Goh C et al. The physician–patient relationship in treatment decision-making at the end of life: A pilot study of cancer patients in a Southeast Asian society. Palliative and Supportive Care / FirstView Article August 2012 , pp 1-7 DOI: http://dx.doi.org/10.1017/

S1478951512000429 (About DOI), Published online: 18 July 2012

9. Foo ASC, Lee TW, Soh CR. Discrepancies in end of life decisions between elderly patients and their named surrogates. Annal Acad Med Singapore 2012;141-53
10. Ho MZJ, Krishna L,Yee ACP. Chinese Familial Tradition and Western Influences: A Case Study in Singapore on Decision Making at the end of life. JPSM2010;40(6):932-6
11. Goh CR. Challenges of cultural diversity. In J Beattie & S Goodlin (eds.), Supportive Care in Heart Failure Oxford; New York: Oxford University Press 2008.pp. 451-461.
12. Goh CR. Culture, ethnicity and illness. In Palliative Medicine. TD Walsh, AT Caraceni, R Fainsinger, KM Foley, P Glare, C Goh, M Lloyd-Williams, JN Olarte & L Radbruch (eds.), PA:Saunders/Elsevier Philadelphia, 2007 pp. 51-54
13. Toh HC. Providing Hope in Terminal cancer: When is it appropriate and when is not? Ann Acad Med Singapore 2011;40:50-5
14. Tan TK, Teo FC, Wong K et al. Cancer: To tell or not to tell? Singapore Med J. 1993;34(3):202-3.
15. Tan JOA, Chin JJL. Kaan TSH et al. What Doctors say about care of the dying. Lien Foundation 2011. Singapore
16. Lien Center Press Release. Doctors are caught between ensuring patient autonomy and respecting families' wish for nondisclosure and collective decisions. Accessed 17/09/2011 http://www.lienfoundation.org/pdf/news/WDS_Press_Release_Final.pdf
17. Low JA, Kiow SL, Main N, et al. Reducing collusion between family members and clinicians of patients referred to the palliative care team. Perm J 2009;13:11-5.
18. Ong WY, Yee CM, Lee A. Ethical dilemmas in the care of cancer patients near the end of life. Singapore Med J 2012;53(1):11-16
19. Low JA, Ng WC, Yap KB, et al. End-of-life issues- preferences and choices of a group of elderly Chinese subjects attending a day care centre in Singapore. Ann Acad Med Singapore. 2000;29(1):50-6.
20. Chan CKL, Yau M. Death preparation among the ethnic Chinese well-elderly in Singapore: an exploratory study. Omega. 60(3):225-39
21. Low YYS.'Who is Responsible for this Patient?': A Case Study Analysis of Conflicting Interests between Patient, Family and Doctor in a Singaporean Context Asian Bioethics Review – 2011;3(3):261-71
22. Phua J, Kee AC, Tan A et al. End-of-Life Care in the General Wards of a Singaporean Hospital: An Asian Perspective. J Palliat Med 2011;14(12):1296-301
23. Liu Q. Core Culture Values and Beliefs of Singapore. Accessed 24/04/2012 http://www.ncl.ac.uk/ecls/assets/documents/pdf/countryfiles/CCC-Singapore.pdf
24. Teo KS. Confucian health care in Singapore in Lee S [ed] The Family, medical Decision making and biotechnology. Springer Direct 2007 pg 207-215
25. Doran C. The Chinese Origins of Democracy: Dynamic Confucianism in Singapore. Nebula 2010,7(4):47-53. Accessed 24/04/2011 http://www.nobleworld.biz/images/Doran2.pdf
26. White Paper, Shared Values. Singapore: Singapore National Printers 1991.
27. Tan C. Our Shared Values in Singapore; A Confucian Perspective. Educational Theory 2012;62(4):449-63
28. Ong A. Government hopes to update Shared Values through National Conversation. Straits Times. Nov 16 2012. Accessed 24 April 2013. http://www.straitstimes.com/breaking-news/singapore/story/update-shared-values-through-the-national-conversation-20121116
29. Tan E. Singapore's Shared Values. Infopedia. Accessed 24 April 2012. http://infopedia.nl.sg/articles/SIP_542_2004-12-18.html
30. Chan D, Goh LG. The Doctor – patient relationship: a survey of attitudes and practices of doctors in Singapore. Bioethics 2000;14(1):58-76
31. Ching JA, Quah YL, Yang GM et al. Patient and family involvement in decision making for management of cancer patients at a centre in Singapore. BMJ Support Palliat Care. Jan 2013 doi:10.1136/bmjspcare-2012-000323
32. Krishna L. Decision making at the end of life: A Singaporean Perspective. Asian Bioethics Review. 2011;3(2):118-126

33. Krishna L. Consent in terminal sedation. Indian Journal of Ethics 2010;VII(3):161-5
34. Krishna L. Nasogastric feeding at the end of life: A virtue ethics approach. Nursing Ethics 2011; 18: 485-494
35. Krishna L. The Position of the Family of Palliative Care patients within the Decision Making Process at the end of life in Singapore. Ethics and Medicine 2011,27(3):183-190
36. Krishna L, Chin J. Palliative Sedation within the Duty of Palliative Care within the Singaporean Clinical Context. Asian Bioethics Review 2011;3(3): 201-215
37. Krishna L. Best Interests Principle in the determination for Palliative Sedation within the Singapore context. Nursing Ethics 2012;19(6):787-99
38. Radha Krishna LK. Personhood within the context of sedation at the end of life in Singapore. BMJ Case Reports2013. doi:10.1136/bcr-2013-009264
39. Krishna LKR, Alsuwaigh R, Sim SW et al. Ring Theory of Personhood. American J of Hospital and Pall Medicine. Am J Hosp Pall Care. 1049909113500136, first published on August 13, 2013 as doi:10.1177/1049909113500136
40. Krishna LKR. Accounting for personhood in palliative sedation: the Ring Theory of Personhood. Med Humanities Published Online First: 26 September 2013 doi:10.1136/medhum-2013-010368
41. Cheng KY, Ming T, Lai A, “Can familialism be justified?” Bioethics (2012);26(8):431-439
42. Tsai DF. “How should doctors approach patients? A Confucian reflection on personhood.” Journal of Medical Ethics (2001);27(1): 44–50.
43. Tsai DFC. Ancient Chinese Medical ethics and the four principles of biomedical ethics. JME 1999;25:315-321
44. Chan EA. “A narrative inquiry into the Hong Kong Chinese adults’ concept of health through their cultural stories.” International Journal of Nursing Studies 2006;43:301-9
45. Fan R. “Which care? Whose Responsibility? And why Family? A Confucian account of long term care of the elderly.” Journal of Medicine and Philosophy (2007);32[5]:495—517
46. Hui E. “Parental refusal of life saving treatments for adolescents: Chinese familialism in medical decision making revisited.” Bioethics (2008);22(95):286-295
47. Yeo G. (1998, September 28). No Single Asian Values System: Senior Minister. The Straits Times.
48. Chan TE, Peart NS,Chin J. Evolving legal responses to dependence on families in New Zealand and Singapore healthcare. Accessed 12 Sept 2013. J Med Ethics published online August 20, 2013 doi: 10.1136/medethics-2012-101225
49. Advanced Medical Directive Act 2007. Ministry of Health Singapore. Accessed 24/04/2013. http://www.moh.gov.sg/mohcorp/legislations.aspx?id=7120
50. Guide to the Mental Capacity Act for Deputies. Office of the Public Guardian. Accessed 17/12/2010. http://www.publicguardian.gov.sg/Resources/Flipbooks/Guide_to_MCA_fo r_Deputies(English).pdf
51. Mental Capacity Act 2008 Accessed 17/12/2011 http://agcvldb4.agc.gov.sg/non_version/cgi- bin/cgi_retrieve.pl?actno=REVED- 177A&doctitle=MENTAL%20CAPACITY%20ACT%0A&date=latest&m ethod=part&sl=1
52. Maintenance of Parent Act 2010. Accessed 12/04/2012 http://agcvldb4.agc.gov.sg/non_version/cgi-bin/cgi_getdata.pl?actno=1996- REVED- 167B&doctitle=MAINTENANCE%20OF%20PARENTS%20ACT%0A&d ate=latest&method=part&sl=1&segid=
53. Healthcare Financing Philosophy. Ministry of Health Singapore. Accessed 24/04/2012. http://www.moh.gov.sg/content/moh_web/home/costs_and_financing.html
54. Medisave. Costing and Financing. Ministry of Health. Accessed 12/04/2012 https://www.moh.gov.sg/content/moh_web/home/costs_and_financing/sche mes_subsidies/medisave.html
55. Medical and Elderly Care Endowment Schemes Act (Cap. 173A, 2001 Rev. Ed. Sing.), Part II; Ministry of Health, Costs and Financing (13 May 2013). http://www. moh.gov.sg/content/moh_web/home/costs_and_financing.html (accessed 12 Sept 2013).
56. National Medical Ethics Committee. Advance medical directives: a report by the National Medical Ethics Committee. Singapore: NMEC, 1995; Guide on Ethical Handling of Communication in Advance Care Planning. Singapore: NMEC, 2010. http://www.moh.gov.sg/content/moh_web/home/Publications/guidelines/national_medical_ethics_committee_guidelines.html (accessed 12

Sept 2013).

57. Wong YS, Verbrugge LM. Living Alone: Elderly Chinese Singaporeans J.Cross Cult Gerontol 2009;24:209–224
58. Teo P. Health care for older persons in Singapore: Integrating state and community provisions with individual support. Journal of Aging & Social Policy. 2004;16(1), 43–67.
59. Lee CY. Do traditional values still exist in modern Chinese societies? The case of Singapore and China Asia Europe Journal 2003;1: 43–59
60. Khan H. Social policy in Singapore: A Confucian Model. The International Bank for Reconstruction/The World Bank. Washington 2001
61. Tay M, Chia SE, Sng J. Knowledge, Attitudes and Practices of the Advance Medical Directive in a Residential Estate in Singapore. Ann Acad Med Singapore 2010;39:424-8
62. Gilbar R. Family involvement, independence, and patient autonomy in practice. Med Law Rev 2011;19(2):192–234.
63. Davidson KA. The Most Efficient Health Care Systems In The World. Huffington Post. Accessed 5/10/2013. http://www.huffingtonpost.com/2013/08/29/most-efficient-healthcare_n_3825477.html
64. Zhang X. “Reflection on family consent: Based on a pregnant death in a Beijing Hospital.” Developing World Ethics (2012);12(3):164-168
65. Fan R. Self determination vs family determination: two incommensurable principles of autonomy. Bioethics 11(997);309-322
66. Ho MC. Death and Dying: Advanced Directives, Autonomy and Family. Bioethics 2004;18: 87-103
67. Cheng CY, “The Concept of face and its Confucian Roots.” Journal of Chinese Philosophy (1986);13:329-48
68. Chai HZ, Krishna LKR, Wong VHM. “Feeding: What it means to patients and caregivers and how these views influence Singaporean Chinese Caregivers’ decisions to continue feeding at the end of life.” American Journal of Hospice & Palliative Care (2013) published online 15 March 2013. DOI: 10.1177/104990911348088350
69. SMC Pang. “Protective Truthfulness: The Chinese Way of safeguarding patients in Informed Treatment Decisions.” Journal of Medical Ethics (1999);25(3):247—253
70. Sperling D. Posthumous Interests. Legal and Ethical Perspectives. (Cambridge University Press, 2008), 8—48
71. Englehart NA. “Rights and Culture in the Asian Values Argument: The Rise and Fall of Confucian Ethics in Singapore.” Human Rights Quarterly (2000);22(2):548—568
72. Sim M. “Family comes first, but not when hiring. Though family unit is very important for Singaporeans, merit beats blood ties: survey.” Straits Times (2010)
73. Cong Y. “Doctor- Family- Patient Relationship: the Chinese Paradigm of Informed Consent.” Journal of Medicine and Philosophy (2004);29[2]:149—78
74. Lee SK. “East Asian attitudes toward death – a search to help East Asian elderly dying in contemporary America.” Permanente Journal (2009);13[3]:55—60
75. Wang F. “Confucian thinking in traditional moral education.” Journal of Moral Education (2004);33[4]:429—47
76. Chuang YC. “Effects of interaction pattern on family harmony and well being; Test of interpersonal theory, relational models and Confucian ethics.” Asian Journal of Social Psychology (2005);8:272—91
77. Tao LPW. “Dignity in long term care for older people.” Journal of Medicine and Philosophy (2007);32:465—81
78. Lu L, Yu YL. “Family roles and happiness in adulthood.” Personality and individual differences (1998);25:195—207
79. Li CY. “Caring for older adults: the parables in Confucian texts.” Nursing Ethics Quarterly (2010);23[3]:266—7
80. Sung KT, “Exploration of actions of filial piety.” Journal of Aging Studies (1998);12[4]:369—86
81. Stuifbergen M, Van Delden JJM. “Filial obligations to elderly parents: a duty to care?” Medicine, Health Care and Philosophy (2010);14(1):63—71
82. Chochinov HM. “Effect of dignity therapy on distress and end-of-life experience in terminally ill

patients: a randomized controlled trial." Lancet Oncology (2011); 12(8):753–62.

83. Benner P. "Seeing the person beyond the disease." American Journal of Critical Care (2004); 13(1): 75–78.
84. Polkinghorne JC. "The person, the soul, and genetic engineering." Journal of Medical Ethics (2004); 30(6): 593–7.
85. Merrill SB. Defining Personhood: Towards the Ethics of Quality in Clinical Care. (Amsterdam-Atlanta, GA: Rodopi, 1998)
86. Himma KE. "A dualist analysis of abortion: Personhood and the concept of self qua experiential subject." Journal of Medical Ethics (2005); 31(1): 48–55.
87. Beckwith FJ, "Of souls, selves and cerebrums: A reply to Himma." Journal of Medical Ethics (2005); 31(1): 56–60.
88. Farah MJ, Heberlein AS. "Personhood and neuroscience: naturalizing or nihilating?" American Journal of Bioethics (2007); 7(1): 37–48.
89. Fins JJ. "Consciousness, imaging, ethics, and the injured brain." American Journal Of Bioethics Neuroscience (2008);8(9): 3–12.
90. Rich BA. "Postmodern personhood: a matter of consciousness." Bioethics (1997); 11(3–4): 206–16.

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Periviability: Translating Informed Assent and Non-Dissent to Obstetrics

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Abstract

Periviable birth between 20 0/7 and 25 6/7 weeks gestation is a complicated obstetric issue that requires collaboration between obstetricians, maternal fetal medicine specialists, neonatal intensive care specialists, and the pregnant patient and her family. In these scenarios decision making about the options for fetal intervention often falls on the pregnant patient, which can cause significant emotional and psychological distress. In this analysis of ethical dilemmas surrounding periviability, we present a representative case of an imminent periviable preterm birth and evaluate various aspects of the case using parameters employed by medical ethicists. We propose that physicians use silent decision making to determine which interventions are offered to the patient, and that, at times, the patient be allowed to not make the decision, using a strategy of informed assent and non-dissent. This counseling method is ethical and appropriate in complex cases of periviability as it offers the patient clear, realistic, nonmaleficent treatment options that seek to avoid both maternal and neonatal harm.

Introduction

"The goal of family counseling regarding anticipated or imminent periviable birth is to provide objective information in a compassionate manner, to permit shared decision making and to support the family…Counseling of the pregnant women can be directive when appropriate."[1]

In May 2014, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Society for Maternal-Fetal Medicine, the American Academy of Pediatrics, and the American College of Obstetricians and Gynecologists published an executive summary on periviable birth. It defined periviability as the period from 20 0/7 to 25 6/7 weeks gestation, a time where infant morbidity and mortality can vary significantly based over a few days.[1] Advances in medical technology have worked to push the threshold of viability earlier and earlier in gestation, but many have questioned: At what cost, and for what end? Infants born during this time period can have a wide range of complications, from a survival rate of near 0% to significant long-term neurologic disability.[1] Hence, ethical dilemmas arise over which options to offer, how to present them, and when to give them. Physicians are trained to provide information to patients in an effort to create informed consent, but there are scenarios where offering physiologically futile options is not appropriate. Hysterectomies are not offered to a 16-year-old girl with benign heavy menstrual bleeding, nor are cesarean sections offered for a 21-week fetus with severe variable decelerations. But the same fetus at 23 weeks presents a more difficult dilemma regarding how to best counsel the pregnant woman about her options, and the likely consequences of each of these options. We believe that patient autonomy requires presenting and explaining not all the possible options to the patient, but rather all the *medically appropriate* options for a given patient and her clinical situation. We agree with Simon Whitney and Laurence McCullough when they argue that physicians have a responsibility to use their experience and knowledge to first determine which options should be presented to the patient given the particulars of the clinical scenario.[2] They refer to this filtering of information and choices as "silent decision making." This is made trickier in periviable decision making in that there is both the pregnant woman and the fetus to be considered. However, especially considering the time limitations inherent in medicine, the woman's values must always supersede the physician's values in determining how much weight the fetal outcome should receive in the decision-making process.

Most of the literature on this topic is presented from the pediatric or neonatal perspective with few reports taking into account the obstetric. In this commentary we analyze the complex decision making that occurs when obstetricians are faced with periviability and how specific methods of obstetric counseling can promote maternal autonomy. We argue that informed assent and non-dissent, concepts that have been used in the pediatric and intensive care literature, should be translated to decision making surrounding periviability.

Our commentary involves a case of periviability. Using the method described by Albert Jonsen, Mark Siegler, and William Winslade in *Clinical Ethics*, we analyze the encounter and differentiate four perspectives that inform medical decision making: medical indications, contextual features, quality of life, and patient preferences.[3] Also referred to as the "four box" approach, this method of doing clinical ethics asks us to dissect a clinical encounter into four overlapping perspectives to reach clarity regarding the best choices for the patient, and also which choices may not be appropriate in any given circumstance. **Medical Indications** encompass the pathologic condition and the indicated therapeutic interventions. **Contextual Features** evaluate the larger background of persons, institutions, and financial and social arrangements that impact care. **Quality of Life** analyzes the overall impact of the interventions and disease processes on the patient. **Patient Preferences** take into account the patient's personal values and assessment of benefits and burdens.[3]

Medical Indications

A 32-year-old G1P0 (first pregnancy) at 21 3/7 weeks gestational age presents to a tertiary care hospital in the United States. The patient is contracting regularly and is 4 centimeters dilated with membranes hour-glassing through the external os. The fetus is footling breech. The medical indications quadrant of decision making must first ask what is known medically about this situation, and how these facts and statistics may be brought to bear on the final clinical decision. To ask what should be done and what choices should be offered, we must know the likelihood of neonatal morbidity and mortality at this gestational age, and also which interventions and therapies have the possibility of altering these statistics and which do not. Should steroids be administered for fetal prematurity? Should magnesium be started for fetal neuroprotection? Should the infant be resuscitated after delivery? Should cesarean be offered? If a classical cesarean section is performed for a fetal indication the negative implications for this patient exceed the immediate risks of delivery and cesarean, extending to her future reproductive outcome and health.

Maternal factors must also come into decision making. Let us suppose that this patient also has a history of severe asthma and has a platelet count of 50. This would preclude spinal anesthesia for cesarean section and place this woman at even higher risk during surgery related to complicated intubation. Now, her BMI is 60, she has a history of obstructive sleep apnea, and is unable to ambulate without shortness of breath. Her risks both during and after cesarean section just logarithmically increased. She is not only at risk for complications related to anesthesia, but also higher surgical morbidity, higher rate of postoperative wound infection, and a higher risk for each of her subsequent pregnancies.[4] This case is more complex than an evaluation based solely upon fetal prognosis. Both fetal benefit and maternal risk must be individually assessed based upon a robust understanding of the clinical situation.

Contextual Features

The physician's side of the therapeutic relationship in a periviable pregnancy can be affected by hospital rules, practices, and the physician's own values. For example, a patient with advanced cervical dilation at 21 weeks might be offered termination at one institution or one physician group, but not at another, based upon the contextual aspects of the clinical encounter. Similarly, exogenous influences from partners, family members, friends, and even electronic sources will impact the patient's expectations and desires. Even in this patient's initial presentation, her decisions are being influenced by a multitude of factors. She enters labor and delivery with social, psychological, and religious beliefs that act as the foundation for her decision making. Furthermore, as a woman, she is influenced by cultural expectations of womanhood, self-sacrifice, and cultural roles.[5,6] So even if sufficient non-directive patient counseling is employed, the patient is considering and being influenced by numerous factors, some of which may be exerting their effect at a subconscious level, and therefore can be difficult to address directly in shared decision making. How, for example, in the time constraints often faced on a busy labor and delivery unit, does one respectfully ascertain if the patient's choices are being unconsciously constrained by socialized ideals of motherhood? Therefore, with the background of all these conscious and unconscious influences, if the physician's input in the decision is limited to providing all medical options, is it *just* to require an explicit and autonomous maternal "choice"? In other words, we believe patient autonomy can be enhanced by a physician-patient relationship that seeks to address these contextual features of maternal decision making, rather than one that takes a "hands-off" approach to informed consent, offering only medical facts and ignoring or disregarding the family, culture, and other pressures felt by the patient.

Physicians must use silent decision making to frame their recommendations and tailor them to what is appropriate in each clinical scenario. Overall, the inability to eliminate all forms of influence does not preclude patient autonomy, but physicians must recognize this influence and use this recognition to frame their counseling approach. This is especially applicable in cases of physiologic futility. Futility as an ethical concept is complex, and most ethicists disagree on the weight that measures of futility should be given in patient decision making. However, we agree with the argument of Tom Tomlinson and Howard Brody, who argue that the concept of futility should also be applied to periviable birth. In our case of the 21 3/7 week gestation pregnancy, medical interventions for fetal survival are physiologically futile as there are no fetuses that will survive. Therefore, in this example, cesarean section and the administration of antenatal corticosteroids or magnesium would offer no benefit, and cause more potential harm. It is in these cases that physiologic futility can enhance patient autonomy, by focusing choices only on options that have the possibility of offering benefit.[7]

Suppose the woman in the case that we presented above is not 32 years old, but rather 16 years old, or that she is 42 years old and this was an IVF pregnancy that required several rounds of ovulation induction to achieve, or that she is not nulliparous, but rather has 5 children at home with no financial or emotional support. Each of these women in these scenarios has very different motivations and exogenous influences that impact her decision making. Feminist bioethicists have explored how autonomy can actually be enhanced by a close supportive relationship, and we believe that this support must include offering recommendations, particularly when patients appear overwhelmed in their decision making either by the amount of medical information, or the need to weigh multiple contextual factors, such as other commitments and care giving relationships to whom they may already be responsible.[8]

Another contextual feature of periviable decision making is the socialized expectation of maternal self-sacrifice. As Lisa Campo-Engelstein, a feminist bioethicist writes, “One of the most dominant norms for reproduction and childcare is self-sacrifice: women are expected to willingly, and happily sacrifice themselves for their fetuses and children, even if there is only the potential for a slight improvement or advantage.”[5] As Janice Raymond describes it, writing on women’s altruism in the *Hastings Center Report*, “The cultural expectation of altruism has fallen most heavily on pregnant women, so that one could say they are imagined as the archetypal altruists.”[6] In the majority of these cases, women will choose the altruistic route of maternal self sacrifice because “the social relations set up by altruism and the giving of self have been among the most powerful forces that bind women to cultural roles and expectations.”[5] Although this seems like a powerful statement, if maternal self-sacrifice has any contribution in periviable decision making, it could potentially overwhelm other motivations and desires, and limit true patient autonomy. We have seen this in many similar scenarios, where women devote large amounts of time and resources in interventions for fetal anomalies that are medically futile. Take for example infants with Potter’s syndrome, previable preterm rupture of membranes, or Trisomy 13. Medical knowledge deems these pregnancies not viable, but there are many cases where the patient attempts to continue the pregnancy to full term, and sometimes remains hopeful despite the prognosis given by the physician. Women in these scenarios are also experiencing emotions of both hope and fear. At 21 weeks gestation, the pregnant woman has had 4 months of anticipation and has developed expectations for the pregnancy. The sudden loss of control that accompanies periviable deliveries can also significantly impact the decisions made about interventions for the pregnancy. All of her motivations are complex and multifactorial.

In our case of periviability, the risks to the mother are related to the surgery and future pregnancies, which, in the acute setting we described, may not be the predominant factors in her decision. However, given the dismal prognosis for a neonate born before 23 weeks, these issues should perhaps be central in her decision. If all possible options are presented without guidance or recommendation, then the woman is likely to choose a classical cesarean delivery of an infant who then dies in the NICU. Such a decision is ultimately neither beneficent nor nonmaleficent, because the neonate did not benefit from the decision, and the woman herself was harmed. If her choice is circumscribed by contextual features, such as societal expectation of self-sacrifice, she has not been able to weigh and consider possibilities and come to an autonomous decision that is consistent with her current responsibilities and future plans. Offering this option supports neither patient autonomy nor nonmaleficent care. Furthermore, a periviable cesarean section should be refused for patients where the risks to the pregnant patient outweigh potential benefits to the fetus. Just as we do not amputate limbs for patients with body dysmorphic syndrome or perform appendectomies on patients electively, we believe that with previable and periviable fetuses cesarean section on maternal request should not be offered, as the risks are significantly higher for complications as compared to a term cesarean, and there is no possibility of fetal benefit. When a patient's desires are inconsistent with medical realities, and the effect of the choice is patient harm, the patient's choice need not be heeded, particularly when the request requires a positive action on the part of the physician, rather than mere forbearance. Furthermore, although the negative of right of refusal has achieved near sacrosanct status under the principle of patient autonomy, the positive right to request procedures or direct one's own care is much more circumscribed, and is bounded largely by what the physician determines to be medically appropriate care. Therefore, the refusal to perform physiologically futile interventions is consistent with the principle of respect for patient autonomy, in the sense that patient autonomy is not synonymous with self-directed medical care with the physician relegated to a technician's role.[7] This is not a vestige of paternalism; this is central to good medical care.

"Informed assent" and "non-dissent" are both concepts in the bioethics literature that may be helpful tools in counseling periviable parents and preventing regrettable outcomes. With informed assent patients are presented with a plan and given an opportunity to agree to allow the physician to decide, and non-dissent provides the patient with an opportunity to disagree with the plan and if nothing is stated, it is assumed the patient agrees.[9] Because the physician can now recommend against a maternal self-sacrifice with little hope of creating a good outcome for her fetus, the pregnant patient can emotionally fall back upon accepting a recommendation rather than being responsible for a life and death decision. Just as with end-of-life decision making in the adult ICU setting, we believe presenting recommendations is the standard way of going through the process of informed consent, and cases of periviability should not be different. The reasons are two-fold: the information and choices can be overwhelming, and the contextual features of the case may make it hard for young women to choose their health and future reproduction over the life of a fetus, even if the fetal prognosis is poor. Although this is a counseling technique that cannot be universally applied to all patients, there are a significant proportion of pregnant patients that would benefit from this. Therefore, physicians should not offer unrealistic interventions and in complex scenarios, collaboration with pregnant patients using informed assent and non-dissent is the ethical choice.

Quality of Life

A central premise of medical decision making uses risk versus benefit analysis and ethical principles of beneficence and nonmaleficence. In cases of periviability, the impact of interventions applies to maternal and fetal quality of life, and both are intricately intertwined. Intervention on the basis of fetal indications, specifically in this case the need for cesarean section secondary to increased fetal morbidity and mortality related to breech vaginal delivery, carries with it significant immediate maternal morbidity and potential mortality. In our example, the implications of the decision for cesarean section extend well beyond this pregnancy. Furthermore, her decision carries with it implications for future reproductive health, including classical cesarean and risks for indicated preterm deliveries and abnormal placentation.[11-13] Using the example of the 16-year-old patient as compared to the older multiparous patient, the younger patient may have more future pregnancies and therefore increasing risks associated with each cesarean.[14] However, regardless of future reproductive potential, both have immediate repercussions from cesarean delivery and are at risk for increased postoperative pain, length of hospital stay, time for recovery, and surgical complications.

Intensive care literature has also demonstrated that there are significant psychological effects associated with the burden of deciding. The ramifications of this can manifest as significant anxiety, depression, and even post-traumatic stress disorder.[9] Even in a scenario where there is no benefit to intervention, the final decision can be emotionally devastating to the pregnant patient. Take, for example, the IVF patient who has undergone multiple rounds of ovulation induction, without success. Asking this patient to make a decision to not intervene on the only successful pregnancy she has achieved could result in psychological harm. Therefore, decision making using informed assent or non-dissent may be the morally appropriate alternative.

Furthermore, the quality of life of a periviable infant/neonate is much debated. At this early gestational age, sustaining neonatal life requires numerous interventions for an extremely poor prognosis. The pediatric literature recognizes a concept termed “unilateral pediatric do not resuscitate orders” for such infants.[9] This is the policy that a physician can make a decision for the neonatal patient without parental or caregiver consent. In these cases it is a physician’s responsibility to make these decisions in order to avoid dysthanasia (prolongation of agony, suffering, and death in a patient). The American Academy of Pediatrics’ Committee on Fetus and Newborn’s 2009 guidelines states, “if the physicians believe that there is no chance of survival, resuscitation should not be initiated. Parental preference regarding CPR in such a case is not elicited.”[9] This same concept is reflected in the obstetric consensus statement on periviability that does not recommend delivery by cesarean for fetal indications at less than 23 weeks gestational age.[1] While informed assent and non-dissent—which allow the possibility of maternal refusal—should be employed in situations when there may be a clinically preferable path but in which there is still some uncertainty of outcome, unilateral physician decision making may be appropriate when there is really only one medically indicated option.

Patient Preferences

A physician’s role is to provide the information necessary for a patient to give informed consent; this is usually in the form of data and descriptions of risks, benefits, and alternative treatment options. In this case one might outline the survival percentages for the fetus based on weight, gestational age, gender, and any other historical factors to be considered before then finally offering the patient interventions. However, as we have already discussed, not all interventions are appropriate and the information presented should be tailored to the unique situation of the particular patient**.** This bioethical concept has been termed “silent decisions” by Whitney and McCullough.[2] This is the idea that physicians are not ethically required to share every step of their decision-making process with the patient, and furthermore that it is unethical to offer or provide services that the physician deems medically inappropriate, or with a highly unfavorable risk/benefit analyses. Silent decision making has global application in the medical field. Whitney and McCullough have used the example of a patient who presents with a headache. As the history is being elicited, the physician forms a differential diagnosis, which includes everything from a tension headache to meningitis. Silent decision making in this instance is the physician’s decision not to offer the patient a lumbar puncture, as the clinical scenario does not warrant it. There are other instances where a headache will require this diagnostic procedure; however, there are even more where it will not. Therefore, these authors conclude that offering this would expose the patient to more harm than potential good.[2] It is in these circumstances of physiologic futility that interventions should not be offered and furthermore should be refused by the physician even if requested by the patient. Similarly, periviability should be treated in this way.

In contrast, should the patient explicitly ask for betamethasone and magnesium or tocolysis, these options may not be wrong to administer, but careful counseling regarding these interventions and outcome should be employed. Not all 22 6/7 week gestational age pregnancies are the same, and options for fetal intervention should not be either.

Conclusion

In conclusion, we propose that the physician offer the patient clear, realistic, nonmaleficent treatment options that seek to avoid both maternal and neonatal harm. These treatment or intervention options should be specifically tailored to the unique clinical situation and must not include any interventions where the harms to either the woman or the fetus are not counterbalanced by benefits that are at least commensurate. There are scenarios where this will involve no treatment or no intervention and this is morally justifiable. Finally, after presenting information, patients and family should be allowed to *not* make a decision, in accordance with informed assent and non-dissent. Recognizing that women may find it hard to protect their own health over the health of their fetus, even when the likelihood of fetal survival is extremely low, we believe an informed assent and non-dissent strategy of decision making may be a way to reduce harm, both physically and emotionally. Periviability is always a complicated medical scenario and decision making in this area will continue to be complex, but prevention of harm and enhancement of patient autonomy with appropriate relational support should always be the twin components of excellent obstetric care.

Acknowledgments

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References

1. Raju TNK, Mercer BM, Burchfield DJ, and Joseph GF. Periviable Birth: Executive Summary of a Joint Workshop by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, Society for Maternal-Fetal Medicine, American Academy of Pediatrics, and American College of Obstetricians and Gynecologists. *Obstetrics and Gynecology.* 2014; 123(5): 1083-1096.
2. Whitney SN and McCullough LB. Physicians Silent Decisions: Because Patient Autonomy Does Not Always Come First. *The American Journal of Bioethics.* 2007; 7(7): 33-38.
3. Jonsen AR, Siegler M, and Winslade WJ. Clinical Ethics. 4th edition. 1998. McGraw Hill.
4. Ayres-de-Campos D. Obesity and the challenges of caesarean delivery: prevention and management of wound complications. *Best Practice & Research Clinical Obstetrics and Gynaecolog*y. 2014; 1-9.
5. Campo-Engelstein L. Competing Social Norms: Why Women are Responsible for But Not Trusted with Contraception. *International Journal of Applied Philosophy.* 2012; 26(1):66-84.
6. Raymond JG. Reproductive Gifts and Gift Giving: The Altruistic Woman. *Hastings Center Report.* 1990; 20(6):7-11.
7. Tomlinson T and Brody H. Futility and the Ethics of Resuscitation. JAMA 1990; 264(10):1276-80.
8. Keller J. Autonomy, Relationality, and Feminist Ethics. Hypatia. 1997; 12(2): 152-164.
9. Mercurio M, Murray PD, and Gross I. Unilateral Pediatric “Do Not Attempt Resuscitation” Orders: The Pros, the Cons and a Proposed Approach. *Pediatrics.* 2014; 133: S37-S43.
10. Curtis, JR. Point: The Ethics of Unilateral “Do Not Resuscitate” Orders. *Chest.* 2007; 132(3):748-751.
11. Osmundson SS, Garabedian MJ, and Lyell DJ. Risk Factors for Classical Hysterotomy by Gestational Age. 2013; 122 (4) : 845-50.
12. Gyamfi-Bannerman C, Gilbert S, Landon MB, Spong CY et al. Risk of uterine rupture and placenta accrete with prior uterine surgery outside the lower uterine segment. *Obstetrics and Gynecology.* 2012 Dec; 120 (6): 1332-1337.
13. Greene RA, Fitzpatrick C and Turner MJ. What are the maternal implications of a classical cesarean? *Journal of Obstetrics and Gynaecology.* 1998; 18(4): 345-347.
14. Silver RM, Landon MB, Rouse DJ, Leveno KJ et al. Maternal morbidity associated with multiple repeat cesarean deliveries. *Obstetrics and Gynecology.* 2006; 107(6): 1226-32.

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Gender Dysphoria and the Ethics of Transsexual (i.e., Gender Reassignment) Surgery

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Abstract

Over the last several years, the relation between one's given biology and one's gender identity has become increasingly prosaic. Insofar as one's gender is increasingly identified by one's thoughts, feelings, and desires, it is now viewed as existing along a continuum. Persons with gender dysphoria perceive their true identity as different from their "assigned" biology. Transsexual surgery, or gender reassignment surgery, is one means of addressing this conflict. Contemporary, principle-based bioethical discussions of transsexual surgery as an effective treatment for gender dysphoria often fail to address more complex issues of identity as it relates to embodiment and too readily view the body as an object over which one can exercise unfettered dominion. The prospect of transsexual surgery challenges Christian ethics, which affirms the goodness of the human body, not by directly questioning the goodness of embodiment as such, but by challenging the goodness of this *particular body vis-à-vis one's "true" identity. However, must transsexual surgery be construed as a gnostic enterprise? Are there ways in which it is possible to affirm the goodness of the body without precluding the possibility of transsexual surgery? This article considers whether transsexual surgery might in some cases be permissible within a Christian ethical framework. We do so by drawing upon Thomas Aquinas, Oliver O'Donovan, and, more recently, the work of Robert Song, who has reflected on the morality of amputation for patients suffering from Body Integrity Identity Disorder (BIID), particularly Song's reflections on the Principle of Totality. Finally, we consider the degree to which this principle might be employed as a justification for gender reassignment surgery, noting several theological concerns that remain problematic.*

Introduction

Over the last several years, discussions concerning the relation between one's given biology and one's identity have become increasingly prosaic. We are in the midst of a cultural revolution of "gender nonconformity" that defies gender stereotypes by celebrating fluidity and gender indeterminacy. As French philosopher Hervè Juvin observes, "The myth of a body without origin, character, country or determination is a powerful presence in fashion, the economy and political discourse."[1] In 2014 Facebook offered fifty-eight versions of gender in response to growing criticism over the limitations of the bimorphic male or female. In 2015 Facebook decided to remove any restrictions in gender identity by allowing users to create their own. Moreover, many who once went to great lengths to hide the felt discrepancy between their gender identity and their bodies have been encouraged by the movement of transgendered celebrities into the cultural mainstream, pace Laverne Cox of the

Netflix drama *Orange is the New Black* and the very public transition of Bruce Jenner to Caitlyn as featured on the cover of *Vanity Fair*. In spite of the growing public acceptance of these figures, situated as they are in the larger narrative of "authentic" self-expression, many self-identified transgendered individuals continue to deal with multiple forms of discrimination.[2]

According to the most recent *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-V*), those suffering from gender dysphoria experience "a marked incongruence between one's experienced/expressed gender and assigned gender."[3] Though for some individuals this incongruence is temporary, for others this perceived discrepancy is persistent over time. Moreover, while not everyone experiences the same degree of dysphoria, for some individuals the resulting anxiety and depression is so debilitating and resistant to psychotherapy that gender reassignment surgery is recommended in order to bring one's body into alignment with one's sense of identity. For these individuals, surgery and continued hormonal treatment offer hope of resolving, or at least significantly minimizing the tension between one's sense of gender and one's biology. Here we consider the morality of transsexual or gender reassignment surgery in these particular instances.[4]

Hippocratic and Contemporary Bioethical Discourse

Though there is not widespread agreement regarding the best form of treatment for those experiencing gender dysphoria, gender reassignment surgery may be offered as an option for individuals who are clinically diagnosed with persistent gender dysphoria, which includes (among other criteria) two referrals (for genital surgery) by qualified mental health professionals, preceded by twelve months of hormonal therapy and living as one's "identified" gender.[5] Contemporary principle-based bioethics, with its focus on autonomy and beneficence (and non-maleficence and justice), generally considers gender reassignment surgery as an appropriate expression of one's autonomy.[6] Such principle-based thinking, however, offers little by way of reflection on the moral significance of the body and too readily views one's body as an object over which one can and should exercise unfettered dominion. Christian bioethicists have also been known to extol autonomy as a core feature of morality in a liberal society. Max Charlesworth (1925-2014), for instance, has argued that we ought to value autonomous moral agents who choose freely for themselves as the inevitable component of a liberal, pluralistic society that is unable to reach any consensus on core values.[7] Though the principle of autonomy does not preclude the considerations of others and has served as a useful corrective to paternalistic impulses of some physicians, it nevertheless tends to underwrite the objectification of the body in ways that preclude "thicker" accounts of the body, particularly with respect to the formation of virtue. Gender reassignment surgery, however, may present more of a problem for medicine insofar as its aims are guided by the Hippocratic tradition. Informed by the principle *primum non cocere*—"first, do no harm"—physicians face the tension between doing the *patient* good while recognizing that mutilating healthy organs is not a *medical* good.[8] Indeed, the Oath may not provide much guidance in determining what constitutes suffering for the gender dysphoric patient and what interventions are morally viable.[9] As one psychiatrist put it, "If we are trying to 'do no harm,' do we harm less by operating more, or harm more by operating less?"[10]

Gender Reassignment Surgery and Christian Ethics

The prospect of transsexual surgery provides a challenge to Christian ethics as well, not by directly questioning the goodness of embodiment as such, but by challenging the goodness of *this* particular body as it relates to one's "true" identity that lies somewhere within. In many respects, gender dysphoria reflects the latest crisis of the modern self, which, as Charles Taylor has noted, is marked by a sense of inwardness where one's identity is thoroughly grounded in an inner conviction, voice, or feeling.[11] This residue of Romantic philosophy, observes Taylor, asserts that "it is through our feelings that we get to the deepest moral and, indeed, cosmic truths," where fulfilling one's nature "means espousing the inner élan, the voice or impulse . . . mak[ing] what was hidden manifest for both myself and others."[12] This observation is not intended to ascribe this condition to modernity, much less to question the reality of any felt dysphoria, but rather to draw attention to the language frequently employed by those suffering from gender dysphoria to describe reality. For if one's *true* sense of identity resides in the "inner self," then the body, it would seem, is given short shrift. So long as this Romantic notion of identity thrives—that the "true" self is to be identified with one's deepest thoughts, convictions, feelings, and aspirations—then gender reassignment surgery appears as a perfectly appropriate means by which to "remedy" the discrepancy.

While there are certainly theological implications for speaking of identity in these terms, we note that this description of the self tends to bring one into conflict with one's body. If, however, we are created as embodied souls and ensouled bodies, then we may rightly wonder whether the body can and should be so readily reshaped to fit one's desires. From a Christian perspective, gender reassignment surgery appears to be a rejection of the Christian doctrine that we are created in God's image (*imago Dei*)—male and female, body and soul. Indeed, Christian ethicists have generally argued that gender reassignment or transsexual surgery either fails to acknowledge the goodness and "givenness" of one's physiological gender or violates the Principle of Totality by doing violence to a healthy organ designed for the welfare of the whole person. The question we consider here concerns whether Christians must always interpret transsexual surgery as a Gnostic or body-denying exercise. Or, are there ways in which it is possible to affirm the goodness of the body along theological lines without necessarily precluding the possibility of transsexual surgery?

In the remainder of this article we take up this question by considering the theological arguments of Oliver O'Donovan, who strongly questions the morality of transsexual surgery. O'Donovan's arguments are convincing, though he relies on some assumptions concerning the nature of gender dysphoria—assumptions of which he seems to be aware—that invite us to consider possible exceptions. In doing so we will examine the work of ethicist Robert Song, who considers whether amputation for those diagnosed with a condition called Body Integrity Identity Disorder (hereafter BIID) might in some instances be theologically warranted. Song's analysis will be useful in considering whether transsexual surgery might in some cases be morally permissible. But first, we consider O'Donovan's powerful critique, for any theological position on transsexual surgery must account for his arguments.

O’Donovan on Transsexual Surgery

Oliver O’Donovan discerns two basic attitudes that underlie transsexual surgery, the “psychological case” and the “social case.”[13] The “psychological case” sees transsexual or gender reassignment surgery as *resolving an ambiguity* between one’s sense of gender and the body. Here the feeling that one is “trapped” in the wrong body or has been “assigned” the wrong sex is accepted as normative. That is, one’s “authentic” self is determined by one’s sense of gender; surgery merely aligns the body to match one’s true identity (note again this very modern construction of identity).[14] One’s body here is treated as “an object set over against the personal subject located in the thinking-feeling mind.”[15] Thus, the new surgically-altered biology is taken for one’s “true” body. This line of thought, says O’Donovan, fundamentally collapses any distinction between one’s gender and one’s body.[16] The new nomenclature of “gender reassignment surgery” that has replaced the older “sex change” or “transsexual surgery” language bears witness to O’Donovan’s claim. Fundamentally, it is a denial of one’s given biology. It represents a failure to recognize “the body as self and . . . the self as obligated to the body’s form.”[17] Claiming to have a “real sex” different from one’s given biology inevitably entails “shrinking from the glad acceptance of myself as a physical as well as a spiritual being, and seeking self-knowledge in a kind of Gnostic withdrawal from material creation.”[18] It is important to pause briefly here and observe that O’Donovan’s critique is not aimed at the experience(s) of gender dysphoria patients themselves or the physicians who seek to help them. He readily acknowledges that such patients are motivated out of an urgent sense of need, and doctors likewise from the desire to relieve psychological distress.

The “social case” on the other hand, views transsexual surgery as creating a *framework of pretense* as a form of case management that enables the patient to cope with the difficulties of life.[19] Unlike the psychological perspective, this view tacitly accords greater significance to the body by denying that one “really is” the gender they feel themselves to be. In this view, one recognizes that he or she is not well. Nevertheless, surgery helps patients cope with life by reshaping the body and thus fashioning a kind of pretense, which then relies on the assistance of society to help reinforce this pretense. Even here, however, the sheer “givenness” of the body is effectively denied. Though this view is certainly more conservative in its reality-claims, O’Donovan notes that this political demand on society to reinforce a patient’s pretense is a heavy burden.[20] We may wonder too whether the church as a social community can and should bear the weight of such pretense, though we are called to “bear one another’s burdens.”[21] Moreover, this social theory raises questions about the use of medicine as a tool for social management.

Confessing the Body as God’s Good Creation

O’Donovan concludes, rightly, it seems, that we are to accept our given biology, male or female, as gifts from God, and to recognize the distinction between the goodness of embodiment as such and the various attitudes we might have towards our own bodies. Nevertheless, some Christians question whether one’s *gender identity* should not be taken as “the given” against which the body must be reshaped. It has been noted that “some transgender people also appeal to ‘givenness’ as a good, but for them it is the gender that is ‘given’ and therefore should not be changed, rather than bodily sex."[22] Others either have pointed out that it would be "theologically unsound" to assume that the physical is good and the psychological defective or argue that the dimorphic configuration of male and female fails to account for the effects of the fall (Gen. 3).[23] Yet, the creation accounts in Genesis seem to give unqualified affirmation that male and female bodies as created by God are good in and of themselves (Gen. 1:27). Being biologically male or female is good, as such. While the material need not have *ontological* priority over the spiritual, in light of the creation accounts, male and female biology should at least be accorded *epistemological* priority. Whatever the interpretation of one's gender—and here we readily admit of a variety of possibilities—one's biology (except in the intersex condition) should be given epistemological priority. Moreover, given that sin entered the world through an act of will, we should expect to find "fallen" attitudes toward our bodies without denying a biological component to our fallenness. Does this rule out transsexual surgery in all cases? Here we turn to the work of Christian ethicist Robert Song, who considers an uncommon condition known as Body Integrity Identity Disorder (hereafter BIID), where individuals experience an intense desire to amputate a major limb or to sever a portion of the spinal cord to induce paralysis due to a perceived mismatch between one's actual and perceived body schema.[24]

A Theological Justification for Transsexual Surgery?

Writing within the Christian tradition that confesses the goodness of the human body as created by God, Song asks whether there might be some allowance for amputation surgery that nevertheless recognizes the theological claims of the body's goodness articulated earlier by O'Donovan. Though Song is wary of contemporary construals of the body as morally neutral with respect to one's own ideal image of oneself, he also recognizes that those diagnosed with BIID not only report significant difficulties in coping with life, but occasionally resort to barbaric methods to remove the perceived limb(s) in an attempt to resolve strong feelings of dysphoria.[25] Moreover, BIID appears resistant to psychiatry and psychotherapy, with ample evidence showing that many who undergo amputation surgery report no need of follow up psychiatric treatment.[26] With these conditions in mind, Song considers whether some cases might allow for the amputation of a healthy limb for the welfare of the whole person. In considering this possibility, he begins with Thomas Aquinas' (1225-1274) discussion of bodily mutilation.

Aquinas on Mutilation

In the *Summa Theologica*, Aquinas argues that one's healthy bodily member ought not to be maimed for some supposed benefit of the whole person, a position that Roman Catholic moral casuistry has developed into the Principle of Totality. Aquinas asserts:

> Since a member is part of the whole human body, it is for the sake of the whole, as the imperfect for the perfect. Hence, a member of the human body is to be disposed of according as it is expedient for the body.[27]

Yet, Aquinas considers three possible exceptions to this principle. For our purposes, the medical and ascetic exceptions are most relevant.[28] The least controversial case concerns the removal of a sick limb. Aquinas affirms removal in such cases in order to secure the good of the whole body.[29] However, he rejects self-castration for spiritual purposes. Though he recognizes some have “made themselves eunuchs” for the kingdom of heaven (Matt. 19:12), Aquinas sides with Chrysostom’s spiritual interpretation; we should “cut off” impure thoughts, not our sexual members. In other words, one cannot pursue spiritual improvement by removing a healthy bodily member, “because sin is always subject to the will.”[30] Castration is therefore a misguided attack on the body in an attempt to curb sin.

So far so good. Song then turns to the casuist remonstrations of Gerald Andrew Kelly, SJ (1902-1964), who, in reference to the Principle of Totality, proposed lobotomy as one possible surgical intervention for cases of severe psychiatric conditions (e.g. schizophrenia). Lobotomies were practiced in the mid-twentieth century in preference to more extreme measures, and remained widely used throughout the 1950s and 1960s—though not without controversy (and mixed results)—before the development of antipsychotic drugs.[31] Kelly quoted approvingly from instruction given to Catholic Hospitals:

> Lobotomy and similar operations are morally justifiable when medically indicated as the proper treatment of serious mental illness or intractable pain. In each case the welfare of the patient himself, considered as a person, must be the determining factor. These operations are not justifiable when less extreme remedies are reasonably available or in cases where the probability of harm to the patient outweighs the hope of benefit to him.[32]

We should not let the specter of lobotomy distract us from the *principle* illustrated here (one is reminded of the song by the physician Randy Hanzlik, “I’d rather have a bottle in front of me, than a frontal lobotomy”). Song himself is aware that defending surgery for patients suffering from BIID by referring to lobotomy is hardly an attractive route.[33]

But Song concludes, somewhat to his own surprise, that amputation for *some* patients suffering from BIID represents a sufficiently analogous situation.[34] He notes the similarities between amputation and lobotomy, for, as in amputation surgery, lobotomies had major irreversible consequences for the patient and were only performed after a full psychiatric assessment—and even then only as a last resort. Though some conditions for which lobotomies were performed may have been more serious than BIID—such as schizophrenias and other psychotic and delusional disorders—lobotomies were also performed for affective disorders, anxiety, and obsessive-compulsive disorders, conditions that are similarly severe among those diagnosed with BIID.

Song also readily acknowledges, however, that these two situations intuitively feel different. He attributes this to the conflicting cultural narratives in which these were/are situated. Though somewhat barbaric, lobotomies were carried out only as a last resort, and were informed by a strong therapeutic motive. When debilitating disorders made life unmanageable and had proven resistant to every other therapy available, a lobotomy was considered a preferable alternative to shock-therapy or commitment to an asylum. Those who turn to amputation to treat BIID, however, are situated in a different cultural narrative that celebrates autonomy over one’s body, which tends to foster a consumerist approach to medicine. Here BIID patients are often unfairly lumped in with cosmetic or enhancement surgeries bent on self-fulfillment or gaining a competitive advantage.

Another reason why lobotomies feel different from amputation surgery is that the former operated on a portion of the brain that was considered diseased in some way, while the latter removes a *healthy* organ. Here Song notes, rightly, it seems, that if it were possible to operate on a patient's brain rather than amputate a limb, this would be preferable. Here at least it could be argued that medicine is dealing with the diseased organ while respecting the integrity of the body *as a whole*, whereas amputating a limb is surgery on a part of the body that is not (necessarily) diseased.[35] But amputation surgery for BIID, notes Song:

> . . . looks more like intervention in a body that is at war with itself, where one organ is in conflict with another, the head saying to the feet, 'I have no need of you' (1 Cor. 12:21). The body does not here point unequivocally to the goodness of creation, but has in its divided nature also become a sign of the fallen creation, a fall which may have originated in the disobedience of the will but which in the increased pains of childbirth is shown also to have bodily consequences.[36]

This is not a general condonation of psychiatry through surgery, observes Song, but would be so in *this* particular case. A significant problem here, however, is that we currently do not have the detailed neurological knowledge required for such a procedure. Indeed, such detailed knowledge might never become available. Song thus concludes that given our current limited state of neurological knowledge, we cannot necessarily preclude amputation for sufferers of BIID in *some* extreme cases, namely, those who have endured a lifelong struggle, who have great difficulties in managing basic tasks of life, who know well the cost of trying and failing to distance themselves from their feelings and the seeming impossibility of doing so.[37] According to Song, the determining factor for surgery in this case "would be the welfare of the patient . . . considered as a person; the totality which the mutilation would serve would be the whole person, body and soul."[38] This line of thought rejects the autonomy-centered reasoning that dominates contemporary bioethics. Song also distinguishes this allowance from mere pastoral necessity "out of a misplaced emphasis on compassion as the sole ground of discernment."[39] Moreover, in such cases surgery would not be considered a "cure" or final solution as such, but would be viewed as a treatment that would provide a modicum of peace to help one cope with life, even as such surgery would entail a new set of problems.[40]

Song is well aware of the potential abuses to which such allowances might be put. It might, for instance, further reinforce the notion that the body is merely an instrument for human desires. This is especially true in an era where bioethics is dominated by concerns over individual autonomy and where individuals place increasing pressure on medicine to meet whatever specific demands they might have in order to align their bodies with their ideal selves or inner identities. Song is also aware that amputation surgery might be consumerized as a way to realize one's florid fantasies of self-creation, rather than viewing such surgery as a last-resort necessity flowing from a genuine psychological need. Finally, he also acknowledges that the adoption of BIID as an official psychiatric classification may so essentialize the experience for some that it precludes other interpretations of their situation, including losing the desire for such surgery in the first place. Here, surgery becomes the sole hope of salvation.[41]

Despite these possibilities, however, Song concludes that there *might* be instances where amputation surgery could be justified from within a Christian framework that still recognizes the goodness of the body—though it is in a sense at war with itself—under the Principle of Totality. In cases of a clinical diagnosis where all other avenues to sufficiently relieve the condition have failed, amputation *might* be the last resort for the good of the whole person. Ultimately, Song concludes that more theological work is needed here before the church can be in a position to reach a mature conclusion.[42]

BIID and Gender Dysphoria

Song's analysis of BIID and the Principle of Totality, it seems, has opened the door (perhaps only temporarily) to amputation surgery in some cases if the right conditions are met. Might the same be said for gender reassignment surgery for those diagnosed with gender dysphoria? There are at least two questions here. The first concerns how analogous Gender Dysphoria is to BIID. The second question asks more directly whether the Principle of Totality might be legitimately invoked by Christians for gender reassignment surgery given the diagnosis of gender dysphoria. We will briefly treat these two questions in order.

In considering the ways in which gender dysphoria is analogous to BIID, we may simply note the ways in which they are similar and dissimilar. At present, both conditions are similar insofar as the specific origins are not known.[43] Both conditions also report a degree of suffering that is rooted in the perception of one's body. There is a sense that something is wrong; their sense of identity appears incongruent with their given physiology.[44] Moreover, both engage in impersonating behaviors that reflect their true identity, whether through cross-dressing or pretending to be partially paralyzed or an amputee (e.g. concealing an arm under clothing).[45] Both surgeries have major, irreversible consequences. Finally, the recipients of surgery—whether amputation, some form of impairment, or transsexual surgery—generally report an improvement in dysphoria and depression.[46]

In spite of the similarities, however, there is at least one glaring difference between BIID and gender dysphoria, for in the latter case the crisis of identity involves one's maleness or femaleness and not just a limb. Stated somewhat crudely, Joe is still Joe after an amputation, but when Joe surgically transitions to Joanne, something more fundamental has occurred, something closer to what constitutes the core of one's identity, which involves (and indeed is constituted by) one's reproductive and sexual organs. The assertion that our sexuality (physiological and psychological) gets closer to the core of one's identity should not, however, be interpreted as an echo of our hyper-sexualized culture increasingly bent on championing sexual fulfillment as a fundamental right, but flows from a transcendent perspective as revealed in Scripture: "male and female he created them." (Gen. 1:27c) Indeed, the most intimate of human actions and the highest calling, "be fruitful and multiply" follow immediately from our being created as male and female (expressed of course in proper context). Much more work could be done here, but we must turn to the second question regarding the application of Principle of Totality for transsexual surgery.

Though Song may have made a case for amputation surgery for those diagnosed with BIID in some instances, it is not at all clear that The Principle of Totality could be used to justify transsexual surgery. Even in cases where a person requesting surgery had the necessary clinical referral, was undertaking this surgery as a last resort, and acknowledged that this surgery was not a way to realize one's true self, but a concession, a way to fabricate a "framework of pretense" (pace O'Donovan's "social case"), it is difficult to avoid the conclusion that such a "concession" still entails a rejection of one's createdness as male or female. Moreover, it seems that the social implications of such surgery entail additional moral difficulties that surpass whatever moral challenges that might follow from living as an amputee or a person who has been surgically disabled. For instance, transsexual surgery clearly has significant implications for marriage.[47] It would also appear to place an unbearable burden on one's spouse, questioning the core of what it means to give oneself fully to another. Moreover, as O'Donovan has observed, if the "social case" of surgery inevitably places burdens on society to "play along" with one's new identity, one wonders how the community of faith devoted to "speaking the truth in love" could accommodate such requests and still be the church.[48] Thus, though the Principle of Totality might allow for amputation in cases of BIID, it runs into difficulties when applied to transsexual surgery.

What then might a Christian perspective have to say about gender dysphoria and gender reassignment surgery? There are three general points that should be kept in mind as Christians engage this phenomenon. First, Christian reflection on issues in medicine should rely on the findings of clinicians, surgeons, psychologists, psychiatrists, and the expertise they bring to the table. This means that Christian ethics ought to take the diagnosis of gender dysphoria seriously. The reports of suffering, depression, and dysphoria that often accompany gender dysphoria—though inevitably subjective in nature—ought not to be dismissed or minimized out of hand. Second, and more importantly, Christian reflection need not be limited to the particular *interpretations* of Gender Dysphoria and the remedies offered it by medicine, for the Christian faith relies on a revelatory account of the human condition as disclosed in Scripture that transcends any diagnostic manual. Though, for instance, the recent change in nomenclature from "gender identity disorder" (*DSM-IV*) to "gender gysphoria" (*DSM-V*) reflects a deliberate withdrawal from the negative implications of being diagnosed with a "disorder," and though the primary emphasis of psychotherapeutic approaches entails enabling one to *cope* with the dysphoria of one's identity rather than *change* one's identity, Christians need not uncritically accept such interpretations.[49] There is a real danger in allowing a diagnosis to so essentialize the experience of dysphoria that all considerations of engaging in practices that might actually refine or change one's identity are precluded.

Finally, and related to this last point, is Song's own conclusion that a Christian perspective on medical diagnoses dealing with crises of identity would benefit from reflecting on the liturgical practices of the church, which remind us of our identity in Christ, particularly the practice of baptism, which "directs us to follow one who did not lay claim to his identity as something to be hung on to."[50] Song's point reminds us to consider how our bodies, created as male and female by God, might help us discipline our desires and shape our identities in the context of the church as the body of Christ where the Baptism and the Eucharist are celebrated. Adding to Song's insight, we might also consider the formative influence of a regular enactment of the Eucharist, where Jesus' words, "this is my body broken for you," might begin to mute the thoughts that “this is my broken body,” enabling a degree of “identity transformation” in this life that will be perfected in the age to come.

Endnotes

1. Hervè Juvin, *The Coming of the Body*, trans. John Howe (London: Verso, 2010), 59.
2. See for instance Jamie M. Grant, Lisa A. Mottet, Justin Tanis, Jack Harrison, Jodie L. Herman, and Mara Keisling, *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey* (Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011). See also Deirdre A Shires and Kim Jaffee, “Factors Associated with Health Care Discrimination Experiences among a National Sample of Female-to-Male Transgender Individuals,” *Health and Social Work: A Journal of the National Association of Social Workers* 40, no. 2 (March 3, 2015): 134-141. More recently, *The Chronicle of Higher Education* released a special on-line issue devoted to transgender issues containing several articles dealing with discrimination. See for instance Faughn Adams, “Transgender Students Deserve Equal Access,” *The Chronicle of Higher Education*, October 18, 2015. Online at http://chronicle.com/specialreport/Diversity-in-Academe-/11; Genny Beemyn, “Leaving No Trans College Student Behind,” *The Chronicle of Higher Education*, October 18, 2015. Online at http://chronicle.com/article/Leaving-No-Trans-College/233754; Timothy Stewart-Winter, “Transgender Students Build on Feminism to Question Male Privilege,” *The Chronicle of Higher Education*, October 18, 2015. Online at http://chronicle.com/article/Transgender-Students-Build-on/233761; Marisa Richmond, “Why Colleges Need to Hire More Trans Faculty,” The Chronicle of Higher Education, October 18, 2015. Online at http://chronicle.com/article/Why-Colleges-Need-to-Hire-More/233762?cid=cp11. All accessed October 23, 2015.
3. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (Arlington, VA: American Psychiatric Publishing, 2013), 302.85 (F64.1). Cf. earlier definitions, R. Crook and K. Baur, *Our Sexuality*, 5th ed. (Redwood City, CA: Benjamin/Cummings, 1995), 55. “A **transsexual** is a person whose gender identity is opposite to his or her biological sex . . . He or she feels trapped in a body of the wrong sex, a condition known as gender **dysphoria**.” More recent terminology refers to “transgender people” who feel their gender identity does not match their biological sex, and “transsexualism” as referring to people who have undertaken surgery or hormone therapy to make their bodies “fit” their gender identity. Cf. Susannah Cornwall, “Intersex and Transgender People,” in *The Oxford Handbook of Theology, Sexuality, and Gender*, ed. Adrian Thatcher (Oxford, Eng.: Oxford University Press, 2015), 659. Susan Scutti refers to a “transsexual” as a person who has transitioned from one sex to another, and a transgendered person whose identity, expressions, behavior, and general sense of self “does not conform to what is usually associated with the sex they were born in the place they were born.” “What Is the Difference between Transsexual and Transgender? Facebook’s New Version of ‘It’s Complicated,’” *Medical Daily* (March 17, 2014). Online at http://www.medicaldaily.com/what-difference-between-transsexual-and-transgender-facebooks-new-version-its-complicated-271389. Accessed June 16, 2015.
4. Though gender dysphoria may have an erotic component, the scenario under consideration assumes this is not the case. As Paul McHugh, University Distinguished Service Professor of Psychaitry at Johns Hopkins Medical School has observed, there may indeed be an erotic component in imagining oneself as a man or a woman. McHugh speculates that Caitlyn Jenner may fit into this category of “men [who] want[ed] to display themselves in sexy ways, wearing provocative female garb,” who remain sexually attracted to women while claiming to be a woman in a man’s body. He notes: “The photograph of the posed, corseted, breast-boosted Bruce Jenner (a man in his mid-sixties, but flaunting himself as if a ‘pin-up’ girl in her twenties or thirties) on the cover of *Vanity Fair* suggests that he may fit the behavioral mold that Ray Blanchard has dubbed an expression of ‘autogynephilia’—from gynephilia (attracted to women) and *auto* (in the form of oneself).” Paul McHugh, “Transgenderism: A Pathogenic Meme,” *Public Discourse*, June 10, 2015. Online at http://www.thepublicdiscourse.com/2015/06/15145. Accessed June 23, 2015. Jenner’s display of femininity has invoked the ire of feminist thinkers like Germain Greer.
5. Eli Coleman et al., “Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7,” *International Journal of Transgenderism* 13, no. 4 (2011): 179

ff. Secondary surgeries (e.g. mastectomy) require one referral from a mental health professional. The "Standards of Care" do not consider psychotherapy as an absolute requirement before or after surgery.

6. Cf. W.P. Bouman et al., "Yes and Yes Again: Are Standards of Care which Require Two Referrals for Genital Reconstructive Surgery Ethical?" *Sexual and Relationship Therapy* 29, no. 4 (2014): 377-389, at 380. "With regard to such chronic conditions then [including gender dysphoria], the centre of clinical decision making in modern medicine is the moral imperative to respect the autonomy of the patient to make an informed decision regarding surgery."
7. Max Charlesworth, *Bioethics is a Liberal Society* (Cambridge, Eng.: Cambridge University Press, 1993), 1. "In a liberal society personal autonomy, the right to choose one's own way of life for oneself, is the supreme value." This is especially the case because "there is no determinate social consensus about a set of 'core values' or a 'public morality' which it is the law's business to safeguard and promote."
8. Oliver O'Donovan, *Begotten or Made?* (Oxford, UK: Oxford University Press, 1984), 28.
9. George R. Brown, "Bioethical Issues in the Management of Gender Dysphoria," *Jefferson Journal of Psychiatry* 6, no. 1 (1988): 33-43 at 35.
10. Brown, "Bioethical Issues in the Management of Gender Dysphoria," 41. Brown is presumably balancing the physiological harm of mutilating a healthy organ (an act of commission) with the psychological harm that may continue if the surgery is not carried out (an act of omission). Almost all medical dilemmas involve some balance of harms. Deciding what counts as harm often entails competing claims from disparate perspectives, and has resulted in several different perspectives of what "medical harm" means, and whether such determinations should be made individually or collectively. See Bettina Schöne-Seifert, "Harm," in *Encyclopedia of Bioethics*, Revised Edition, ed. Warren Thomas Reich (New York: Simon and Schuster Macmillian, 1995), 2: 1021-2026.
11. Charles Taylor, *Sources of the Self: The Making of the Modern Identity* (Cambridge, MA: Harvard University Press, 1989), 111, 374.
12. Taylor, *Sources of the Self*, 370, 374. "Expressive individuation has become one of the cornerstones of modern culture." (376) Taylor traces this thought to the work of Jean-Jacques Rousseau (1712-1788) and Johann Gottfried Herder (1744-1803).
13. O'Donovan, *Begotten Or Made?*, 22 ff. Cf.
14. Cf. Carl Elliott, *Better than Well: American Medicine Meets the American Dream* (New York: W. W. Norton and Co., 2003), 30 ff., who notes that "authenticity" where one seeks to find one's "true self" now serves as a kind of moral ideal that has replaced older quests where humans sought the transcendent good: "Finding yourself has replaced finding God." (p. 35).
15. O'Dovovan, *Transsexualism and Christian Marriage* (Bramcote, Eng: Grove Books, 1982), 10; Cf. O'Dovovan, "Transsexualism and Christian Marriage," *Journal of Religious Ethics* 11 (1983): 135-162.
16. *Begotten Or Made?*, 24. "Nature, nurture, and artifice have become indistinguishable elements in an undifferentiated process of necessity," so much so, that there appears no particular point at which human decision can supervene on this natural process." What lay back of this, says O'Donovan, is a collective societal will, a social epistemology that replaces the epistemology of the natural sciences:

    > It is evident that the dominant factor in it is society. The most significant moments in the 'natural' process of sex-differentiation which begins with the XX chromosome and ends, now, with the construction of artificial male genitalia, are those in which society 'assigns' and 'reassigns' the patient, first to one sex and then to another. These are the only moments in the process that are conclusively determinative. (24)

    Hervè Juvin is less charitable in describing transsexualism as a celebration of choice in response to "the frenzied hatred of discrimination." *The Coming of the Body*, 59.
17. O'Donovan, *Transsexualism and Christian Marriage* (Bramcote, Eng: Grove Books, 1982), 16.
18. O'Donovan, *Transsexualism and Christian Marriage*, 11. O'Donovan recognizes it could be argued that transsexuals are preoccupied with their bodies, whose activities actually bear witness to psychosomatic unity.
19. "The strength of this approach is that it involves not difficult theories about the ontology of sexual opposition. It appears to be theoretically neutral, making no reality-claims and demanding no

conceptual revisions." *Transsexualism and Christian Marriage*, 17.

20. *Begotten or Made?*, 27-28. "The 'social case', though much more conservative than the psychological case in its reality-claims, has gone a lot further in the licence it has asserted for 'management.' It represents at its strongest the claim that political management (for it is essentially a *political* rationale that is here being offered) should relieve individuals of the burden of tragic reality by taking responsibility for dealing with reality out of their hands."

21. Bearing another's burdens hardly necessitates that all burdens are borne on the given terms of those who need help in bearing them. The community should obviously bear burdens in ways that are for the good of that person.

22. Cornwall, "Intersex and Transgender People," 667-668. Cf. Rachel Mann, *Dazzling Darkness: Gender, Sexuality, Illness and God* (Glasgow: Wild Goose Publications, 2012).

23. Fraser Watts, "Transsexualism and the Church," *Theology and Sexuality* 9, no. 1 (2002): 63-85 at 80. "It would be theologically unsound to assume that the physical is good, but that the psychological is defective." Watts is writing in response to The Evangelical Alliance Policy Commission's report on transsexualism (2000), which considered the degree to which it has a biological basis. Cf. Heather Looy and Hessel Bouma III, "The Nature of Gender: Gender Identity in Persons Who are Intersexed or Transgendered," *Journal of Psychology and Theology* 33, no. 3 (2005): 166-178 at 175.

    Using science (general revelation) to help us understand more deeply God's special revelation must be done with great care. There mere observation that a phenomenon exists in nature does not by definition mean that it is part of God's intended good creation order. It may well reflect the consequences of the fall into sin. Neither the physical-biological world nor our cultural worlds are exempt from this brokenness, and this may include both intersexed and transgendered conditions as well as our cultural—including theological—beliefs about gender.

24. Rianne M. Blom, Raoul C. Hennekam, and Damiaan Denys, "Body Integrity Identity Disorder," *PloSOne* 7, no. 4 (April 2012): 1-6. Online at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3326051/. Accessed October 31, 2015; Michael B. First, "Desire for Amputation of a Limb: Paraphilia, Psychosis, or a New Type of Identity Disorder," *Psychological Medicine* 35, no. 6 (2005): 919-928. BIID is not considered a type of body dysmorphic disorder insofar as the desire for amputation rarely results from a perception that a particular body part is ugly, nor is amputation requested by the desire to be more attractive or socially acceptable, but rather by a felt need to be more "complete" or "authentic." See Robert C. Smith, "Less is More: Body Integrity Identity Disorder," in *The Legal, Medical and Cultural Regulation of the Body: Transformation and Transgression*, ed. Stephen W. Smith and Ronan Deazley (Farnham: Ashgate, 2009), 150-152.

25. Smith, "Less is More," 148-150. Methods of amputation include deliberately crushing an appendage in machinery, the use of dry ice, chain saws, laying their legs across train tracks, and shooting themselves.

26. According to psychiatrist Russell Reid of Hillingdon Hospital in London, psychotherapy for cases of BIID "doesn't make a scrap of difference in these people . . . . You can talk till the cows come home; it doesn't make any difference. They're still going to want their amputation, and I know that for a fact." Reid is quoted in Elliott, *Better than Well*, 209. Surgeon Robert Smith at the Falkirk and District Royal Infirmary in Scotland reported "remarkable" results in the two amputees on which he performed surgery. In both cases minimal post-operative analgesia was necessary; both reported a profound sense of transformation that was so strong that neither felt the need for any subsequent psychiatric treatment, where before their lives where marked with frequent depressive and often debilitating episodes. Robert C. Smith, "Body Integrity Identity Disorder: The Surgeon's Perspective," in *Body Integrity Identity Disorder: Psychological Neurobiological, Ethical and Legal Aspects*, ed. Aglaja Stirn, Aylin Thiel, and Silvia Oddo (Lengerich: Pabst Science, 2009), 41-48. For other reports claiming complete resolution by surgery, see Arjan W. Braam and Nicole de Boer-Kreeft, "Case Report—The Ultimate Relief; Resolution of the Apotemnophilia Syndrome," in *Body Integrity Identity Disorder: Psychological Neurobiological, Ethical and Legal Aspects*, ed. Aglaja Stirn, Aylin Thiel, and Silvia Oddo (Lengerich: Pabst Science, 2009), 148-150. More recent study of 54 BIID individuals concluded that "surgery is found helpful in all subjects who underwent amputation and those subjects score significantly lower on a disability scale than BIID subjects without body modification." See Blom, Hennekam and Denys, "Body Integrity Identity Disorder," 1.

27. Thomas Aquinas, *ST* IIaIIae q. 65, art. 1, in *Summa Theologica: Complete English Edition in Five Volumes* [hereafter *ST*], trans. Fathers of the English Dominican Province (New York: Benzinger Bros., 1948), vol. 3, 1467. The Principle of Totality finds a contemporary statement in Pope Pius XII (d. 1958), *The Moral Limits of Medical Research and Treatment* II.13. Online at http://www.papalencyclicals.net/Pius12/P12PSYCH.HTM. Accessed July 7, 2015.

    As for the patient, he is not absolute master of himself, of his body or of his soul. He cannot, therefore, freely dispose of himself as he pleases. Even the reason for which he acts is of itself neither sufficient nor determining. The patient is bound to the immanent teleology laid down by nature. He has the right of use, limited by natural finality, of the faculties and powers of his human nature. Because he is a user and not a proprietor, he does not have unlimited power to destroy or mutilate his body and its functions. Nevertheless, by virtue of the principle of totality, by virtue of his right to use the services of his organism as a whole, the patient can allow individual parts to be destroyed or mutilated when and to the extent necessary for the good of his being as a whole. He may do so to ensure his being's existence and to avoid or, naturally, to repair serious and lasting damage which cannot otherwise be avoided or repaired.

    Cf. Martin Nolan, "The Positive Doctrine of Pope Pius XII on the Principle of Totality," *Augustinianum* 3, no. 2 (July 1963): 290-324.
28. The other exception concerns maiming as punishment. Based on his understanding of the Old Testament *lex talionis* (Ex. 21:24), Aquinas allows some forms of punishment carried out by public authority that maim a bodily member—even though this member is healthy—in order to secure the general welfare of the community. Aquinas reasons that even though the removal of this bodily member may be detrimental to the whole body, it is proper insofar as its removal as punishment restrains sin, and therefore serves the welfare of the community. *ST* IIaIIae q. 65, art. 1, reply. ". . . it may happen that although the removal of a member may be detrimental to the whole body, it may nevertheless be directed to the good of the community, in so far as it is applied to a person as a punishment for the purpose of restraining sin."
29. *ST* IIaIIae q. 65, art. 1; *ST* IIaIIae, q. 61 art. 2. In this case it is permissible for an individual to give consent without reference to anyone else to have the diseased member cut away, since the individual's health is the responsibility of that person.
30. *ST* IIaIIae q. 65, art. 1, ad. 3.
31. Gerald Kelly, SJ, "The Morality of Mutilation: Towards a Revision of the Treatise," *Theological Studies* 17 (1956) 322-344.
32. Robert Song, "Body Integrity Identity Disorder and the Ethics of Mutilation," *Studies in Christian Ethics* 26, no. 4 (2013): 498, quoting Kelly, "The Morality of Mutilation," 340, who is quoting *Ethical and Religious Directives for Catholic Hospitals*, no. 44.
33. He notes that the Soviet Union banned the procedure in 1950 on the grounds that it was inhumane. Bilateral Cingulotomy is a contemporary surgical procedure that has proven effective for sufferers of extreme OCD for whom pharmacologic or behavioral therapies have proven ineffective.
34. Song, "Body Integrity Identity Disorder," 498. " . . . if lobotomies were at least on some occasions morally and medically justified, then so too should surgery for BIID be."
35. Song, "Body Integrity Identity Disorder," 499.
36. Song, "Body Integrity Identity Disorder," 500.
37. Song, "Body Integrity Identity Disorder," 502. Note that Song is not concluding that because we simply do not know how the biology of the brain might contribute to BIID, then we may as well allow for amputation. This would effectively be an argument from ignorance. Song is basically asserting that the least controversial case of surgery for BIID would be brain surgery—if we had such knowledge.
38. Song, "Body Integrity Identity Disorder," 500. Cf. however Gilbert C. Meilaender, *Body, Soul, and Bioethics* (Notre Dame, IN: University of Notre Dame Press, 2002), ch. 1, who has argued that bioethics has "lost the body" through the concept of "personhood."
39. Song, "Body Integrity Identity Disorder," 503. Here Song may be envisioning cases where religious leaders uncritically bless an upcoming amputation surgery based on appeals to pity.
40. Song, "Body Integrity Identity Disorder," 502-503.
41. Song, "Body Integrity Identity Disorder," 501-502.
42. As Song observes, if the church is to be free, it must also be free to say "no" on this issue as well.

"Body Integrity Identity Disorder," 503.

43. There is no conclusive evidence to suggest that gender dysphoria is merely a psychological problem, but may very well have a physiological origin. Earlier this year researchers at Boston University claimed to have found a biological basis for transgendered identity. Aruna Saraswat, Jamie Weinand, and Joshua Safer, "Evidence Supporting the Biologic Nature of Gender Identity," *Endocrine Practice* 21, no. 2 (2015): 199-204. Other scientists suggest that there is a disparity between the brains of transgender and non-transgender people, with some "female" physical brain characteristics in transgender women. Cf. Louis Gooren, "The Biology of Human Psychosexual Differentiation," *Hormones and Behavior* 50, no. 4 (2006), 589-601; Jiang-Ning Zhou, Michel A. Hofman, Louis J. Gooren, and Dick F. Swaab "A Sex Difference in the Human Brain and its Relation to Transsexuality," *Nature* 378 (1995): 68-70. These findings have been contested, however. Cf. J. Schneider, J. Pickel, and G. Stalla, "Typical Female 2nd-4th Finger Length (2D:4D) Ratios in Male-to-Female Transsexuals—Possible Implications for Prenatal Androgen Exposure," *Psychoneuroendocrinology* 31, no. 2 (2006): 265-269. Others attribute transgender people have variant genes. Cf. E. Bentz, L. Hefler, U. Kaufmann, J.C. Huber, A. Kolbus and C. B. Tempfer, "A Polymorphism of the CYP17 Gene Related to Sex Steroid Metabolism is Associated with Female-to-Male but Not Male-to-Female Transsexualism," *Fertility and Sterility* 90, no. 1 (2008): 56-59; L. Hare, P. Bernard, F. Sanchez, P. Baird, E. Vilain, T. Kennedy, and V. Harley, "Androgen Receptor Repeat Length Polymorphism Associated with Male-to-Female Transsexualism," *Biological Psychairty* 65, no. 2 (2009): 93-96. Still others, like Harry Benjamin, believe that there is no clear biological basis for transgender and that it arises from psychological or social reasons. Recently Paul McHugh, Distinguished Service Professor of Psychiatry at Johns Hopkins Medical School has asserted that "plenty of evidence demonstrates that within him and most others, transgendering is a psychological rather than a biological matter." Cf. "Transgenderism: A Pathogenic Meme."
44. First, "Desire for Amputation," 919-928.
45. See for instance Elliott, *Better than Well*, 221. Michael First, "Desire for Amputation," 926-927.
46. See Coleman et al., "Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7," *International Journal of Transgenderism* 13, no. 4 (2011): 199. See also J. J. Hage and F. H. de Graaf, "Addressing the Ideal Requirements for Free Flap Phalloplasty: Some Reflections on Refinement of Technique," *Microsurgery* 14, no. 9 (2000): 592-598; De Cuypere et al., "Sexual and Physical Health after Sex Reassignment Surgery," *Archives of Sexual Behavior* 34, no. 6 (2005): 679-690; L. Gijs and A. Brewaeys, "Surgical Treatment of Gender Dysphoria in Adults and Adolescents: Recent Developments, Effectiveness, and Challenges," *Annual Review of Sex Research* 18 (2007): 178-224; C. Klein and B. B. Gorzalka, "Sexual Functioning in Transsexuals following Hormone Therapy and Genital Surgery: A Review (CME)," *The Journal of Sexual Medicine* 6, no. 11 (2009): 2922-2939; F. Pfäfflin and A. Junge, "Sex Reassignment: Thirty Years of International Follow-up Studies after Sex Reassignment Surgery: A Comprehensive Review, 1961-1991," *International Journal of Transgenderism*. Online at http://web.archive.org/web/20070503090247/http://www.symposion.com/ijt/pfaefflin/1000.htm. Accessed October 29, 2015; J. Eldh, A. Berg and M. Gustafson, "Long-term Follow Up after Sex Reassignment Surgery," *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery* 31, no. 1 (1997): 39-45; M. H. Murad et al., "Hormonal Therapy and Sex Reassignment: A Systematic View and Meta-analysis of Quality of Life and Psychosocial Outcomes," *Clinical Endocrinology* 72, no. 2 (2010): 214-231; R. Green and D. Fleming, "Transsexual Surgery Follow-up: Status in the 1990s," *Annual Review of Sex Research* 1, no. 1 (1990): 163-174; A. Johansson, E. Sundborn, T. Höjerback, and O. Bodlund, "A Five Year Follow-up Study of Swedish Adults with Gender Identity Disorder," *Archives of Sexual Behavior* 39, no. 6 (2010): 1429-1437; Y. L. S. Smith, S. H. M. Van Goozen, A. J. Kuiper, and P. T. Cohen-Kettenis, "Sex Reassignment: Outcomes and Predictors of Treatment for Adolescent and Adult Transsexuals," *Psychological Medicine* 35, no. 1 (2005): 89-99. For studies on the success of amputation surgery for BIID, see footnote 26 above.
47. Cf. O'Dovovan, "Transsexualism and Christian Marriage," 135-162.
48. Nevertheless, the Church of England is considering recent requests to accommodate the spiritual needs of transgendered individuals by conducting a "rebaptizing" service in order to be "recognized in their 'chosen' name . . . to be publically introduced to God. See Ruth Gledhill, "Church of England to Consider 'Transgender Baptism' Service," *Christian Today*, May 22,

2015. Online at http://www.christiantoday.com/article/church.of.england.to.consider.transgender.baptism.service/54463.htm. Accessed May 27, 2015.

49. This change in nomenclature is an attempt to destigmatize and existentialize the condition. Cf. Wynne Parry, “Normal or Not? When One’s Gender Identity Causes Distress,” June 3, 3013. Online at http://www.livescience.com/37087-dsm-gender-dysphoria.html. Accessed June 16, 2015. Even in *DSM-IV* however, “identity disorder” was not defined. Concerning the goals of psychotherapy, see E. Coleman et al., “Standards of Care for the Health of Transsexual,” 183-184. “Psychotherapy is not intended to alter a person’s gender identity; rather, psychotherapy can help an individual to explore gender concerns and find ways to alleviate gender dysphoria . . . the overarching treatment goal is to help transsexual, transgender, and gender-nonconforming individuals achieve long-term comfort in their gender identity expression.” Cf. K. Seikowski, “Psychotherapy and Transsexualism,” *Andrologia* 39 (2007): 248-252, who asserts that “it is important to note that the aim of psychotherapy is not to treat gender dysphoria in the sense of ‘curing’ patients of their ‘misperceptions’ about their gender. Rather it is to help them feel comfortable in their gender identity, allowing them realistic chances to succeed in relationships, education, and work.”
50. Song, “Body Integrity Identity Disorder,” 498.

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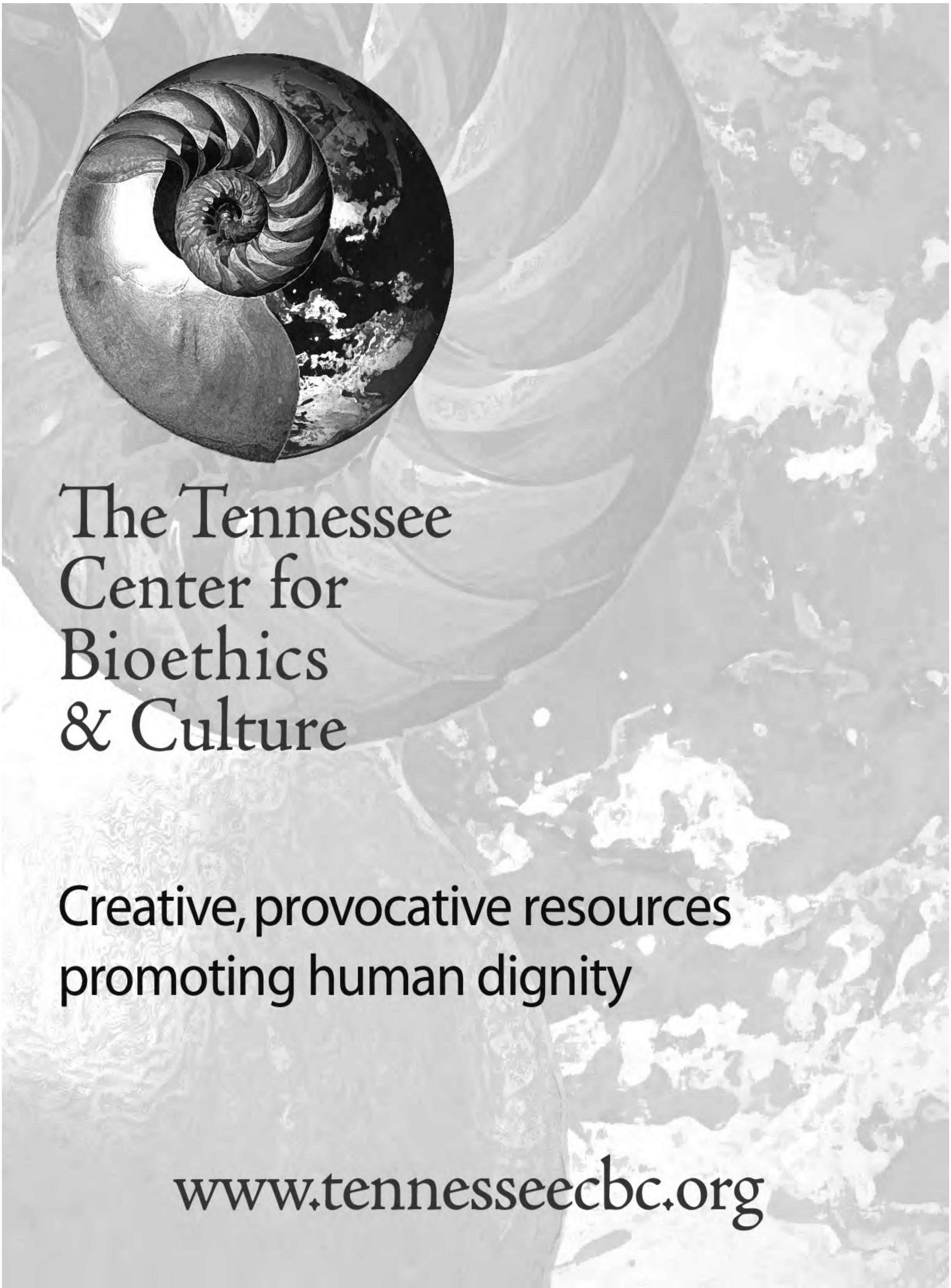

BOOK REVIEWS

The New Kinship: Constructing Donor-Conceived Families

Naomi Cahn. New York and London: New York University Press, 2013.

ISBN: 9780814772034, 250 PAGES, CLOTH, $35.00.

Over 50,000 children are born annually from gamete donation in the United States; worldwide there are over one million donor-children. Addressing this emergent topic in *The New Kinship: Constructing Donor-Conceived Families*, George Washington University Law professor, Naomi Cahn, explores the situations of egg and sperm donors, donor-conceived children, and donor siblings in the United States. Cahn's stated objectives are to "focus . . . on families/relationships conceived through donors [and] document… these newly developing connections . . . propose a legal basis for . . . these new communities . . . [and] show how donor families . . . [offer] lessons for all families." (3)

While her stated purpose is threefold, the thrust of the text is the legal analysis and her proposition that donor kin families should be recognized under the law. *The New Kinship* proceeds in four parts followed by a conclusion. In Part I, Cahn lays out the landscape of the donor world. She builds on this in Part II, introducing us to real-life donors and children of donors through interviews and survey data. Parts III and IV are concerned with legal matters. She describes the current legislation and the need for reform, then anticipates and rebuts anti-regulation arguments.

Cahn clearly states her objectives for each chapter, reminding the reader what she is building on from previews chapters. This style makes it a good text for the classroom with the added benefit that any chapter can be read alone. Throughout, Cahn astutely intertwines a variety of sources, from popular culture (*My So Called Life*), to interviews, PEW data, legal history, statistics, and international comparisons. These sources keep the text informative and engaging.

Early on, Cahn provides useful definitions and distinctions for thinking about family: "traditional families" (biologically related, nuclear families), "donor-conceived families" (families who use donated eggs, sperm, or embryos), "donor-conceived family communities" or "donor kin families or networks" (the relationships between donors and offspring and donor siblings), legal family ("a group that is subject to legal protections for privacy, with a specific structure"), and her notion of family (focus on "people not genes"). (2, 3) These categories become crucial to the later part of the book where Cahn argues for new legislation based on the relationships of donor kin families.

Cahn's analysis reveals two important insights about the donor world: medicalization and dehumanization. She worries that the social and legal issues of infertility (with the relatively easy solution of donor sperm insemination) have been commandeered by the medical community and she laments that other types of infertility are categorized as "diseases."

Cahn describes donor selection and donor children seeking donors and/or donor siblings, highlighting the commodification endemic to the processes. Donors' genes are abstracted from donors' humanity, so that donors become conduits for desirable genetic traits (hair color, eye color, SAT score, etc.) with a price. While donor children and their parents often later seek out the donor, this is rarely done in order to form a relationship, but rather to procure genetic information. Cahn poignantly captures this sentiment through the case of Alice Crisci, who used a sperm donor to conceive. Crisci did not desire much information about the donor because that "would create a false intimacy between us that I did not want. It would humanize his DNA too much for me." (79) Conversely, Cahn explains that donor-children often seek out their donor siblings in order to form relationships with them. These donor-sibling connections make up donor-kin communities, but have no legal recognition.

These mixed attitudes uncover a complicated relationship with genetics. On the one hand, genes are important (parents indicate certain preferences), while on the other hand, genes are irrelevant (parents do not feel disconnected from their child when they do not share genes).

Cahn goes on to describe many problems with the current system. For instance, there are no laws regulating gamete extraction or requiring counseling to prepare donors and donor parents for possible psychological effects. Moreover, the effects of oocyte donation are unknown. Additionally, because of the culture of secrecy surrounding gamete donation and its anonymity, the CDC does not track donor sperm. Cahn argues that this becomes problematic for a variety of reasons. For one, the anonymity does not take into account the future wishes of the resultant third party (the child), who may desire to find his/her donor or donor-siblings. While some private organizations and websites have been created to this end, Cahn relays the difficulties for donor children to find their genetic kin, and protecting the wishes of donor-conceived children is a priority for Cahn. Furthermore, donors have no way to verify whether their requests for how to use the donations are followed. Anonymity also prevents the tracking of genetic diseases. Finally, there is no limit on the number of donor children one can create, thus increasing the possibility of incest. Cahn believes that many of these problems would dissolve if the courts recognized donor kin families and their desire to connect, and suggests specific legislation to protect donor kin families, but also to move public opinion to recognize this emergent family structure.

Cahn's legislative agenda relies heavily on the view that it is the US government's role to nurture family relations. She offers this as an assertion without vigorously defending her view. Subsequently, I fear she will lose a significant number of readers who do not agree with this premise and who find no argument in the text to persuade them. Others may disagree with her assertion that the law should sway public opinion. While these are not insurmountable problems, her argument would have more widespread appeal if she engaged readers by defending these claims. She also does not engage with readers who may be wrestling with supporting donor kin families, while not agreeing with the condition of the possibility of donor kin families—*in vitro* fertilization. Cahn could have drawn in these readers by providing tools for thinking about the role of law in a pluralistic context. Also, additional attention to socio-economic status and minority groups would have added another layer of critical analysis. Nevertheless, *The New Kinship* is an excellent introductory text for anyone interested in the intersection of gamete donation, family, and the law.

Reviewed by Kate Jackson-Meyer, MA (Religion), who is currently a doctoral student and Flatley Fellow in theological ethics at Boston College, is co-coordinator of BC Theology Partakers Group (providing academic support to the imprisoned), and Graduate Assistant in Medical Humanities at Boston College, Boston, MA, USA.

God, Freedom, and Human Dignity: Embracing a God-Centered Identity in a Me-Centered Culture

Ron Highfield. Downers Grove: IVP Academic Press, 2013.

ISBN-978-0-8308-2711-4, 229 PAGES, PAPER, $22.00.

Why is it that so few who claim to be Christian have a passion for God that governs their lives? According to Ron Highfield, the reason is located in our "me-centered culture"—a cultural perspective that locates dignity and fulfillment within the self, and proclaims that self-worth and happiness are dependent upon constructing ourselves according to our will and desires. From this vantage point, the idea of God becomes a moral offense to human dignity and freedom; as the divine will is set against the human will, Promethean defiance, lamb-like subservience, or sleepy indifference is generated. (82) The solution: establishing a God-centered identity grounded in the incredible love of God for humankind as evidenced in creation and manifested in the cross of Christ, a love grounded in an eternal relationship with God.

God, Freedom, and Human Dignity is therefore a book about human identity—the self. Highfield begins by exploring the origins of the modern self and then deconstructing this illusionary false self, constructed on the sinking sand of human potentiality. He then reconstructs the true self on the basis of a "God-centered" identity, one based on a Biblical and Trinitarian understanding of human identity and on God's great love for His children, where our dignity, freedom, will, and morality are found in Christ, our true image and identity.

The book is unique in its philosophically-oriented meditational character. Highfield draws on both ancient and modern philosophical and theological sources to stimulate in readers not only a new identity, but also a new passion for God in response to His love. The first part of the book examines the "me-centered self," drawing largely on the works of Alasdair McIntyre and Charles Taylor, examining the resulting view of God that is evoked and demonstrating that this view of self and God provokes envy and competition rather than love. The second part of the book explores the view of God and humanity that are illuminated by Jesus Christ, developing a compatibilist and non-competitive image, first of God, then of humanity, based on an identity grounded in Christ and in God's great love for us. According to Highfield, God is the perfect persuader, moving us without coercion by enabling us to move ourselves toward perfect joy and fulfillment. (136) The book concludes with a picture of true selfhood, perfect freedom, and the ultimate dignity found in Christ.

The book asserts that it was written for all: students, teachers, ministers, laypersons, believers, searchers, and skeptics. It explores the influence of great thinkers such as Descartes and Locke, as well as the mythological figures that have been incorporated into the modern concept of the self, and does so in a highly readable and accessible format. While it is academically grounded, it lacks the depth required for many academic venues but may provide a basic springboard for deeper academic discussions and research.

"Who am I?" is the question that reverberates at the heart of our human existence and for which we spend our lifetime designing an answer. Yet our true identity is discovered, not designed; it is encountered in an eternal relationship with God. Ultimately, I am God's beloved. It is that heart knowledge that gives substance to our identity, meaning to our existence, and adds passion to our living.

Reviewed by Susan M. Haack, MD, MA (Bioethics), MDiv, FACOG, recently retired from consultative gynecology at Hess Memorial Hospital and Mile Bluff Medical Center in Mauston, Wisconsin, USA.

Intuition in Medicine: A Philosophical Defense of Clinical Reasoning

Hillel D. Braude. Chicago, IL: The University of Chicago Press, 2012.

ISBN-13: 978-0-226-07166-4, 256 PAGES, CLOTH, $54.00.

Since antiquity, the practice of medicine has been considered an art—the practitioner investigating and managing a patient and illness using both knowledge as well as insight into the pathophysiology of disease. Medical practice also involves a physician drawing on past experience while using an intuitive sense to guide clinical decision making. In the past, physicians relied heavily on intuition. Medical science had not yet matured to the degree it has in the present day.

The last decade of the twentieth century saw the emergence of the phenomenon of evidence-based medicine—the practice of basing medical decision making and treatment plans on the best evidence available from highly structured clinical trials that have undergone rigorous statistical analysis. The most ardent of those who support this approach would suggest that this is all that is really required to guide clinical practice. Such is the thinking behind the development of clinical practice guidelines, preprinted order sets, and clinical pathways that direct patient therapies. A shortcoming to this approach, however, is that it fails to account for the varying contingencies in patients. Thus, intuition as it guides clinical reasoning remains an important aspect of the practice of medicine.

Hillel D. Braude, in his book *Intuition in Medicine*, provides a look at the role of intuition in clinical reasoning from a philosophical perspective. He suggests that intuition provides a link between reasoning in the medical sense, in the moral sense and what it means to be human. Throughout the book, Braude brings a philosophical understanding to intuition and its role in clinical reasoning. He begins with a discussion of the role of intuition in the emergence of medical ethics in the 1970s and 1980s and progresses to moral intuitionism. From the philosophical understanding of moral intuitionism, Braude moves on to Aristotle's concept of phronesis as a model for clinical reasoning. The discussion continues with a look at Aristotle's practical syllogism and a consideration of its link with physiognomy and the subsequent development of medical statistics.

The use of medical statistics in modern medicine has led to the widely accepted practice of evidence-based medicine and the tension between intuition and statistical reasoning. Braude takes the time in his discussion to offer his critique of the statistical epidemiology that is the heart of evidence-based medicine, distinguishing it from clinical epidemiology. He is critical of evidence-based medicine in that intuitive reasoning suffers by it, a point well taken by a clinician that often finds that evidence-based medicine falls short in accounting for the varying contingencies with individual patients. In his final analysis, Braude examines Pierce's theory of abductive reasoning, one that moves from hypothesis to facts, as it brings all of the previously studied elements together.

Through his treatise, Braude brings an important study of intuition in medicine worthy of careful study. He draws from the disciplines of philosophy, science, and ethics in his writing, bringing insight from his own personal experience as a physician and philosopher. As a physician who did his specialty training at McMaster University, arguably the birthplace of evidence-based medicine in its modern form, I found it particularly helpful, acknowledging that intuition and reasoning remain an important part of clinical medicine.

Reviewed by Jeffrey G. Betcher, MD, FRCPC, MA (Ethics), who is clinical assistant professor at the College of Medicine, University of Saskatchewan and is Department Head and Medical Director of Critical Care at the Regina Qu'Appelle Health Region in Regina, Saskatchewan, Canada.

Shaping Our Selves: On Technology, Flourishing, and a Habit of Thinking

Erik Parens. New York: Oxford, 2015.

ISBN 978-0-19-021174-5, 200 PAGES, CLOTH, $35.00.

In *Shaping Our Selves*, Parens suggests we set aside typical arguments "for" or "against" enhancements and instead think "about" the meaning of enhancement. He aims not to provide crisp answers to questions that preclude them; rather, he provides a compelling alternative method—a habit of thinking—for considering enhancement in particular situations. He calls it "binocularity" and traces it to the work of Jonathan Glover. People typically view enhancement through one of two lenses: people as *subjects* (who freely create themselves) or people as *objects* (whose actions are determined). Instead, we must "oscillate" between viewing people as subjects *and* objects in order to "conceive of and help facilitate a process of truly informed consent." (37)

Along with this helpful metaphor, other strengths emerge (though I can treat only a few here). Parens demonstrates that two stances dominate the enhancement debate. First, the creativity stance emphasizes humans as subjects who can shape themselves. Second, the gratitude stance underscores humans as objects and thankful recipients of the ways things are (Parens resists any religious rooting of this stance). While these stances appear contradictory, both center on what Charles Taylor calls "the moral idea of authenticity" (47), or the idea that "each of us should find our own way of being in the world" and thus be true to the self. (48) In brief, Parens argues that binocularity helps people to pursue "true enhancement," which leads to "true human flourishing," which comes from being in contact with the world as it really is (see esp. ch. 5). Parens goes on to expand this vision, showing how it leads to action and decision in particular cases.

Two major weaknesses emerge. First, Parens's "binocular" metaphor doesn't quite work. He acknowledges this problem later in the book. (172) Since we can only look through one lens at a time, he actually advocates a set of monocles used in succession. Using "binocularity" so prominently with the caveat that you cannot look through both lenses at once muddies the water and weakens the overall proposal. Second, Parens's "truly informed consent" relying on "true human flourishing" simply moves arguments from particular enhancements to the purpose of human life, the definition of flourishing, and other contestable issues. In short, Parens is too optimistic that we can agree on "true human flourishing." For individuals and communities who have a strong sense of human flourishing and the purpose of life, Parens's method is helpful (even as a set of monocles). But if there is no discoverable human purpose and it must instead be constructed, the method merely shifts the argument to a new (perhaps better) locale.

Even with those two weaknesses, this is an important and helpful book for considering enhancement. In it, a seasoned and realistic bioethicist draws from over two decades of experience and thinking to propose something new. It introduces the reader to the major sides, helpfully notes commonalities, and provides at least a suggestion of a way forward (even if that suggestion is limited).

Reviewed by Jacob Shatzer, PhD, MDiv, who is assistant professor of biblical and theological studies at Sterling College, Sterling, Kansas, USA.

Robot Ethics: the Ethical and Social Implications of Robotics

Patrick Lin, Keith Abney, and George A. Bekey, Editors. Cambridge and London: The MIT Press, 2012.

ISBN 978-0-262-01666-7, 356 PAGES, PAPER, $47.00.

"It is change, continuous change, inevitable change, that is the dominant factor in society today." Despite our recognition of the veracity of Isaac Asimov's statement, the rate of technological progress always seems to outstrip our ability to reflect ethically on those advances. In *Robot Ethics: the Ethical and Social Implications of Robotics*, the authors attempt to intercept these changes mid-stream by providing a thorough, thoughtful, and stimulating reflection on the array of ethical issues posed by our current and future engagement with robots, both personal and societal.

In twenty-two essays by an international panel of authors, the book covers the many facets of our current engagement with robotics as well as foreseeable future developments. Following a presentation of three general areas of ethical concern in robotics—safety, responsibility, and privacy—the specific manifestations of these issues across the applied field of robotics is explored: design and programming, military, law, medicine, psychology, sex, and culminating with the issue of robot rights. Although some authors argued on philosophical and ontological grounds that a fully autonomous robot was an unlikely possibility, almost all authors addressed the possibility and the ethical dilemmas that such a development would precipitate.

The primary driver of robotic research and development is the military; therefore, considerable attention was given to the ethical issues surrounding the use of robots—especially autonomous robots—in combat. As artifacts that lack emotional overlay and a theory of mind necessary for decision making, the danger of using robots in today's civilian theatres was addressed. Closely related was the issue of responsibility for such robotic "decisions" and actions. Furthermore, by adding greater separation between combatants and enemies, the use of autonomous robots will change not only the way wars are fought, but also our attitudes toward war.

The section on law as it applied to robotics was especially informative, addressing issues of agency, responsibility, product liability, and reform. Distinctions were drawn between causal responsibility and moral responsibility.

Privacy issues are another significant area of concern related to the relational phenomenon that occurs between humans and robots. Robots are becoming increasingly ubiquitous; with the robotic capacity for direct surveillance, combined with the known tendency of humans to anthropomorphize robots and to form emotional attachments to them, they are becoming a potential source of privacy invasion. The ability of robots—especially those with internet connectivity—to record personal data that is legitimately and illegitimately retrievable will pose an increasing threat to privacy.

The pros and cons of sexbots preceded the discussion of the possibility of having a robot lover. Central to this issue is the definition of love that is crucial to our human relationships. The authors present a helpful analysis of the ways in which robots pose a threat to the rights to liberty and privacy, as well as the potentially negative impact of robots on the socialization of children.

Concerns about "robot slavery" led to a discussion of the issue of cyborg robots. This was the weakest link in an otherwise thoughtful collection of essays. The tone of this essay was arrogant and challenging; the author's work—impregnating machines with human neurons and claiming they are conscious—is repugnant and disrespectful of human life. On the basis of reductionistic presuppositions he argued that robots containing human neural tissue are conscious until proven otherwise, and, if conscious, entitled to human rights. His concluding exclamation alone ("Shame on you!") should have discredited his essay, demonstrating it to be non-academic and unworthy of inclusion in this publication. Was it included as an exemplar of extremist thinking and attitudes? One can only wonder.

The final essay in this section was provocative and insightful, arguing that as thinking is reduced to a mere computational process and as internality is replaced by action, we are walking a tightrope over the chasm of ethical nihilism. Correspondingly, the epilogue developed the concept of agency as necessarily entailing interiority, embodiment, and conceptual reasoning. A complex program can imitate human syntax but never understand its meaning.

Despite its wide diversity, the book was well crafted and coherent, as themes raised at the end of each chapter segued seamlessly into the next section. It is highly commendable for both its breadth and depth of coverage of the ethical issues involved in robotics. Given the increasing pervasiveness of robots and the changes they will bring to our lives, it is appropriate reading for anyone who engages with these entities. However, the real value of discussions about robots may turn out to be what these conversations teach us about ourselves. Furthermore, one can only wonder if we are about to encounter the "Great Exchange": as humans are increasingly forced to think algorithmically, will we lose our ability to reason and hence become ever more machine-like at the same time that robots become more human-like? Could this be the ultimate change about which Asimov hints?

Reviewed by Susan M. Haack, MD, MA (Bioethics), MDiv, FACOG, recently retired from consultative gynecology at Hess Memorial Hospital and Mile Bluff Medical Center in Mauston, Wisconsin, USA.

Why the Church Needs Bioethics

John F. Kilner, Editor. Grand Rapids, Michigan: Zondervan, 2011.

ISBN 9-780310-328520, 304 PAGES, PAPER, $26.99.

Edited by John F. Kilner, *Why the Church Needs Bioethics* is the fruit of an impressive team of leading theologians, Bible scholars, Christian ethicists, medical doctors, and academics from fields such as law and business. Directed at church leaders, Christian healthcare workers, and students, the aim of the book is to show how the word and work of the Lord may give wisdom to his faithful and help them deal with evermore challenging bioethical issues. Like John Kilner, Professor of Bioethics and Contemporary Culture, Director of Bioethics Programs at Trinity International University, and Franklin Forman Chair of Ethics, most of the contributors are attached to Trinity International University, which offers a Christ-centred Scriptural approach to learning.

Centred on three cases, the book is an excellent example of problem-based learning. As Miriam Charter, author of the last chapter, observes, this approach entails much more than acquisition of information. It involves critical exploration. It teaches transferable skills applicable to other situations. Homing in on real-life issues such as infertility, drug-taking and cognitive enhancement, terminal care, and death, each case is addressed from different perspectives, including biblical, professional, counselling, and pastoral perspectives.

Richard Averbeck opens the discussion of the case raising issues about IVF, surrogacy, and egg donation. This is with reflections on the Old Testament stories about infertility and the Genesis understanding of the image of God, marriage, one-flesh union, and the effects of human sinfulness on familial relationships. Turning to the business side of the fertility industry, Scott Rae and Helen Eckman critique its lack of regulation and its profit-driven nature. Stephen Greggo and Miriam Stark Parent look at the case from yet another angle and call for holistic counselling attending not only to medical matters, but also to mental and spiritual needs. Pitching a Christian understanding of the human embryo and child in terms of the sanctity and giftedness of all human life against that of the fertility industry, which views an embryo as disposable and a child as something to which adults have a right, John Kilner closes the discussion of the case.

Starting with Kevin Vanhoozer's discussion of our fallen nature and human hubris, the second case highlights the difference between restoration of health and enhancement. Not content with our role as stewards, humans seek means to take over the role of Creator and reshape nature, including our own. As Vanzooer argues, this means the triumph of pride over reverence and a reductionist understanding of ourselves as objects that may be manipulated. Taking different routes, Paige Cunningham evaluates the role of the law in regulating the use of drugs, while Harold Netland, Bruce Fields, and Elizabeth Sung talk about different aspects of cultural ministry in a pluralist society. Rounding off, William Cheshire returns to the theme of hubris with reference to transhumanist aspirations to transcend our God-given nature.

The focus of the third case is on euthanasia, assisted suicide, terminal care, palliation, and the difference between letting die and killing. While embracing a holistic understanding of our earthly life as an embodied existence, subject to pain, suffering, and death, D. A. Carson reminds us of the Gospel message that death does not have the last word. Thus he argues that euthanasia and assisted suicide are options only in the eyes of those of little or no faith in the Christian God of love and grace. Likewise, recognizing human nature as both bodily and spiritual, Robert Orr and Susan Salladay emphasise the importance of holistic end-of-life care. With reference to the principle of double effect, they also make a convincing case for palliative sedation as a last resort to alleviate unbearable suffering. Stephen Roy's thoughts on pastoral care for the dying and John Dunlops' thought on bioethics and better death conclude the discussion by further emphasizing the importance of dying well in both a spiritual and a physical sense.

Reflecting more generally on Christian wisdom and worship, Greg Scharp's reflections on preaching, showing how even those not facing immediate ethical dilemmas may benefit from the wisdom of the Scriptures and the Spirit, and Miriam Charter's chapter on Christian and problem-based education fittingly close this engaging book on life and death issues and the meaning of life.

Reviewed by Agneta Sutton, **PhD,** Lecturer at Heythrop College in the University of London, UK.

Deconstructing Dignity: A Critique of the Right-to-Die Debate

Scott Cutler Shershow. Chicago/London: University of Chicago Press, 2014.

ISBN 978-0-226-08812-9, 216 PAGES, CLOTH, $37.50.

The title of this volume has to be taken at its full force. “Deconstructing” is sometimes used loosely today, meaning something like “getting behind” an issue by analyzing what is really going on in the hidden historical or conceptual depths. Scott Cutler Shershow would doubtless give such a timorous operation short shrift. This is the real thing: a consideration of the right-to-die debate armed with Jacques Derrida and Georges Bataille. It is true that the author explicitly permits readers who want to get on to the substantive issues to skip the first chapter where the relevant apparatus and the paths of deconstruction are laid out. Yet, it is also true that the deconstructive approach informs the character of the discussion which follows, even when discussion follows lines or uses vocabulary more familiar to most of those involved in bioethical discussion.

Shershow does not take sides and try to resolve right-to-die questions. Rather, he invites us to look from a different angle—from the point of view of “Dignity.” After exploring the conceptual relations, first of dignity and sanctity and then of dignity and sovereignty, he traces the way in which human dignity has been understood from Cicero through Immanuel Kant. Doing so enables him to map the contemporary debate against its historical background before exploring a second historical account, this time of “Suicide and Sacrifice from Plato to Kant.” This account sets up the longest chapter in the book, which explores the concept of sacrifice in the context of the right-to-die debate. Shershow contends that an “economy of calculation and incalculability” features in both sides of the argument; i.e., both principle and calculation (I domesticate and risk being unjustly reductive with this terminology) attend the reasoning of all concerned. This is laid bare through the examination of dignity. Against that background, the notion of sacrifice “seems to structure this entire debate.” (122) When it comes to the right-to-die, individual decision, whichever way it goes, may be embedded in sacrificial logic. If so, how can we decide on the grounds of abstract, disembodied or *a priori* principle whether the impetus to live and act sacrificially should favor *either* a right-to-die *or* a rejection of the right-to-die? Whichever way it is cut, when dignity is rightly deconstructed, a principled resolution one way or another is shown to be impossible.

Shershow’s book can be read on two levels. On one level, he offers reflections and arguments which can be incorporated into ways of conceiving the right-to-die debate that do not depend on the deconstructive approach. That will not make for a very satisfactory reading. At a deeper level, the persuasiveness of his proposal depends on the conceptual scheme which he brings to it. While the scheme does not quite dictate the open-ended conclusion—it is open-ended insofar as no side is definitely taken—Shershow does demonstrate how adopting it entails revising our way of viewing the debate. However, if we have no reason to buy into Derrida or Bataille, then this volume will not fruitfully advance the right-to-die debate overall, even if it contains particular discussions which are independently illuminating.

Reviewed by Stephen N. Williams, MA, PhD, who is a Professor of Systematic Theology at Union Theological College in Belfast, Northern Ireland and serves on the Editorial Board of *Ethics & Medicine*.

Free Will

Mark Balaguer. Cambridge, MA: The MIT Press, 2014.

ISBN 978-0-262-52579-4, 140 PAGES, CLOTH, $12.95.

Ethics, including bioethics more specifically, is all about freely choosing among moral options and making an informed, rational choice. Good data about the relevant possibilities is part of the ethical analysis, which undertakes to reach a decision based on various theories such as Kantian ethics, divine command theory, utilitarianism, and so forth. This is the subject matter of ethics courses and ethics textbooks.

Yet the very process of *choosing* among options, so natural to ethics, is contested territory in the modern realm of moral philosophy. We say that an ethical decision must be freely chosen. Moral praise and moral blame hinge on our inner deliberations and ability to choose whether or not to do the right thing. If we were mere automatons that have no free will, then the study of ethics would be meaningless. Yet a growing number of philosophers make exactly that claim.

Dr. Mark Balaguer is a philosopher at California State University, Los Angeles who has a special interest in these questions. He takes to task such contemporary thinkers as psychologist Daniel Wegner and neuroscientist Sam Harris, who claim that free will is merely an illusion.

Now it may appear to many of us, as people of faith, that we have a simple dividing line here: the spiritual, religious view of human nature versus the scientific, materialistic view. The first allows for an independent free will because our Creator has a free will. The second would militate against free will, claiming that all material things have a prior determinant cause or are simply random. Balaguer demonstrates that the question is not that simple. Though he is not himself religious, Balaguer claims that this is irrelevant to his discussion, and that his arguments are still valid, independent of faith claims.

Balaguer argues persuasively that there are no good reasons to abandon the basic components of our perceived free will: that we are the agents of our own actions and that we could have chosen otherwise. In particular, the author analyzes studies performed by Libet and Haynes that would seem to imply neural activity occurring in the cerebral cortex before the conscious decision to act in a certain way. Balaguer shows convincingly that such experiments do not undermine our ability to freely choose.

This is a short, pithy, and entirely readable book. Mark Balaguer demonstrates that the classical arguments against our having a free and independent will simply do not work. His claim is a modest one, for he concludes that the actual existence of free will remains an open question. For those of us who think about ethics and moral philosophy, this is a helpful introduction to the question of moral agency.

Reviewed by Dennis M. Sullivan, MD, MA (Ethics), Professor of Pharmacy Practice and Director of the Center for Bioethics at Cedarville University in Cedarville, Ohio, USA.

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