



## CONTROVERSIES IN BIOETHICS

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## CONTROVERSIES IN BIOETHICS

### ABSTRACTS

#### 1. FOUNDATIONAL CONTROVERSIES

##### ***THE ANTHROPOCENE: THE END OF HUMANISM IN BIOETHICS?***

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Over the last decade bioethics scholars have advocated a return to bioethics' roots in Van Rensselaer Potter's call to foster a discipline integrating the humanities and the sciences: bioethics. Potter's vision was to join ethics and biology to support ecology. These scholars have noted that the discipline of bioethics diverged from this vision, and today its focus is on human health. These scholars' advocacy is to propose the reintegration of Environmental Ethics with Bioethics. This paper's ultimate argument is that these scholars do not appreciate the radicalness of this proposal and its potential to disrupt the discipline. The argument unfolds in four parts. In the first part, the paper makes the case that humanism is the philosophical orientation of Potter and contemporary bioethicists. Potter's vision of bioethics is mutually transformative: humanistic understanding is impacted by scientific knowledge, and vice versa. The second part and third parts of this paper are interrelated in the former manner. The second part of this paper reviews the scientific fact of man-made climate change and its inauguration of a new geological epoch, the Anthropocene. Then, the third part of this paper reflects on this fact's impact on the category of humanist understanding. The central idea in the third part of this paper is that the Anthropocene undermines the traditional dichotomy between man and nature, which is conceptually necessary for humanist philosophy. If the human is not a distinct category, then attributing preeminent value to humans is invalid, undermining the system of thought centered on humans. The final part of this paper argues that the consequence of reckoning with contemporary ecology is that it generates a demand for a new system of values that deprioritizes the end, human good, that Potter and contemporary Bioethicists use environmentalism as a means. This paper concludes with speculation about what that system of value might look like and its impact on conceptualizing the challenges within Bioethics.

##### ***WHY 'IS ADDICTION A DISEASE?' IS THE WRONG QUESTION***

David G. Limbaugh, *University at Buffalo*

The aim of this paper is to elucidate and answer what we take to be a conceptual confusion in the addiction literature, and then apply that answer in the form of suggested revisions for the DSM



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and clinical practice. There is currently a debate in bioethics that asks whether or not addiction is a disease. What fuels this debate is the assumption that if addiction is a disease, then addicts are less morally responsible than they would have been otherwise. We argue for two conclusions. 1) Whether or not a particular addiction is a disease will depend on the type of addiction. 2) There is no relationship between addiction being a disease and addiction mitigating the moral responsibility of an addict; though, it is still true that in some cases, being an addict may mitigate moral responsibility. We argue for these positions by assuming the harmful dysfunction account of disease and the systematic loss of control account of addiction. We also make the minimal commitment that for a person to be moral responsibility is for them to be praiseworthy or blameworthy for her actions. The project unfolds by, first, showing that the neuropsychological factors in many cases of addiction do not entail the presence of a harmful dysfunction, and thus they do not entail the presence of a disease. Rather, there are some types of addictions that are diseases and some that are not. Second, we examine both the basic desert and consequentialist accounts of moral responsibility and argue that, in either case, whether or not an addict is morally responsible must be assessed on a case-by-case basis. Finally, we take each of these conclusions and apply them in the form of suggested revisions to the current DSM and clinical practice.

### ***CONSIDERING OBESITY AS DISEASE: THE ETHICAL IMPLICATIONS***

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In June of 2013, the American Medical Association (AMA) announced a change to their nomenclature. Obesity henceforth would be considered a disease and not simply a risk factor. The decision to categorize obesity as a disease is both a scientific and a moral one, a decision that forces society not only to confront the meaning of disease itself but the implications of medicalizing mass and drawing norms based on its measurement.

Cast in an historical light, medicalization of conditions has led to dramatic social and political effects on those with the given condition of interest. While there are many ways to define disease, most definitions are indefinite regarding the classification of risk factors like obesity. In such cases, the decision to classify obesity as a disease should be pragmatic, focused on how such decisions will impact society. This seminar and associated paper outline how best to determine what ought be considered a disease before concluding that in those cases where disease status is indeterminate, conditions should be categorized as disease only if such categorization will improve health outcomes for those individuals.

Obesity, as a condition, exists in such an indeterminate zone of categorization. It does not fit



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neatly into a Wittgensteinian notion of disease nor do other methods of disease ascriptions hold weight. As such, only the outcomes matter – and if obesity is designated a disease, the health outcomes for those effected will be worse. Disease ascription will promote stigma and thus poor eating and inactivity. Disease ascription will promote individual-level interventions for a condition that requires public health and community-level interventions. Finally, disease ascription will gloss over the inaccuracy of BMI as a means by which to determine health. Ultimately, disease ascription will cause more harmful health outcomes for an already vulnerable population. In light of such outcomes, the AMA should reconsider its decision.

### 2. DEATH AND DYING CONTROVERSIES

#### ***AGAINST RATIONALITY: A CASE FOR THE PERMISSIBILITY OF EUTHANASIA/ASSISTED SUICIDE IN INDIVIDUALS WITH DEPRESSION***

Cheryl Frazier, *University of Oklahoma*

In 2015, the Netherlands released their annual report from the regional euthanasia review committees (RTEs) which outlined, in part, specific cases of euthanasia from that year (van Wersch). This report came under fire in a 2016 article entitled “Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014.” As authors Scott Y. H. Kim, Raymond G. De Vries, and John R. Peteet (2016) noted, Dutch regional euthanasia review committees have increasingly permitted euthanasia or assisted suicide (EAS) for psychiatric patients, most frequently in cases of depressive disorders. This phenomenon, coupled with society and scholars’ increased willingness to permit more cases to be applicable for EAS, has sparked controversy amongst bioethicists.

Many charge that individuals with depression are ineligible to elect for EAS given that they are not competent or rational in the same way as those without mental illnesses. As Mark Sullivan and Stuart Youngner (1994) state, “refusal of lifesaving psychiatric treatment is regarded as a symptom of an illness that psychiatrists treat rather than the rational choice of an autonomous patient that should be respected.” In this paper I will argue that if we find EAS to be morally permissible in cases of terminal illness, especially on the basis of terminal illnesses causing unbearable suffering, then we ought to allow EAS in the case of (at least some cases of) depression. I will center my argument under the societal stereotype under which the mentally ill are seen as irrational as a result of their mental illness.

On this basis, many have argued that we should not allow them to choose EAS as a response to



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their mental illness. We frequently allow people without mental illnesses make what we would consider irrational decisions, both inside and outside of medical contexts. For example, I am allowed to eat dinner at Sonic every night despite this being an irrational (and horribly unhealthy) decision. Further, someone in need of a surgery to remove ear tumors could refuse to get the surgery to avoid having to shave their head before surgery. While we may advise against these irrational decisions, we ultimately may respect them because we deem the *agents* making them rational. I will similarly argue that individuals with some forms of depression can be rational agents despite making irrational decisions. Individuals with depression are seen as sufficiently rational to decide whether to attend grad school, to choose a spouse to marry or a career path to pursue. However, they similarly make irrational decisions like those made by individuals without depression. As such, I will argue that we should not ban individuals with depression (and more specifically treatment resistant depression) from choosing EAS on the basis of rationality, since this wrongfully discriminates against those with mental illness in ways that we do not limit those without mental illness.

### **ASSISTED SUICIDE AND EUTHANASIA**

Kristen Hine, *Towson University*

In *The Future of Assisted Suicide and Euthanasia*, Neil Gorsuch (2006) explains and defends the inviolability-of-life principle. According to this principle, human life is valuable in itself, not for instrumental reasons. With regards to assisted suicide, Gorsuch (2006) argues that such a principle would "...rule out cases where the doctor intends to kill his or her patient."

In this paper, I do not argue against the principle. Rather, I consider whether the inviolability-of-life principle is, in fact, inconsistent with all cases of assisted suicide. Defenders of the inviolability-of-life principle are willing to grant that one's right to self-defense permits one to end the life of another. I argue that by making this allowance, defenders of the principle may provide an avenue through which one can argue in support of assisted suicide in some cases.

My basic line of argumentation is as follows: according to some, *person* is ambiguous (see Feldman, 1992). It makes no sense to talk merely of persons; rather, we should recognize a distinction between biological persons and psychological persons. When we call something a *biological person*, we mean to say that it is a member of the species *Homo sapiens*, and when we call something a *psychological person*, we mean to say that it is self-conscious, intelligent, rational, and so on.

I suggest a similar distinction can reasonably apply to *human life*. If so, the inviolability-of-life





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principle could mean one (or both) of the following: human (psychological) life is intrinsically valuable, or (and) human (biological) life is intrinsically valuable. I argue that the most reasonable interpretation of the principle implies that both aspects of human life are intrinsically valuable. I then suggest that in some end-of-life situations, the biological aspect of life threatens the psychological aspect of life. This can happen when, for example, the continued existence of one's biological life results in one's psychological life experiencing nothing but suffering, humiliation, a lack of autonomy, and so on. I suggest that in those cases, one's psychological self has a right to defend itself against the attacks made by one's biology, just as one has the right to defend oneself against the attacks made by another. Provided that such a defense results in an *unintentional* termination, the inviolability-of-life principle would imply that ending one's (biological) life is permissible.

Now, I grant that this argument shows that one has a right to suicide, not assisted suicide, if the inviolability-of-life principle is true. I argue, however, that just as one is sometimes *permitted* to assist another in the defense of oneself, a person is at least sometimes permitted to assist another in her suicide. This does not show that an individual has a *right* to assisted suicide, but it does show that some cases of assisted suicide may be consistent with the inviolability-of-life principle.

### ***IS BRAIN DEATH A LEGAL FICTION?***

John P. Lizza, *Kutztown University of Pennsylvania*

There has been a rising chorus of discontent with accepting brain death as death. Cases of post-mortem pregnancy in which brain-dead pregnant women are sustained to allow the foetus to gestate and then be removed by caesarean section, and the extraordinary case reported by D. Alan Shewmon in which a whole brain-dead body was sustained for over twenty years, challenge whether brain function is necessary for the continuation of a human life. Recently, Franklin Miller, Robert Truog, and Seema Shah have endorsed Shewmon's arguments that brain death is not death, if death is understood in strictly biological terms as the irreversible loss of integration of the organism as a whole. They maintain that accepting brain death as death departs substantially from a biological and common sense understanding of death, and that interest in organ transplantation was the primary motivation for accepting brain death as death. Moreover, they claim that the public has not been informed of these "facts." Since it is unlikely that this information can remain hidden from the public for long, they suggest that we acknowledge that brain death is a kind of "legal fiction" and become more transparent about how this fiction may be useful and ethically appropriate in permitting vital organ transplantation. Since they believe that the use of organs from brain-dead donors is justified, even though these donors are not really



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dead, they believe that such transplantation can and should continue. In addition, they believe that donors in DCD (Donation after Circulatory Death) protocols, whose circulatory and respiratory functions have ceased for two to five minutes, are not really dead, since their loss of circulatory and respiratory functions is not truly irreversible. So, if we wish to continue donation from brain-dead and DCD donors, this is best achieved, according to them, by accepting a transparent “legal fiction” that such donors are dead.

In this paper, I argue that Miller, Truog, and Shah’s view is seriously flawed. I argue that the truth should be told. However, the truth is that defining death is not a strictly biological matter, as Miller, Truog, and Shah incorrectly assume, but involves metaphysical, moral, and cultural considerations. Such considerations do not make brain death a “legal fiction.” Indeed, I will argue that biological, metaphysical, moral, and cultural considerations strongly support acceptance of the truth that human persons do not survive total brain failure and therefore brain death is really death. If anything, recognition that defining death involves metaphysical, moral, and cultural considerations may support a more pluralistic approach to the legal definition of death, rather than perpetuating a legal fiction or noble lie that brain death is death.

### ***BIOETHICS AND THE LAW: SHOULD COURTS BE ALLOWED TO MAKE END OF LIFE DECISIONS? REFLECTIONS ON THE CHARLIE GARD CONTROVERSY***

Michael S. Dauber, *Northwell Health, Long Island, USA*

In June and July of 2017, the case of Charlie Gard, an 11-month old boy with mitochondrial DNA depletion syndrome, sparked a significant public controversy. Charlie’s condition had progressed extensively, and his doctors argued that palliative care and comfort measures were his best options given the high likelihood that he had suffered brain damage. Charlie’s parents disagreed, however, and wished to try an experimental treatment called nucleoside bypass surgery. The English High Court, the Court of Appeals, and the European Court of Rights successively ruled that the medical team should withdraw Charlie’s life-support and allow him to die, arguing that continued treatment produced significantly more harm without a reasonable prospect of benefit.

The case developed into an international controversy, with international figures from Pope Francis to Donald Trump offering commentary and offering to accommodate Charlie and his parents. Significant political and moral debates ensued; in the United States, many pundits pointed to the case as an example of the horrors of single-payer healthcare systems, claiming that the reason the hospital could not offer any further treatments was because the government could not pay for them. In previous articles, I have argued that the true controversy arose not from the



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nuances of single-payer healthcare systems, compassionate use policies, or the courts' thinking, but from the fact that the United Kingdom allows courts to decide to withdraw life-sustaining treatments over the objection of parents or other surrogate decision-makers, while such a decision is practically unthinkable in America.

This paper will examine whether or not courts should have the power to decide to withdraw life-sustaining treatment over the objection of surrogate decision-makers, as they did with Charlie Gard in the United Kingdom. In doing so, I consider the ways in which giving courts this power might be better for individual patients, but worse for family members and other stakeholders who must live on after the patient's death. I also examine some of the cultural and historical reasons that handing such power over to courts or other government agencies may be seen as unthinkable in the United States, namely, moral transgressions like the Tuskegee Syphilis Experiments, which have given the public significant reasons to be wary of government intervention in healthcare and life-or-death decisions.

Drawing on the Charlie Gard case, bioethical theory, political philosophy, and my experiences as a clinical ethicist, I conclude that courts should not have the power to withdraw life-sustaining treatment over surrogate objection in *most* cases because doing so creates significant chaos, fear, and distress in patients and their families, and that taking positive stances on end of life issues violates the principles of liberal democracy, under which intimate decisions about the unknown should be left to patients and their surrogates. Unless surrogates are preventing a patient who is very likely to be physically suffering or who wishes to die from doing so, giving courts such power is likely to create significant moral distress that could be avoided or solved by facilitating transparent communication.

### 3. PERSPECTIVE CONTROVERSIES

#### ***HARM REDUCTION STRATEGIES & THE PROBLEM OF FEMALE GENITAL CUTTING: BRINGING SECULAR AND ISLAMIC PERSPECTIVES INTO CONVERSATION***

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Aasim I. Padela, *University of Chicago*

The arrest of Dr. Jumana Nagarwala and her colleagues, in what has become the first US case tried under a federal law prohibiting Female Genital Mutilation, has brought ethical controversies about the practice of female genital cutting (FGC) into public and policy discourse once again. The “secular” bioethics discourse, and associated global health policy discussions,





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remains divided between zero-tolerance advocates and harm-reduction strategists. Islamic bioethical debates on FGC similarly comprise of two camps. The first grounds the relationship between FGC and Muslim practice in statements from the Prophet Muhammad and in classical legal manuals that permit or recommend a minimal female genital procedure. The other camp disputes the authenticity of Prophetic reports, analyzes the issue through the lens of other Islamic ethico-legal constructs, and re-examines the issue in light of contemporary perspectives on women's rights and health risks of the procedure.

This paper begins by outlining each of these camps, secular and Islamic, explaining their main premise, supporting rationale, and identifying the principal actors in the discourse. After this overview, the paper argues that a "harm reduction" strategy can be authentically supported by the scriptural texts and Islamic ethico-legal analyses. In other words, we argue that the principal scriptural sources discussing FGC cohere with the overarching Islamic principle of removing harm as they acknowledge the existence of the practice but pose limitations on its severity. Furthermore, FGC arguably made its way into Islamic law as a custom-based (as opposed to revelation-based) practice, and thus jurists can limit or even delegitimize the practice when there are established, previously unknown, harms. Taking this view on the Islamic "roots" of FGC allows for alignment with "secular" harm-reduction strategies. Indeed, bringing the secular into conversation with the Islamic furnishes a common ground for collaboration on the eradication of harmful genital procedures among Muslim communities while acknowledging the legitimacy of ritual nicking within the house of Islam.

### ***CONTROVERSIES IN ISLAMIC BIOETHICS ON ORGAN DONATIONS: BETWEEN PRESUMED CONSENT AND EXPLICIT CONSENT***

Vardit Rispler-Chaim, *University of Haifa*

The bioethical rulings in Islam are formulated nowadays by muftis – religious scholars or jurisconsults who issue fatwas (legal opinions), and the physicians who consult them. The source material for my study is the "medical fatwas" from the last four decades, issued by muftis in various parts of the Islamic world.

Organ transplantation as a therapeutic procedure is considered permissible by most religions today, including Islam. In Islamic bioethics, organ transplantation is welcome as it serves one of the five main objectives of the Shari'a – to preserve life and well-being.

There are two general types of donations – the donation of a living donor (kidney, part of one's liver, etc.) and donations from the dead. Statistics have shown that Muslims (like others) are



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more likely to donate while alive, but less eager to donate from the dead. There is thus a shortage in cadaveric donated organs almost everywhere in the world and in Islamic societies as well. Muslim ethicists, the muftis, have debated among themselves how to encourage cadaveric donations; several suggestions appear in the fatwas, but no uniform solution has been reached. I will review and analyze in my talk the suggested methods, their respective dilemmas, as well as their advantages or disadvantages.

The worldwide efforts to increase supply of cadaveric organs have recently concentrated on the presumed consent method. In this route, every person is a potential donor of organs after death unless he or she signed a "refusal" during their lifetime. This route is juxtaposed with the explicit consent method, wherein upon death, the family is asked to donate from its dying member, and then explicitly say "yes" or "no". I will depict the various aspects of the question (such as possible conflicts among the family members of the deceased, or between the latter and the deceased's own will as expressed in his/her lifetime, and more). Another dilemma is which method would deliver better results, that is, more organs for transplantation. Muslim ethicists have contributed to this debate too, and their attitudes for and against presumed consent will be analyzed as well, as much as how the various Islamic ethical attitudes have influenced the practice in several Arab and Islamic countries.

Finally, I will survey the Iranian method in obtaining organs from the dead, as a middle way, and explain why it is acceptable in Iran but not elsewhere.

### ***THE ETHICS OF THE (TUSKEGEE) SYPHILIS EXPERIMENT***

David Augustin Hodge, *Tuskegee University*

African Americans lead in excess deaths in most statistical categories (diabetes, kidney and heart disease, etc.). This makes them excellent candidates to be beneficiaries of the significant positive gains on health and healthcare that xenotransplantation research can offer. Traditionally, blacks have been pursued and used in studies but they are not equally pursued and luxuriated with the positive genius that comes as a result. This maintains a distrust they didn't initiate and leads to a suspicion of systems, even if the systems are noble. Philosopher Mark Owen Webb, in his essay "The Epistemology of Trust and the Politics of Suspicion," extends this distrust to moral epistemology. For example, utilitarianism as a moral theory is wholly inadequate as a formula that would motivate African American participation. Utilitarianism is far too friendly to the majority population. Thus, a more constructive ethical consideration would have to be one that is endorsed by those negatively affected. Why? Because they *know* that they have been used. In other words, (in accordance with Webb) African Americans are justified in being suspicious of



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medical projects (e.g., Henrietta Lacks). African Americans are also justified in being suspicious and distrusting of researchers' motives (recall U.S. Public Health Service Syphilis Study at Tuskegee)?

Being used as a means to an end is a deontological ethical violation that perpetuates health disparities and leads to ongoing mortality and morbidity concerns. African Americans, and others of good will, should be advocates staunchly committed to a deontic public health care ethic and reject utilitarian ethical theory. A non-discursive research agenda unfairly promotes (or prioritizes) benevolence over beneficence. Beneficence should be prioritized over non-maleficence and benevolence.

Thus, trust and trustworthiness should be grounded in something more deontological, then begin to address concerns like the risk/benefits calculations, how statistical numbers are represented and demystified, and the canvassing of the community to ensure an equitable distribution of the moral education on this very controversial medical area. How are terms in the informed consent material like "sterile" to be understood and trusted? How is the social stigma to be addressed? Is there a chance that an unknown disease can be contracted, then passed on during intimate contact? And to what extent are recipients obligated to inform their partners that they have non-human animal parts in their person? Is there a chance for an unknown contagion to be passed *in utero*? If the life expectancy of the pig is five human years, are we to believe that a xenotransplanted organ can sustain life for humans who have a life expectancy of about seventy-five years? If a donor human organ becomes available post-xenotransplantation, would the recipient be able to change the non-human animal organ for a human one? Who will decide when events like these present themselves? And how are African Americans to trust this process?

### 4. APPLICATION CONTROVERSIES

#### ***DISPARITIES IN ARTIFICIAL REPRODUCTIVE TECHNOLOGY FOR US PEOPLE LIVING WITH HIV***

Marielle Gross, *Johns Hopkins University*  
Mindy Christianson, *Johns Hopkins University*  
Jenell Coleman, *Johns Hopkins University*  
Jean Anderson, *Johns Hopkins University*

Background: The American Society for Reproductive Medicine (ASRM) states that there is no medical, legal or ethical basis for withholding artificial reproductive technology (ART) from people living with HIV (PLHIV). However, as of 2015, less than 3% of American fertility clinics



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handled gametes from PLHIV, making mainstays of infertility treatment, including intrauterine insemination (IUI), in vitro fertilization (IVF), and intracytoplasmic sperm injection (ICSI), effectively unavailable to this population. We suggest that current ASRM recommendations may perpetuate disparities in infertility care for American PLHIV.

Context: (1) ART has been used safely and effectively among PLHIV for the past 20 years, most commonly in Europe. (2) There is extensive moral precedent for the obligation to provide ART access to PLHIV, appealing to the duty to care, justice, fairness, and reproductive rights. Table 1 summarizes authoritative academic publications on the topic spanning over 20 years. (3) The Americans with Disabilities Act mandates equal access to healthcare for PLHIV. Refusing to provide equal care for PLHIV was successfully prosecuted as discrimination in Supreme Court case *Bragdon v. Abbot*, which defined HIV as a disability vis-à-vis impaired fertility. (4) In 2017, in light of evidence that current antiretroviral therapies and sperm washing techniques are highly effective for preventing HIV transmission, the CDC retracted its 1990 prohibition against using seropositive men's sperm for insemination. Importantly, this eliminates the basis of state-specific insemination statutes.

Argument: Disparities in ART access for PLHIV persist despite the medical, ethical and legal precedents above as a result of ASRM's recommendations for unnecessarily stringent laboratory practices for preventing viral transmission, compounded by a loophole in ASRM guidelines for ethical care of PLHIV. First, the ASRM's interpretation of US statutes includes recommendations for separate laboratory spaces and storage tanks, and additional processing for specimens from PLHIV. While there is no evidence that these precautions are safer than universal precautions, they are prohibitively expensive for most fertility centers and thus may constitute an "undue burden" with regard to complying with the Americans with Disabilities Act. Also, the ASRM suggests an obligation to "treat or refer" PLHIV without specifying who should treat or to whom one should refer. Lack of organizational transparency regarding which fertility programs offer ART services to PLHIV makes referral problematic, and the paucity of treatment providers nationwide implies that following up on referrals may require an impractical amount of travel for most patients.

Conclusions: The ASRM is complicit in the ongoing disparities in access to ART for PLHIV through its concomitant recommendations for laboratory practices too burdensome to enable most fertility centers to offer treatment, and its acceptance of referral as fulfillment of the ethical and legal obligations to PLHIV without providing substantive means for referral. We call for a critical re-examination of these policies, which demonstrate disregard for the reproductive intentions of PLHIV, especially given their disproportionate rates of infertility and socioeconomic disadvantage.



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### ***UNNECESSARY MEDICAL CARE***

Barbara A. Noah, *Western New England University*

Physicians acknowledge that they are providing unnecessary medical care for a variety of reasons, including fear of malpractice litigation, Medicare's fee-for-service reimbursement mechanism, patient and family requests for care, a culture of denial of mortality, and a physician culture which views a patient's death as a professional failure. Recent data suggest that more than one-fifth of medical care provided is unnecessary and that the inappropriate use of invasive medical technology adversely impacts patients. Although the problem of over-provision of medical care at the end of life is now well recognized in the legal and medical literatures, the solutions considered to date, such as providing additional communication training to physicians, will have only marginally ameliorating effects.

The inherent challenges in physician-patient communication when making treatment decisions during terminal illness become even more complex when patients are unable to make decisions for themselves. Although patient autonomy, implemented via informed consent, is the primary principle that governs medical decisions, including those made on behalf of patients who have lost decisional capacity, insufficient evidence of the patient's wishes coupled with uncertainty about prognosis often leaves physicians and family members in a quandary as to whether to implement or to continue providing therapeutic treatment or life-prolonging care.

Recent data suggests that, in the final weeks of life, approximately 75 percent of patients with life-threatening illnesses and 90 percent of patients in ICUs have lost decisional capacity. For these individuals, a surrogate decision-maker, typically a family member or a legally-appointed proxy, must make difficult choices on behalf of the patient about how much medical care to request or accept. Additional empirical evidence suggests that surrogate decision-makers experience significant stress and grief during and after making health-care decisions for their loved ones. The default operation of the surrogate consent process means that, for patients who do not clearly opt out of life-prolonging treatment before losing decisional capacity, the path of least resistance will often lead to decisions in favor of initiating or continuing life-prolonging care. The pressures on physicians to offer and provide medically inappropriate care make this pattern even more problematic.

This paper considers the potential utility of a Canadian decision-support mechanism in this context. In 1996, the provincial government of Ontario implemented a Consent and Capacity Board (CCB), an independent body comprised of appointed psychiatrists, lawyers and members of the general public. The CCB's mission includes adjudication of matters of capacity, consent, and what Canada refers to as "substitute decision-making." There is evidence that CCB hearings





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promote a better shared, less confrontational, and more robust decision-making process. Thus, a CCB-like mechanism has the potential to improve surrogate decision-making to the extent that it is capable of being “transplanted” into the U.S. health system on a state-by-state basis. Although political opposition in some states is likely, the medical community has demonstrated interest in mechanisms which could both reduce some of the external pressure on physicians to provide what they believe to be medically inappropriate care and provide support for family members serving as surrogate decision-makers.

### ***LIVES AND CHOICES, GIVE AND TAKE: ALTRUISM AND ORGAN PROCUREMENT***

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Globally, the two most common systems for managing organ procurement are opt-in and opt-out. Within the United Kingdom, organ procurement in England, Scotland and Northern Ireland is managed via an opt-in system. Consent is required prior to organs being retrieved for transplant. The United States also practices an opt-in system, with individuals able to express their intentions to donate by way of enrolling on a national or state registry and/or signifying their wishes on a driver’s license. In 2015, Wales introduced a deemed consent: soft opt-out system for organ procurement in order to address the chronic shortage of organs for transplant. Justification for a change in legislation was based upon the desire to increase the number of organs and tissues available for transplant in Wales, underpinned by evidence demonstrating that globally, the number of organ donors per million population (PMP) in countries which have adopted an opt-out system are recognized as being the highest. Early statistical evidence suggests that this has had a positive impact on the number of cadaveric organ retrievals in Wales.

Such a system for procurement has previously been dismissed by the Organ Donation Taskforce, a government advisory committee responsible for advising the UK Government on the organ donation management in this country. The Taskforce suggested that opting out would be too problematic to introduce as coordinating procurement in this way may undermine the concept of a gift given freely, relating this specifically to the idea that an opt-out system negates the opportunity for individuals to make an altruistic gesture of actively pledging one’s organs for transplant. Such a measure could potentially undermine the concept of donated organs as gifts, which could negatively impact the number of organs offered for transplant. Such a position rests upon the premise that organs should only ever be donated through choice, and this can only truly be achieved through a policy that encourages voluntarism. There are, however, certain difficulties which maintaining such a strong reliance upon altruism presents. One difficulty is that its prominent feature in a system potentially confines options for procurement to a very limited route and thus may prevent us from exploring other means to increasing the supply of



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cadaveric organs, for example, a soft opt-out policy, proven to be a more efficient system for generating organs to help more of those in end stage organ failure.

It is this which this paper will focus discussion upon. Taking a broad utilitarian approach, the strong altruism position will be considered before putting forward arguments in favour of adopting a weak altruism position, which, arguably, reflects society's disposition towards organ procurement more accurately. Enabling this position to guide policymaking in this area may not shackle the opportunity for a change to a default opt-out system, which coupled with a combined registry would allow those who feel strongly about giving a 'gift' to be able to explicitly opt-in.

### ***BIOETHICS AND BIOSOCIAL CRIMINOLOGY: HURDLING THE STATUS QUO***

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Biosocial criminology is the fastest growing line of research within the field of criminology. Much of the findings suggest that genetic influences (certain genetic polymorphisms) are involved in anti-social behavior including criminal behavior with the environment and genes working in a synergistic manner. According to researchers in the field, the continued accumulation of biosocial criminological data and the development of biosocial theories are imperative to the advancement of this perspective (Beaver et al., 2015). Recently some have argued for the use of biosocial research findings to move the field of criminology from one of the etiology of crime using a purely environmental approach, to a biosocial approach that emphasizes prevention using scientific findings and methodologies to prevent crime as a public health problem (Gajos, Fagan and Beaver, 2016). However, there is considerable opposition and controversy in mainstream criminology circles to the biosocial approach because it involves, among other things, genotyping offenders for genetic risks to elucidate the etiology of antisocial behavior. This paper will consider the ethical issues raised by critics, address the ethical dimensions of conducting such research on the subjects, and whether recent findings in biosocial criminology can be integrated into current approaches to crime prevention while balancing harm and public safety.